CHAPTER ONE

Life and Work with "Invisible" Chronic Illness (ICI): Why Bother?

At the bottom of all philosophy, of all science and of all thinking, you will find the one all-inclusive question: How is man to tell truth from error? The ignorant man solves this problem in a very simple manner: he holds that whatever he believes, he knows; and that whatever he knows is true. This is the attitude of all amateur and professional theologians, politicians and other numbskulls of that sort. . . . Opposed to this childish theory of knowledge is the chronic doubt of the educated man. He sees daily evidence that many things held to be true by nine-tenths of all men are, in reality, false and he is thereby apt to acquire a doubt of everything, including his own beliefs (Mencken, 1967: 147, emphasis in the original).

A Problem Illuminated

The first question the researcher should ask is not how to proceed, but why he or she is involved (Drew, 1989: 431). A quiet evening with friends depicted in the Prologue was the catalyst for this study into "invisibie" chronic illness (ICI) and its impact on people's lives - especially their working lives. It is a study that inherently questions what the majority believe to be true; a questioning of the common fallacy that if you look well, you must be well. It is, perhaps, a clumsy but well-intentioned attempt to seek some form of "truth". A misguided initial belief, not uncommon in modernist philosophy, that if one could perhaps take the
problem apart then one would somehow "own" it, "understand" it and be able to move
towards the solution.¹ One learns there are no easy solutions. What there may be is a
commencement of the protest march against 'death by invisibility' (Geertz, 1986: 376) and
against 'unacknowledged dogma' in organizational consciousness and analysis (Kouzmin,
1980: 131). It is, perhaps, a chronicling of the individual struggle to establish 'one's own
meaning' (Denhardt, 1981: 2) and, more importantly, a seeking of context, of understanding
how events relate to one another and of formulations which help us make sense of the world
through a process of negotiation and renegotiation (Denhardt, 1981: 3) - a world involving
illness "unseen".

The people chronicled in the Prologue all live with what is termed an "invisible" chronic
illness (Vickers, 1996a; 1996b; 1997a; in press) detailed in the next section. We are all
professionals, working (or, in my case, studying) full-time. We all manage these conditions
in our lives as best we can. These are conditions that are not necessarily workplace related
nor workplace caused. They are illnesses that cannot be seen, but can be felt; illnesses that
are poorly understood in the West²: by greater society; by the medical profession; by families

¹I am indebted for this last idea to Professor Camilla Sivers of Cleveland State University, who,
thankfully for me, introduced another "shi-ha" experience for me, at, most aptly, the plenary session for the 10th
National Conference of the Public Administration Theory Network, the theme of which was "Discussing the Un-
discussable". She spoke, almost as if directing her communique personally to me, beginning with the distinction
of the two areas of the "un-discussed". First, there are those issues that aren't discussed that could be and should
be. I agreed, inwardly, thinking hard about my work. Then she pursued what she described as the
"constitutively un-discussable"; those issues that we can't always talk about; that defy our attempts to explain
them: for example, the "other" of otherness, the uniqueness of our own experiences, the necessary vagueness
and "betweeness" of relationships; those things that cannot easily be communicated and the limits of our
abilities to communicate them, including the difficulties of understanding the point of view of another, given that
one can never truly occupy their place. These words (or, at least, my very best attempt at recollection from
hastily scribbled notes) resonated with me so profoundly at a time when I was trying to make sense of it all.

²The seemingly parochial distinction between West and East is made deliberately. Eastern medicine
and culture have a unique range of properties, treatments and cultural ethics which should be explored at another
time. It is widely documented that beliefs about death, disease and illness differ between cultures and are
influenced by cultural differences (see, for example, Fabrega, 1981a: 503; Helman, 1990: 117; Good, 1994: 52;
and friends; and by colleagues.

In this study, the researcher's experiences were considered data as it was recognised that they would influence the outcomes of the research (Drew, 1989: 431; Osborne, 1990: 83). Thus, it was considered vital to include the researcher's perspective (Oiler, 1982: 181; Swanson-Kauffman and Schonwald, 1988: 103), particularly as an 'insider' or 'intimate' to the phenomena (Wilmot, 1975: 59). Hence, the reader will find numerous soliloquies, annotations and reflections included in this story; a term used deliberately. It was deemed vital to spotlight for the reader a modicum of the dramatic life experiences that unfolded for the researcher concurrent to a search for some understanding of the life-world and perspective of others with ICI.

Another question that plagued this researcher is what one may have achieved from this endeavour and how it should be undertaken. The reader may find this work an example of what Clifford Geertz has called 'blurred genres' (Gergen, 1991: 113); the inroads of postmodernism are undeniable in this work, an outgrowth perhaps of the 'postmodern consciousness' (Gergen, 1991: 111), an exemplar work from a scholar who has felt 'free to combine and synthesise in any way that communicates effectively' (Gergen, 1991: 113). Not


Elements of the 'postmodern consciousness' (Gergen, 1991: 111) emerge, even without my being aware. The increasing acceptance of a multiplicity of perspectives demands of this researcher the breakdown of the straightforward, modern, structured, bordered, ordered, simplistic, "truth-seeking" discourse. What unfolds, instead, is the dissolution of these borders through the most creative use of multi-disciplinary knowledge that can be mustered: an eclectic blend of the structure and stream-of-consciousness; of rich stories overlaid with current, and extant, theoretical groundings; of multiple perspectives, mine and theirs.
only does one find oneself in an increasingly postmodern world, but it becomes increasingly
difficult to draw the lines that define the human self, the multiple self, 'and with this
mounting complexity the boundaries grow fuzzy' (Gergen, 1991: 119). This work is an
exemplar of eclecticism. It is not a rejection or denial of modernism; neither is it an
uncritical embrace of the "hard" postmodernist epistemology: to choose either of these paths
would be distinctly modernist and, more importantly, would not serve to tell the story that
this researcher believes desperately needs to be told.

The why of what has been done was similarly elusive: as a researcher in a modern world, the
project commenced, naturally, pragmatically. "Invisible" chronic illness is arguably under-
researched and, whilst strenuously avoiding legitimisation of this work through following
research 'performativity' principles (Lyotard, 1979: 41; Connor, 1989: 32) or focusing on the
'bureaucratic "usefulness" of the project rather than on its broader impact' (Denhardt, 1981:
6), it is acknowledged that the purpose of research and any important definitions should be
laid bare for the reader at the outset.

"Invisible" Chronic Illness (ICI): What Is It?

The author has elsewhere (Vickers, 1993; 1994: 66; 1995a: 121-122) described chronic illness
as an ongoing condition; one which may be physical, emotional or cognitive; one that may,
or may not be, treatable or curable. An "invisible" chronic illness (ICI) is one that entails all

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"Indeed, modernism has 'served as an incubator for the multiplication of competing perspectives' (Gergen, 1991: 87), as evidenced in this work. What is rejected here is the modernist myth of progress built on objectively grounded knowledge (Gergen, 1991: 89); of science perceived as 'pre-eminently rational' and moving, ever forwards, in an inexorable, self-correcting, progressive manner (Gergen, 1991: 90) - the 'ideology of progress' which symbolises all systems of regulation (Denhardt, 1981: 65)."
the above characteristics and combines the attributes Goffman (1963: 65) ascribed to *invisible stigma*: a condition that is not perceptible, not noticeable, not evident to others. In short, a condition "unseen" by others that may arise from disease, disability or injury.

The ICI is likely to have been diagnosed and labelled (deviant) by a medical practitioner (Veatch, 1981; Register, 1987: 3; Turner, 1987; Liggett, 1988: 264; Nijhof, 1995: 200) with all the problems inherent with labelling theory (Gething, 1984; Yelin, 1986: 623-624; Turner, 1987: 73; Liggett, 1988: 275) and associated implications in a normalising society.

The condition's "invisibility" is distinguished here from its 'known-about-ness' (Goffman, 1963: 64-68). Known-about-ness refers to knowledge by other 'normals' about the existence of the condition: an ICI may or may not be known about and, yet, still beget a conflagration of complexities for the bearer. Social interaction may be disrupted by knowledge of the condition alone, for example, for an individual with HIV (Cacioppo, 1988; Sontag, 1988; Stone, 1994: 55). "Invisible" illness may impose limitations on the bearer that disqualify them from fully participating in work-related activities directly, physically, or through labelling, stereotyping, stigmatisation or discrimination.

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6The term "chronic illness" is chosen deliberately, with the researcher believing it to be an area where the boundaries grow fuzzy (Gergen, 1991: 119). Illness frequently "dis-ables" one from doing things that one would like to do, that one must do, that one should do and, sometimes, that one does not want to do. Disablement is, in my estimation, a continuum, not a bin, where PwICl fitfully reside. The visibility of the disability or illness does not confirm a static, or even a shifting, place on the continuum and certainly does not confer residence at either end. Chronic illness is a "shifting" target and where one resides on the disability continuum is a matter of current circumstance, not visible criteria.

4Issues surrounding labelling and normalisation will be detailed in the next chapter.

7Following Susman (1994: 16) the term 'normal' (Goffman, 1963; 1974a; Susman, 1994: 16) is adopted, as others before me have, for convenience and with no pejorative implication intended. The term is used, as Goffman (1963; 1974a) has done, to describe the unmarked.

8These issues will also be fully explored in the following chapter.
The question of "invisibility" must also be considered in terms of the perceived ability of organisational normals to decode (Goffman, 1963) the illness: to "see" the condition and its impact. For example, a person who is intimately acquainted with another who has impaired hearing or has impaired hearing themselves will be far more likely to "see" such a condition. It is proposed here that many organisational 'normals' (Goffman, 1963; 1974a; Saylor, 1990; 65; Susman, 1994) are unsensitised: they do not understand (Goffman, 1963). The stories related in Chapters Five and Six further substantiate this claim.

Donoghue and Siegel (1992: 13) list the following as exemplars of ICI: Charcot-Marie-Tooth disease (CMT); chronic fatigue syndrome (CFS); endometriosis; fibromyalgia; HIV infection; colitis; Crohn's disease; irritable bowel syndrome (IBS); lupus erythematosus; lyme disease; migraine headaches; multiple sclerosis (MS); post-polio syndrome; premenstrual syndrome (PMS); and thyroid disease. In order to further explicate what may be deemed an "invisible" chronic illness, one may add: asthma; arthritis; epilepsy; depression; schizophrenia; cystic fibrosis (CF); diabetes; heart disease; head injuries; multiple chemical sensitivities (MCS); sarcoidosis; nephritis. This list is not intended to be comprehensive and it is recognised that some conditions may result in highly visible manifestations over time. Nevertheless, the examples serve to vivify the number and variability of conditions which may be described as "invisible"; for most of the time, they cannot be "seen" by other people.

In the West, a society valuing "science" has historically taken a reductionist, positivist stance to the chronicling of illness dating back to the positivist theories of René Descartes (1596-1650). Indeed, it has been argued that 'science, as a limited rationality, with overt commitments to empiricism, causality and universality, can constitute a political, as well as
an epistemological choice' (Kouzmin, 1983: 234). Archer (1995: 27-28) wrote that Descartes’ "truths", which included the certainty and "knowability" of scientific discovery, had profound implications: 'people, like clocks, could be understood if they were broken down into small components that could be studied. This process of analysis moved Western medical science progressively and reductionistically through the centuries’. Armstrong (1995: 45) described this approach to treating, researching and chronicling illness and disability as an attempt 'to reduce all illness to a single, intra-corporal lesion and, thereby, through appropriate investigative procedures and treatments, reduces the body . . . to a collection of separate systems, organs, tissues and cells.’ This approach has been deliberately avoided here, positing, instead, the notion that 'persons with different stigmas are in an appreciably similar situation and respond in an appreciably similar manner’ (Goffman, 1963: 156, my emphasis). The research methodology detailed in Chapter Three philosophically supports this anti-reductionist stance, as do the stories articulated in Chapters Five and Six.

Aspects of the centrality of the illness must be considered: How much is illness pivotal to that individual’s life? How much, and what aspects, of life is "viewed" through the lens of chronic illness? Most ICI will have symptoms that affect the bearer: at different stages of illness, invisible (and visible) symptoms may be reflected in acute exacerbations or chronicity, or both (for example, Register, 1987; Schmidt, 1989; Wheeler and Dace-Lombard, 1989; Conant, 1990; Curtin and Lubkin, 1990; Szasz, 1991; Donoghue and Siegel, 1992). Some conditions may be life threatening; some may not. Few will be understood by colleagues because the symptoms cannot be seen (Kantor, 1991: 81; Tate, 1991) or, perhaps, because some in power may not be interested in understanding the experience of another (Fiske, 1993). Being chronically ill presents problems for anyone trying to work. Chronic illness does not
follow the predictable route of warning signs, illness, recuperation and full recovery: 'rather, the sufferer lives with a baseline of unwellness that is interrupted by periods of exacerbation and remission, relapse, and remission' (Donoghue and Siegel, 1992: 56). What has previously been described in organisational life as a 'creeping crisis' (Jarman and Kouzmin, 1994: 407; Korac-Boisvert and Kouzmin, 1994: 68; Kouzmin et al, 1997: 20), a 'protracted crisis' (Korac-Boisvert and Kouzmin, 1994: 68), a crisis that is time related and indicative of incipient decline (Jarman and Kouzmin, 1994: 407) is one which, it is argued here, may also be personally experienced - it is a personal disaster (Raphael, 1986: 5); a chronic disaster:

one that gathers force slowly and insidiously, creeping around one's defences rather than smashing through them. People are unable to mobilize their normal defences against the threat, sometimes because they have elected consciously or unconsciously to ignore it, sometimes because they have been misinformed about it, and sometimes because they cannot do anything to avoid it in any case (Erikson, 1994: 21).

There is a dearth of literature about "invisible" chronic illness, especially in the management and organisational arenas. There have been some works completed that pertain specifically to "invisible" illness, disability or injury (for example, Falvo et al, 1982; Whittington and Wykes, 1989; Baggerly, 1991; Kantor, 1991; Donoghue and Siegel, 1992; Vickers, 1996a; 1996b; 1997a; in press) or to "hidden" illness and disability (for example, Laurent, 1985: 543; Lawson, 1987: 250; Day, 1988: 21; Seymour, 1990: 17; Gaze, 1991: 49; Haydon, 1991: 18; Tate, 1991: 25; Ayala and Lederman, 1994: 9; Polk and Kramer, 1994: 51; Dyck, 1995: 307;
Fitzgerald and Paterson, 1995; Shearer and Davidhizar, 1995). However, few of these works have focused specifically on life and work issues for the Person with "Invisible" Chronic Illness (PwICI). Issues that have been raised include: the difference between appearance and reality (King, 1981); the potentially serious nature of a disease lupus erythematosus, even given its invisibility to others (Kuper, 1994: 26); difficulties surrounding unseen illness at work (Cacioppe, 1988; Tate, 1991; Kantor, 1991); the fact that some hidden conditions, such as psychosis, may constitute medical emergencies (Polk and Kramer, 1994: 51); the revision of the self-concept, disruption of roles and lengthy adjustment processes involved (Falvo et al, 1982: 3); the problems of the stigmatising nature of some "invisible" conditions (Scambler, 1984; Leonard et al, 1989; Jacoby, 1994; Nijhof, 1995; Small, 1995; Vickers, 1996b); the dilemma associated with the disclosure of "invisible" illness in the workplace (Vickers, 1996a; in press); and the fact that chronic illness remains a neglected management challenge (Vickers, 1993; 1995c: 363) and one warranting long-overdue organisational consideration (Vickers, 1993; 1994; 1995c: 365).

Some examples of "invisible" or "hidden" illnesses in the literature include: psychosis (under which the problems of schizophrenia, depression and bipolar disorder are subsumed) (Polk and Kramer, 1994: 51); epilepsy (Scambler, 1984); multiple sclerosis (Fitzgerald and Paterson, 1995: 19); arthritis (Seymour, 1990: 17); heart disease (Johnson, 1991); and chronic fatigue syndrome (Conant, 1990; Manu, 1992; Shepherd and Lees, 1992; Blake, 1993a; 1993b). Other authors have alluded indirectly to the problems of "invisibility" of illness, whilst not

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3The distinction between "hidden" and "invisible" is made deliberately, as Fitzgerald and Paterson (1995: 15) have done, choosing the latter for this research project. Whilst the reader will see in subsequent chapters that much of the time "invisible" illness may be hidden, and certainly the issues surrounding disclosure are complex and compelling, it is this author's contention that whilst the illness is "unseen" it is not necessarily, and certainly not always, "hidden". Hence, the term is chosen with care in the absence of another more suitable.
overtly recognising this, or doing so only in passing. For example, the problems associated with others' lack of understanding of heart disease, including the adjustment and normalising process (Johnson, 1991: 17-19) are made with others not "seeing" what is going on for the affected person. Whilst Jones and colleagues (1984: 29) argue that visibility plays a central role in producing negative perceptions, it is argued here that this may not always be the case.

The "unseen" nature of "invisible" illness may create specific problems: difficulty in diagnosis and assessment by medical professionals when, for example, vague feelings of malaise and fatigue are present; misunderstanding and disbelief by family, friends and colleagues resulting in reduced social support; co-worker fear and ignorance resulting in inappropriate stereotyping, discrimination and stigmatisation; and symptoms such as dysphoria, common in persons with disability or chronic illness (Frank et al., 1992: 231), not being recognised.

Views that reflect the misperceptions of the wider community were also found: "invisible" disabilities were thought to provide the least discomfort for co-workers, compared to visible disabilities (Jones and Stone, 1994: 5); "invisible disability" was often thought of as not being a "real" disability (Stone, 1995: 418). The myth of bodily perfection (Stone, 1995: 413), and that disease and dysfunction is somehow a moral failing (Stone, 1995: 414), stand as testament to the common belief that illness, especially "invisible" illness, is something that can and should be overcome with sheer guts and determination or, at least, lashings of positive thinking.

Some behavioural responses to "invisible" disabilities have been reported. For example, 'covering up' behaviour, underpinned by the need to convey a picture of an essential

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10 Social support, and its associated benefits and difficulties, is discussed at length in Chapter Six.
normalcy (Robinson, 1993: 16) and the need for some to conceal the stigmatising "mark" (Jones et al, 1984: 7), have been reported. Hidden geographies and changing lifeworlds have been highlighted (Dyck, 1995: 307), as has the dilemma of preservation of self and the need for legitimisation of "invisible" or "hidden" illness (Fitzgerald and Paterson, 1995: 15), including the notion of a 'hidden paradox' associated with 'hidden illness' (Fitzgerald and Paterson, 1995: 19): "To reveal one's identity may decrease the problems associated with disbelief but by revealing their identity these people risk other negative responses which can be as damaging, or more damaging, to the sense of self" (Fitzgerald and Paterson, 1995: 19).

An ICI such as MS was described as a 'lonely disease' (Fitzgerald and Paterson, 1995: 19) with PwICI talking about times in their life prior to illness as how 'I used to be' (Fitzgerald and Paterson, 1995: 19). Finally, and very pertinentlly, Watters and Biernacki (1989: 417) highlighted the problems of researching hidden populations.

There are parallels in the issues facing people with "invisible" chronic illness and those with more visible disabilities. Indeed, many people with chronic illness may also be disabled, although the reverse is not necessarily true. Whilst the popular notion of physical disability is frequently aligned with a dependence on, or use of aides for, mobility (such as a wheelchair) or self-care tasks of feeding, washing, toileting and dressing (Tate, 1991: 25), physical disabilities may be very real and yet not be seen: fatigue can be a most debilitating

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11 Other paradoxes will become evident as this volume unfolds.

12 Assumptions that all disabled people must use wheelchairs is promoted by the use of the universal disability symbol (depicting a person seated in a wheelchair) which is used to designate, for example, disabled parking or disabled toilet facilities. Such assumptions in the wider community may present problems for people with "invisible" disability making use of such facilities. Reports in the literature confirm that people who don't "look" disabled may be routinely challenged in car parks (Szasz, 1991: 75; Donoghue and Siegel, 1992: 63). The author certainly has been verbally challenged although, worse, is the venomous stare or judgemental shake of the head.
symptom for many chronically ill individuals (Wheeler and Dace-Lombard, 1989: 47) and stands as a basic mobility resource (Miller, 1992c: 197), with physical strength being regarded as a 'power resource' in overcoming powerlessness (Miller, 1992a: 9). Looking able-bodied part of the time can create much confusion (Gaze, 1991: 50).

Conversely, a disability "status" may be incorrectly attributed to the chronically ill person based on the perceived future abilities (or inabilities) of that person, whether these are accurate or not. Employers face difficulties in assessing the abilities of people with visible disabilities: this difficulty is magnified when the disability cannot be seen (Kantor, 1991: 81). They may either ridiculously underestimate or far overstate the person's capabilities. One case reported a young police woman with MS (Kantor, 1991: 81) who was reassigned to a more physically demanding job. Another case described a woman with head injuries and subsequent cognitive impairment. She found others' incorrect assumption was that her deafness was the primary disability, when memory loss presented her with much greater difficulties (Brown, 1992). Psychosocial disability is similarly "invisible", referring to the 'repertoire of skills needed to function independently in the community . . . vocational/avocational, interpersonal relationships and living skills' (Tate, 1991: 25), and may be similarly misjudged by others.

The notion of what constitutes an "invisible" chronic illness has been defined. The current literature has been canvassed and this researcher's conclusion is that the documented concerns seem to be the "tip of the iceberg"; an indicator of a much greater problem and one worthy of further exploration. The reader needs to be cautioned, however, that neither the research approach, nor the outcomes, are presented from a positivist, rationalist, objectivist or
functionalist viewpoint. Needing to start somewhere, research begins with pragmatic concerns: these comprise the beginnings of a frame of reference, a commencement to contextual understanding and the reinforcement of the potential magnitude of issues later elucidated. These pragmatist notions are germane to discussions in this introductory chapter, but are not a hypostatic component of this work.

**Pragmatic Concerns**

Chronic illnesses are now the biggest form of health problem confronting medicine (Fitzpatrick, 1984: 29).

Critical and acute illness is abating in Western society (Nettleton, 1995: 11) with this being due, in large part, to improved nutrition and hygiene and, perhaps, to a lesser extent, to advances in medical science (Bennett, 1996: 1). Conversely, one sees that chronic illness is an increasing phenomenon (Kubler-Ross, 1969: 2; Fitzpatrick, 1984: 20; Gould, 1985; Turner, 1987: 8; Helman, 1990; Nettleton, 1995: 11) and, consequently, one that must impact on the workforce. The Australian Bureau of Statistics (ABS) reported, in the 1977-78 Australian Health Survey, 45 per cent of Australians with one or more chronic conditions (Goldstein, 1983: 54), with the 1989-90 National Health Survey reporting **66.2 per cent of Australians with a chronic or long-term condition** (ABS, 1990). Whilst it is recognised that chronic

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13 Not that everything one reads from the ABS is deemed correct, nor worth referencing. For example, the ABS (1992) report Persons Not in the Labour Force shows a rather interesting taxonomy: Table 6 (ABS, 1992: 12) shows various reasons why people were not actively looking for work. One category was entitled 'Own ill health/physical disability/pregnancy'. It is argued that such category contamination is medicalised, illogical and patriarchal. Unfortunately, the ABS are not done in this; seminar discussions have highlighted the ubiquity of the belief (especially from male colleagues) that pregnancy should somehow be considered an illness.
illness and disability predominates in the aged population (persons aged 60 years or over) (ABS, 1988: 1), this problem cannot be dismissed as only affecting the aged in the community, although it becomes increasingly vivified in an aging workforce (ABS, 1988: 2; Buhler, 1991: 17; Vecchio et al, 1992: 9). In 1988, over one million Australians (of the then population of approximately 16 million) between the ages of 15 and 60 years of age (of working age) were considered by the ABS to be disabled (ABS, 1988: 2). The 1989-90 National Health Survey indicated that, for the same working age group, there were over 8 million reports of long-term conditions (although it is noted that each person reporting may have reported more than one type of illness) (ABS, 1990: 23).\textsuperscript{14}

Having a disability reduces your chances of getting a job (Gaze, 1991: 49). Problems associated with employment have long been explored for people with disabilities (for example, Safilios-Rothschild, 1970; Blaxter, 1976; Junor, 1985; Northdurft and Astor, 1986; Yelin, 1986; 1989; Buhler, 1991; Navran and Zibula, 1991; Robins, 1991; Weisenstein and Koshman, 1991; Gilchrist, 1992; LaPlante, 1992; Rayner, 1992; Hooijberg et al, 1994; Klimoski, 1994; Jones and Stone, 1994). However, less attention has been given to these same problems for people with chronic illness: concern for those who are working and also have a chronic illness is long overdue (Vickers, 1993; 1994; 1995a), especially when the disability cannot be seen. The introduction of anti-discrimination legislation in the areas of gender, religion and race has been implemented in Australia for a number of years. More

\textsuperscript{14}Some may reasonably argue that only spurious conclusions can be drawn from these figures, given the definitional and statistical reporting differences. However, other sources confirm that chronic illness is increasingly problematic in the West due, in part, to increasing longevity arising directly from improved treatment of acute and life-threatening conditions (Bates and Lapsley, 1985: 193-194; Gould, 1985: 4-7; Turner, 1987: 8; Nettleton, 1995). It is reiterated that this thesis is epistemologically anti-positivist (Surrell and Morgan, 1979: 5); the statistics included are purely to elucidate and exemplify a potential problem rather than to "scientifically" and unequivocally demonstrate "truth".

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recently, the enactment of the Federal *Disability Discrimination Act* (DDA, 1992) in Australia makes it unlawful to discriminate against people on the basis of their disability in areas such as:

work, accommodation, education, access to premises, clubs and sport; and the provision of goods, facilities, services and land; and existing laws; and the administration of Commonwealth laws and programs (DDA, 1992: 2).

The DDA promotes equal rights for the disabled, as well as trying to promote recognition and acceptance of disabled and chronically ill people’s rights within the community (DDA, 1992: 2). It is argued that the DDA, administered by the Human Rights and Equal Opportunity Commission (HREOC), was far better than the previous state-by-state legislation where communities were afforded different (or no) levels of protection depending on the location of the alleged discrimination. It is relevant here to mention the experience of the United States of America (USA) where, similarly, prior to the *Americans with Disabilities Act* (ADA) a melange of disparate programs was also administered on a state by state basis (Putney and Atchley, 1994: 25). The ADA was regarded as a potential catalyst for initiating change in the US community, not just in the employment and judicial setting, but with the spirit of the law enabling opportunities to open for qualified individuals (Putney and Atchley, 1994: 26).

Unfortunately, there have been some unintended and unforeseen side effects of the ADA; for example, the fear of litigation resulting in this legislation actually *increasing* discrimination against the disabled, rather than reducing it (Klimoski, 1994) and a lack of understanding of the implications of the legislation (Bento, 1994: 12). Weakening of the powers of the DDA have similarly been evident. A High Court decision in February 1995 arguably overshadowed
the perceived power of the new DDA legislation: findings and financial compensation ordered by the HREOC were made constitutionally invalid; the High Court found the Commission could not operate as a court as it was unconstitutional (Farr, 1995). The powers of the HREOC were substantially reduced (Toten, 1995): a "toothless tiger" left to uphold the intentions of anti-discrimination legislation.\footnote{Discourse on legislative changes would not be complete without some consideration of the political underpinnings of these decisions. In 1992, during "Ability Week", the then Minister for Science and Technology, Ross Free, gave a speech describing the importance of making employers aware of the capabilities of people with disabilities and the difficulties they face (Free, 1992). A thinly veiled political agenda was evident with the speech encompassing substantial praise for the then labour government's Disability Reform Package. The recent "watering down" of the powers of the HREOC could be construed as similarly political: regardless of the positive aspects of tribunal court proceedings administered by the HREOC, the High Court justices of Australia appear not to want "dripot" tribunals usurping their powers in any way.}

Legislation cannot force a positive change in people's perceptions (Noel, 1990: 27) and is no guarantee of immediate implementation of affirmative action programs (Kramar, 1988: 322), nor of responsible administering of equal opportunity management plans (Kramar, 1988: 322). It remains to be seen what long term impact the DDA will have on perceptions of employers in Australia.\footnote{This would be a worthwhile research project in itself, but beyond the scope of this work.}

Living in a capitalist society, the pragmatist would be remiss not to consider economic issues. The hiring of the disabled has been proffered as the solution to economic problems, due to the problems of the shrinking labour pool, the aging population and the need to utilise every possible resource to its best advantage (Buhler, 1991: 17). Additionally, concerns with increasing numbers of people on the invalid pension and disability panels reporting low levels of employment (Taylor, 1992: 1-5) are confirmed by ABS research - according to ABS Projections of the Populations of Australia, States and Territories, 1987 to 2031 (cited in
Vecchio et al, 1992: 9), 'the median age of the Australian population in 1971 was 27.5 years while the projected median age for the year 2001 is around 35.7 years'. Further, it is noted that 'disability and handicap increases with age' (ABS, 1988: 1). Changing patterns of illness indicate that infectious disease stopped being the major cause of death in Western societies about sixty years ago, with more than half of current deaths from heart disease, a fifth from cancer and the rest in accidents or respiratory diseases (Bates and Lapsley, 1985: 193). Chronic illness, a twentieth century phenomenon, is 'considered to be the number one health problem in the United States' (Hastings, 1992: 222). They are now slow rather than quick deaths (Bates and Lapsley, 1985: 193, my emphasis), which need recurrent care and which are often disabling (Bates and Lapsley, 1985: 194).

The result? The burden of cost on taxpayers: in Australia, during the six years between 1984 and 1990, there was a 46 per cent increase in the combined amount paid to recipients of Age and Invalid Pensions, from $A7,109,000,000 to $A10,862,000,000 (ABS, 1991: 32). Even with inflation accounted for, such an increase should be of concern, especially when the combined increase in the number of recipients was only five per cent! One can intuitively see that an aging workforce results in fewer working to support an ever increasing number of aged and invalided pensioners (and retirees). With the number of Australians having a disability in 1988 at greater than 2.5 million (ABS, 1988: 1), the Australian economy endures a substantial proportion of the population having markedly reduced spending power due to survival on a pension. 45 per cent of income units containing disabled people state that their principal source of income was a government pension or cash benefit (ABS, 1988: 1 and 5). Whilst strenuously denying functionalist and economic rationalist arguments as being a primary motivation for this work, the issue of cost cannot be ignored.
From an organisational perspective, there are those who suggest convincing management that equal access to employment for disabled or chronically ill individuals is a good business strategy (Noel, 1990: 26; Free, 1992) requiring a major change in management and co-worker attitudes and perceptions, away from being charitable towards disabled and chronically ill, to being based on good business sense (Buhler, 1991). Disabled workers are variously described as being reliable, productive and dependable (Noel, 1990: 30; Buhler, 1991; Free, 1992), with a USA survey finding that, almost universally, employers disagreed with the statement that 'handicapped people just don't fit in with most nonhandicapped employees'. Additionally, nearly 50 per cent of top managers rated the job performance of employees with handicaps to be better than that of non-handicapped employees in the areas of 'willingness to work hard, reliability, attendance and punctuality on the job' (Noel, 1990: 30). Junor (1985: 298) confirmed that 'not only can they be quite usefully employed, they may prove to be better investments than the able-bodied' (Junor, 1985: 298).17 For the functionalist, then, Stephen Hawking's life illustrates that people with disabilities may not only offer equal benefit, but may be of far greater value than their able-bodied counterparts:

Hawking's practical uselessness became one of the positive side effects of his illness. It may take him a long time to get up and go to bed, but he doesn't have to run errands, do home repairs, mow the grass, make travel arrangements, pack his suitcase, draw up lecture schedules or serve in time-

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17Comments such as these are arguably nauseating and extremely patronising, but are characteristic of some community, business (and academic) attitudes towards people with disabilities in a functionalist society. The author has previously referred to other people's attitudes as 'the most malignant disability' (Vickers, 1994: 67), including some mention of them here as part of the conceptual attitudinal map which must necessarily portray the ubiquity of such attitudes towards people with illness and disability, even from those who purport to be on their side. The attitudes of 'normals' are variously described as: remaining a barrier for the disabled (LaPlante, 1992), the major problem facing those with disabilities and chronic conditions in the workplace (Kantor, 1991) and especially problematic in a modern context (Woffensberger, 1994).
consuming administrative positions in the DAMTP or at Caius. Such matters are left to Hawking’s colleagues and assistants and to his wife. He can spend all his time thinking about physics, a luxury which his colleagues envy him (Ferguson, 1991: 88).18

The situation remains that "problems in employment of disabled people arise from poor understanding of disablement by employers and the community generally, poor occupational preparation and self-presentation by disabled workers, and the current tight job market" (Junor, 1985: 295). Nowhere, it is argued here, is that lack of understanding greater or more pervasive than with "invisible" illness.

Numerous pragmatic reasons have been cited for this research: legal requirements (DDA, 1992); the dwindling labour pool and an aging population (ABS, 1990; Vecchio et al, 1992); the ubiquity of chronic illness in modern times; and the problems that present in an economic rationalist social framework. To conclude, thoughts from Huxley’s (1932/1983) chilling social commentary, Brave New World. We join the 'Director of Hatcheries and Conditioning' who speaks to the imperative of hastening the maturation process of Epsilons; human beings decanted and produced solely for use in low-level factory work:

If they could discover a technique for shortening the period of maturation, what a triumph, what a benefaction to Society! ..."But in Epsilons," said Mr. Foster very justly, "we don’t need human intelligence." Didn’t need and didn’t

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18One may reasonably ask whether Hawking’s colleagues similarly envy the fact that Hawking is unable, even if he wanted, to mow the grass or pack his suitcase; and whether they have even thought about that.
get it. But though the Epsilon mind was mature at ten, the Epsilon body was not fit to work till eighteen. Long years of superfluous and wasted immaturity. If the physical development could be speeded up till it was as quick, say, as a cow's, what an enormous saving to the Community! (Huxley, 1932/1983: 27-28)

One may argue that we are not far from such thinking today.

**Humanitarian Motives**

No-one has, to the knowledge of Thomas Szasz, ever advocated an ethic of 'inhumanism' or referred to themselves as an 'inhumanist' (Szasz, 1977/1988: 87) and, yet, all around us are examples of same. Whilst having postulated (or at least acknowledged) pragmatic reasons motivating this research, humanitarian concerns are deemed to be of greater import to this researcher: there is a perceived need to consider other people without the voice of capitalism amplifying the motive. Where have humanitarian concerns disappeared to? What has happened to concern for other people because it is warranted rather than because it is profitable?

The principles of avoiding harm to others, respecting the autonomy of others, avoiding lying and honouring agreements (Quinn and Jones, 1995: 30) should apply in all settings, including organisations, and should not be overshadowed by the commonly held belief that shareholder wealth takes precedence. The economic rationalist setting for organisations encourages, instead, an 'instrumental ethics' - a language of ethics, used predominantly to serve the goal
of firm value maximisation (Quinn and Jones, 1995). Surely, one needs to consider something other than money:

Despots and ruling cliques can succeed in dominating and exploiting their fellow man, but they cannot prevent reactions to this inhuman treatment. Their subjects become frightened, suspicious, lonely and, if not due to external reasons, their systems collapse at some point because fear, suspicion and loneliness eventually incapacitate the majority to function effectively and intelligently. Whole nations, or social groups within them, can be subjugated and exploited for a long time, but they react (Fromm, 1956: 18, emphasis in the original).

If Fromm’s insights are applied to the organisational setting, this research may be regarded as one such reaction. The idea of people living ethical (as opposed to purely self-interested) lives is not new (Singer, 1993): noninstrumental ethics, or principled moral reasoning (Quinn and Jones, 1995: 23), portrays the assumption that morality is intrinsically good, and important, and should not be justified with reference to the gain of shareholder wealth. The ‘agent morality’ view of business policy, where managers should develop business policies with first regard to moral duties and second regard to shareholder wealth, should be a philosophical perspective on the moral obligations of managers (Quinn and Jones, 1995: 22). However, it is recognised that ethical values do not exist in a social vacuum (Child, 1987; cited by Korac-Boisvert and Kouzmin, 1994: 71) and that contextual factors have a bearing upon the ethical conduct of organisational actors (Korac-Boisvert and Kouzmin, 1994: 71):

‘Our actions can never be fully explained without due consideration for the social practices
and social institutions which surround us' (Denhardt, 1981: 68). Organisations provide standards of moral behaviour that may be impersonal and morally untenable for the individual, and yet may, through its own logic, accept blame for amorality - the "system" becomes the means of defence (Denhardt, 1981: 12-13). The administrative and the rational dominate, rather than a moral (Denhardt, 1981: 13): 'We are time and time again confronted with instances in which the viewpoint of the organization takes precedence over individual morality' (Denhardt, 1981: 13).

It is argued in later chapters that it is frequently the individual manager (or other organisational members) who consciously, or unconsciously, are responsible for causing much harm to PwICl, a direct result of the ideologies of capitalism and managerialism, and the managerialist imperatives of efficiency and control. The principal-agent model (Quinn and Jones, 1995: 32) reminds one that moral principles are 'antecedent to the contract between the principal and the agent' (Quinn and Jones, 1995: 35) - making money is not necessarily the most important thing. To finish:

moral philosophy is philosophical inquiry about norms or values, about ideas of right and wrong, good and bad, what should and what should not be done .... Moral philosophy cannot, and does not try to, tell us what we ought to do. We must decide that for ourselves (Raphael, 1994: 8-9).

At one level, this work is one of philosophical inquiry; of considering what is happening to PwICl and of thinking about that. This is not a work that will tell one what one ought to do; but it is research that may prompt a re-examination of standard practice; that may promote
a reflexive analysis, the questioning of previously unchallenged dogma (Kouzmin, 1980: 131) and one that may shift the focus of attention - a form of collective and professional reflexivity (Gouldner, 1976).

**Epistemological Imperatives**

The fact that a situation is ubiquitous does not absolve us from examining it. On the contrary, we must examine it for the very reason that it is or can be the fate of each and every one of us (Miller, 1983: 197; cited in Tal, 1996: 1).

Epistemological imperatives are a central justification for this research. When considering the subjective-objective dimensions of this research (Burrell and Morgan, 1979: 3) and the epistemological stance taken, a distinctly subjectivist standpoint emerges: a stance upheld by a clearly ideographic (versus nomothetic) research methodology (Burrell and Morgan, 1979: 5) (as detailed in Chapters Three and Four); a distinctly anti-positivist (Burrell and Morgan, 1979: 5) research flavour, with an ontological dimension that is clearly nominalist (Burrell and Morgan, 1979: 5). The 'human nature' debate seems to be unquestionably voluntarist in emphasis (Burrell and Morgan, 1979: 6).

It is epistemological imperatives that burn brightest: the desire to tell the PwICP’s story; to ensure the voices are "heard"; to learn what has not yet been learned. Kellehear’s (1989) research into the experiences of those with terminal cancer mirrors this research effort - clearly, there was a heartfelt belief by all involved that the story should be told:
The reason for the high participation rate (only four out of 104 declined to participate); the reason why only one person withdrew mid-interview; the main reason why embarrassment, pain, the absence of voice boxes and the presence of tears did not deter, was the explicit and persistent belief that others should know their story and that others might benefit from knowing it. I believed it too. Together we strapped ourselves in to weather the consequences of our mutual belief in the value of this research. It seems that most people want to leave something of themselves to others. When one is dying, this is even stronger. The actual benefit to the participant is hard to define. The hurt experienced by researcher and participant is difficult to endure (Kellehear, 1989: 65-66).

The intrinsic value of this research is of personal interest to the researcher and combines with the notable lack of past research into ICI, especially in organisational life. Literature addressing chronic illness is mostly found in nursing, health and illness sociology, disability and rehabilitation, and occupational health and safety arenas. There has been little to specifically address the concept of a non-work-related "invisible" chronic illness and the potential problems for PwICI at work, especially research valuing the primacy of subjective experience. Indeed, it has been suggested that giving primacy to the growth of the individual rather than the efficiency of the productive process is a necessary, yet 'radical reordering' of priorities (Denhardt, 1981: vii). The value of new knowledge in this area cannot be underestimated. In order to potentially ameliorate the working life of PwICI, one must know and understand what one is dealing with:
It can be argued that perceivers form and maintain prejudice not only because they are under the influences of social, group, motivational or cognitive factors that promote prejudice, but also because they either lack the alternative knowledge structures, cognitive capacity, ... or motivations ... to categorize, evaluate and explain social stimuli according to the standard of the social reality or justice or have never been exposed to the opportunity for the accurate knowledge construction (Sun, 1993: 1153, my emphasis).

Knowledge is needed about the existential and ontological life experiences of PwI CI. Until their voice is heard, one cannot consider its impact, its implications or compare it with the voice of others.

Research Objectives

Following Sarantakos (1993: 16), the theoretical research objectives are defined here (and revisited in Chapter Three). They are:

1. To explore the psychically and socially constructed workplace reality for PwI CI, as interpreted by individual actors;

2. To (hermeneutically) interpret these subjectively experienced phenomena; in particular, what is the lived experience of PwI CI, their response, and the experiences and issues of deepest concern to them;
3. To explore themes and build possible linkages and explanations about the subjective interpretations reported by PwICl and their work-world through thematic analysis of multiple case-studies;

4. To aid in the amelioration of the working lives of PwICl, including the empowerment and emancipation of PwICl in organisations, by understanding more about life and work with ICI, recording the reported experiences, identifying what the issues of import may be, and attempting to explain why they may exist; and,

5. To assist organisation theorists and practitioners in understanding the issues and problems that exist for a sizeable proportion of the workforce.

Thesis Outline

This thesis consists of seven chapters. The reader is soon to conclude Chapter One, which acts as an introduction and some form of justification for research in this area. The introductory sections serve also to introduce some of the contextual factors of importance. Chapter Two serves as a guiding theoretical framework for the research effort based on a literature review, discussions with other PwICl, colleagues and, of course, the personal reflections of the researcher. As the reader will find, it reveals a very complex research setting indeed. Much thought, and appraisal of the views of others (written and otherwise), was undertaken before settling on the preferred research methodology which is set out as transparently as possible in Chapter Three. The Heideggerian, hermeneutical
phenomenological approach (which recognises the importance of both personal and sociological factors, including the need for the researcher's "prepared mind" prior to entering the field) is set out, as are the philosophical imperatives for selecting such an approach. Chapter Four documents the research design and process, the problems encountered, limitations of the study, even serendipitous outcomes.

Chapters Five and Six constitute the phenomenological model which documents the themes, concepts and clusters developed through long and arduous reflection, field note transcription, coding, review and analysis. These two chapters, it is hoped, closely reflect the voices of the PwICl who participated in this research. Chapter Seven concludes this volume, recognising the 'fractured identities' (Haraway, 1991: 155) of PwICl (the researcher included) and asking many difficult questions - questions that may have no answers. Future research directions are canvassed in light of new knowledge, both substantive and methodological, through the kaleidoscope that critical postmodernism (and critical modernism) offers researchers today.
CHAPTER TWO

The Life-World of People with "Invisible" Chronic Illness (PwICI): Complex and Challenging

A Theoretical Framework: A Social Constructionist Paradigm

In order to make some sense of the world of chronic illness and its impact on the PwICI and, because of the complexity of issues involved in constructing the "reality" of illness in the workplace, there has been an endeavour to model the author's understanding; a "view of the world"; a conceptual framework (Miles and Huberman, 1984: 28) which 'explains, either graphically or in narrative form, the main dimensions to be studied--the key factors or variables--and the presumed relationships among them' (Miles and Huberman, 1984: 28). This requires addressing fundamental elements of sociology: the meaning of social action, the relationship between human agency and the structural determination of social relations (power), and the problem of social order and integration through the presence of 'consensus and constraint' (Turner, 1987: 3).

A model of the PwICI's 'lifeworld' (lebenswelt) (Kvale, 1983: 184 and 195; Cohen, 1987: 33; Good, 1994: 116; Dyck, 1995: 307; Nijhof, 1995: 193) is presented to illustrate the researcher's understanding of the complex network of social and psychological forces that interrelate and act upon the PwICI. Miles and Huberman (1984: 28) describe this as a laying out of bins; bins that are derived from both theory and experience and which are set out to
give some clarity about the interrelationship between "entities" of import. This is articulated using the fundamentals of social constructionism, as posited in Schutz's (1932/1967) *The Phenomenology of the Social World* and, later, Berger and Luckmann's (1966) *The Social Construction of Reality*. These seminal works emphasise the socially created nature of social life - that "reality" is produced by human beings; an interpretive mesh of individuals and groups:

We cannot compartmentalize each other. We cannot consider the environment independent of the ways in which people construe their environments . . . nor can we consider person's experiences of their environments without considering ways in which those environments have influenced person's experiences of them (Osborne, 1990: 80).

This depiction is not supposed to include every possible "entity" of interest, content or contact; it is an attempt to describe to the reader where the boundaries of this research lie, and why, and how the "entities" nominated interrelate in ways that, it is argued here, profoundly affect the lives of PwICIs. It is used to "set the scene" and, whilst much of the discussion in this chapter does not include ideas of novelty, what is new is the application of current and extant theory to a group of individuals not previously widely considered (PwICIs), especially in the context of the workplace and using a methodology not routinely utilised in the organisational literature. In order to understand this life-world, it was important to take into account social, ontological and personal characteristics and influences. It was recognised that:

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19 Indeed, it is acknowledged that the nominated "entities" are social constructions in themselves, but one has to start somewhere.
Whoever, then, wishes to analyze the basic concepts of the social sciences must be willing to embark on a laborious philosophical journey, for the meaning-structure of the social world can only be deduced from the most primitive and general characteristics of consciousness (Schutz, 1932/1967: 12).

The author has borrowed from Turner's (1987: 4-5) model of sociology of health and illness. Turner described three levels of analysis: individual, social and societal. Using part of Turner's model allowed description suitable to the intended purpose. The domain of interest for this research included the individual or phenomenological perspective and, clearly, a thorough understanding at this level necessitates a diligent excavation of what Turner described as the social level. The discussion that follows was developed from an extensive literature review, personal experience, informal discussions with PwI CI and much thought.

Without sufficient understanding of what social and environmental pressures exist for the PwI CI, there is little hope of being able to "hear", much less understand or interpret, the existential experience. A sociological perspective is needed, including both a micro level (what people do and why) and a macro level (such as the social organisation of the community including the economy, education, religion and employment) and the integration between the two (Thorogood, 1992: 43). Cooley's 'looking-glass self' (Horton and Hunt, 1972: 94; Scheff, 1994: 284) suggested that a person's self-image may bear no relation to fact, comprising our perception of how we see others, our perception of their judgements of us and our feelings about those judgements (Horton and Hunt, 1972: 95). There is no question

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20. The third level of Turner's (1987) analysis involved health care systems and politics of health at a societal level. These were deemed to be beyond the scope of this study, although a general review of the medical profession was included because of their perceived direct influence on the lives of PwI CI.
that socialisation and culture have an influence on the life of PwICI: illness is a socially constructed phenomenon (Turner, 1987: 18; Nettleton, 1995: 18), as is identity.

"Entities"²¹ of Influence: Illness in the West

The inclusion of an entity incorporating aspects of "Western society" may, for some, raise more questions than it answers. Such an amorphous concept begs some description of what is really intended. The researcher is concerned with the aspects of Western society that influence PwICI: culture and ideology, especially that which unleashes capitalist, individualist and functionalist expectations that are socially constructed; (mostly negative) attitudes towards illness and disability and, finally, issues surrounding the constructs of deviance, labelling, stigmatisation and discrimination.

The Constraints of Capitalism²²

The most pernicious constraint ever laid on a public organisation is the doctrine of efficiency, a precept that appears so self-evident and so much a

²¹ Use of the term entity is used here in lieu of another that is better. It includes any thing, person, group or concept of interest: ‘Something having real or distinct existence; a thing, especially when considered as independent of other things’ (Wilkes, 1979: 488).

²² This section is not intended as a critique of capitalism - such a discussion would require a thesis in itself and would certainly demand a heavier emphasis on critical theory (for example, Fromm, 1942/1960: 1956; 1962; Adorno, 1951; Marcuse, 1964; Giddens, 1982; Habermas, 1987; Agger, 1992; Therborn, 1996: 56) as explored by the Frankfurt School (Gouldner, 1976; Burrell and Morgan, 1979: 291; Denhardt, 1981: 60; Agger, 1992) under the leadership of Max Horkheimer (Denhardt, 1981: 60): its core - ‘the Marxist concept of exchange’ - in a capitalist society (Therborn, 1996: 57) and associated processes of social formation, state functioning and economy (Therborn, 1996: 57); the positivist debate (Burrell and Morgan, 1979: 291; Therborn, 1996: 58); the problems of capitalist, bourgeois, money-focused organisations (Adorno, 1951: 34); technology being seen as a political force and an increasingly effective means of domination and social control (Burrell & Morgan, 1979: 293); and even delving into the views of "Western Marxists" (Merleau-Ponty, 1955; cited in Therborn, 1996: 62). What is intended here, instead, is to underscore only those aspects of capitalism which were viewed during the embryonic stages of this work to be likely concerns for PwICI as they live and work.
matter of common-sense, as to be beyond doubt. If, however, common-sense is not enough of a warrant, we have the weighty pronouncements of economists, accountants and junk-bond peddlers who continually urge that our salvation is to be found under its banner (Landau and Chisholm, 1995: 67).

The calculated, rationalist, utilitarian notion of capitalist life, described by Weber in *The Protestant Ethic and the Spirit of Capitalism* (1904-5/1958: 18; cited by Beilharz, 1991: 225), no doubt exacerbates problems for the chronically ill in organisations: negativity is associated with illness due to the real, or perceived, dysfunctional performance of social roles. Capitalism is central to the Western notion of success and underpinning the essence of capitalism is the need for fully functioning individuals to provide utility to organisations. The problem of health is intimately involved in the functioning prerequisites of the social system, in that any level of illness that takes the individual below optimal capacity becomes a problem for a functionalist society (Parsons, 1951: 430). Health is regarded as a commodity; a resource in a capitalist structure (Turner, 1987: 172).

Reflection on Huxley’s (1932/1983: 27-28) fictional *Brave New World* emboldens the possibilities for efficiency gone awry. Is this what is desired in modern organisations? The primacy of efficiency is so firmly ensconced in our Western psyche as to have become a guiding truth (Landau and Chisholm, 1995: 67). Whilst there are those who seek a humanitarian emphasis in corporations and research settings for its own sake (for example, Kellehear, 1989: 70-72; Fine, 1993: 267; Kendler, 1993; Sarantakos, 1993: 23; Singer, 1993; Erikson, 1994: 239; Lipson, 1994: 340; Stone, 1994: 58; Jones, 1995: 412; Quinn and Jones, 1995), in the West society inherently views illness as 'abnormal' (Maslow and Mittleman,
1981), even "bad", in that it reduces member productivity and utility: sick individuals don't fit happily, or neatly, into capitalist structures.

Individualism can be instrumental in sustaining negativity toward illness: society frowns upon the sick person who does not do everything in their power to achieve wellness\(^\text{22}\) and, additionally, on those who would knowingly disseminate a communicable disease (Lambert and Lambert, 1979: 4). Members of society are inclined to see an illness, not just as being the responsibility of the individual concerned, but also as a failure on the individual's part to adhere to exercise or hygiene regimens, or appropriate diets. Thus 'the structural and environmental causes of illness are obscured by this individualistic approach, reflecting the individualism of capitalist society' (Turner, 1987: 173). Finerman and Bennett's (1995: 1) editorial entitled *Guilt Blame and Shame in Sickness* confirmed this concept.

Organisational members also see illness as the responsibility of the individual, especially when economic conditions allow: 'Where there is an abundant supply of labour, the owner of capital does not have to take responsibility for the health of the worker. Where the supply of human capital is highly elastic, the capitalist employer can readily replace the workforce with fresh supplies of labour' (Turner, 1987: 172). Virtanen's (1994: 394) study confirmed the existence of an 'epidemic of good health' in an organisation that overtly threatened the jobs of workers who took "too much" sick leave. Certainly, since the late 1980s in Australia, there has been an abundant labour supply enabling employers plentiful choice. Thus, with the exception of occupational health problems that are recognised as being the responsibility of the employer

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\(^{22}\) One respondent indicated that no matter how much she "tried" to get well, failure to achieve wellness was not well received by some of her friends. She believed that she was thought not to have been praying enough, thinking positively enough or trying hard enough.
in Australia, most organisations happily absolve themselves of any responsibility for illness brought to the workplace; though they may do so at their peril.\textsuperscript{24}

Additionally, the individualistic emphasis of capitalism creates another problem for PwICl: 'The structure of modern society affects man in two ways simultaneously: he becomes more independent, self-reliant, and critical, and he becomes more isolated, alone, and afraid' (Fromm, 1942/1960: 90). The "freedom" associated with capitalism, a freedom from the traditional bonds of medieval society, has resulted in new feelings of independence. This "freedom" has also left 'modern man' [sic] to 'feel alone and isolated, filled him with doubt and anxiety, and drove him into new submission and into a compulsive and irrational activity' (Fromm, 1942/1960: 89).

The intervention of state in the lives of PwICl is also of concern. Turner (1987: 193-194) asserted that legislation protecting individual rights in the areas of health at work, occupational hazards and stress-related illness is less than adequate, especially when contrasted with legislation protecting, for example, private property. Even with advancements in protective legislation (as outlined in Chapter One), certainly there is evidence, in Australia, that surveillance of the chronically ill is far-reaching: the Roads and Traffic Authority (RTA) demonstrate aspects of Bentham's Panopticism (Foucault, 1977: 249) in their unobserved

\textsuperscript{24}Examination of the Occupational Health and Safety Act (Brooks, 1993) demonstrates that employers have a bona fide obligation not to further exacerbate an existing illness or disability. This issue was raised in Australia with the case \textit{Zanardo v. Continental Check Point Pty Limited} where the question of reasonable foreseeability was tested with a worker who was susceptible to hearing impairment at a level of noise that would have affected only three per cent of the population. Australian employers may be surprised to learn that the Supreme Court of New South Wales (Court of Appeal) found that, even if the condition is only found in approximately one in every 33 persons in the community, this is significant enough to warrant consideration from an employer: 'If there is a greater risk of injury to a worker with a disability, in that the injury is more likely to happen because of the disability, then the accident to that worker may be reasonably foreseeable even though it would not be foreseeable as happening to another worker' (Brooks, 1993: 56).
surveillance of road users. Anyone who has a condition which may affect their driving, either currently or in the future, must declare the condition responsible to the RTA. The details of the individual and the condition will then be placed on a database allowing unobserved monitoring of the health of that individual. The corollary of this is the need for approval from a medical practitioner to determine the individual’s ongoing ability to drive a car. This medical check for a driving licence is made at intervals determined by the RTA\textsuperscript{25}. The individual affected has no input to, or recourse from, this particular state intervention. One is reminded of Marcuse’ (1964: 6) fears:

As long as they are kept incapable of being autonomous, as long as they are indoctrinated and manipulated (down to their very instincts), their answer to this question cannot be taken as their own. . . . The more rational, productive, technical, and total the repressive administration of society becomes, the more unimaginable the means and ways by which the administered individuals might break their servitude and seize their own liberation (Marcuse, 1964: 6-7).

Support organisations may engender powerlessness. Whilst recognising some of the positive

\textsuperscript{25}What is most infuriating about this particular surveillance is the subjective, and arbitrary, nature of its enforcement. The medical checkup largely involves the medical practitioner asking about one’s ability to drive. Given an ability to walk into consulting rooms, read the eye chart on the wall and answer in the affirmative to questions regarding driving capability, one is presumed fit to drive. For conditions such as MS, where symptoms may be present but no medically determinable signs of illness exist (Poser and Aisen, 1987: 25), assessment becomes, necessarily, very subjective. Fortunately, I have been determined by my own GP to have “mild” multiple sclerosis; a label argued here to be as absurd as someone being “mildly pregnant” when one considers what effect it has had on my life to date and what the future may offer. What would be more reasonable, and appropriate, is the term “relapsing/remitting” multiple sclerosis (Graham, 1992: 22). Whilst recognising another medicalised construction, at least this label more closely aligns the experience and nature of the condition and avoids subjectively attached and, frankly, misleading connotations about its seriousness. I say nothing though - after all, one needs to drive the car. The final point here is that the “rigorous” medical checkups are, in my case, at yearly intervals: over the period of twelve months the ability of someone with MS to safely drive a car may vary enormously. When unable to safely drive, I have taken it upon myself not to endanger the lives of myself, or others, without the surveillance of the RTA.
aspects of many such groups in supporting people in need, providing a sense of solidarity and encouraging independence (Nettleton, 1995: 97), there is no doubt that they may be inclined to foster a negative, dependent view of illness and disability (Robinson, 1988: 114; Szasz, 1991: 94) whilst collectively attempting to demand support and resources from the state or other sources (Nettleton, 1995: 97). Negativity and dependence are also engendered by the media and the politically correct:

"Accepting" persons with chronic disabilities is now one of the favourite pastimes of otherwise frequently narrow-minded Americans proffered on the premise of tolerance, attempts to "mainstream" the handicapped are largely self-satisfying. Television "telethons" focused on raising money for a particular disease or disability exhibit a hideously patronising approach. They emphasize how different the diseased and disabled are from normal, healthy people—typically, by displaying the victims on the screen. The fact that these campaigns are waged most enthusiastically for diseases and disabilities which can be visibly portrayed illustrates how much the "normals" want to see themselves as better off than the "abnormals" (Szasz, 1991: 136, italics in original).

Finally, individual self-esteem and self-perceptions may be similarly affected by capitalist expectations. For many (presumably non-ill) careerists, the implications of the protestant ethic, promoting a strong desire for upward mobility and career advancement, are likely to invite disappointment (Kets de Vries, 1995: 47) and place additional pressure on PwICl. When the real, and perceived, functional constraints of illness are applied to our careerist, the
combination can be devastating as 'work is valued not only for its instrumental usefulness, 
... but also for the psychological "side effects" which such economic independence gives. 
It is valued for its "intrinsic" importance for a person's psychological and moral makeup. 
Work is thought to play a crucial role in the formation of the core identity, in self-esteem, in 
overall organisation of life, and in family life, as well as in mental and physical health' 
(Safilios-Rothschild, 1970: 194).

Negative Attitudes and the Myth of "The Body Perfect"

The functional emphasis has been highlighted in the sections above: our bourgeois philosophy 
dictates that success is attributed to academic excellence, wealth, power, status, youth and 
beauty. Society is organised around ideal persons; those who are without deficiencies 
(Gething, 1984: 45), with positive community feelings existing regarding "health". Lay 
beliefs describe health in positive terms (Blaxter, 1995: 26-32). Youth and physical perfection 
are the norm, and stigma associated with physical deformity arises because of the perceived 
deficit between expected perfect physical condition and actual physical condition (Saylor, 
1990: 68)\textsuperscript{26}. The deformity and disfigurement associated with disease is, according to Sontag 
(1988: 41), attached to our moral judgements of the illness and an attendant moral judgement 
of the "beautiful" and the "ugly".

The modern, Western 'myth of bodily perfection' (Stone, 1995: 413) exemplifies an obsession 
with whole, perfect, beautiful individuals (Junor, 1985; Galbally, 1988: 8); a society organised 
around those without deficiencies (Gething, 1984: 45). Youth and physical perfection are

\textsuperscript{26} Paradoxically, PwICl may be considered by others to be "good" physical specimens; "normal", even 
"attractive", by social standards, whilst the reality of life may be considerably different. The visual paradox 
merely adds to the burden; an ever-widening gulf between what is "seen" and what "is".
perceived as eminently desirable (Saylor, 1990: 68) resulting in the able-bodied being fearful of becoming sick or disabled (Wang, 1992; Morris, 1995). Ironically, able-bodied individuals deliberately risk their health to achieve bodily perfection: Helman (1990: 144-145) described the cultural emphasis on female slimness and beauty resulting in depression, poor self-image and eating disorders such as anorexia nervosa. Social pressure in the West is sufficient for people to starve themselves to death (anorexia-nervosa), voluntarily vomit on a regular basis (bulimia), pay thousands of dollars (and suffer considerable pain and bruising) to have chins, hips, thighs and bellies vacuumed free of fat (liposuction), submit to (and pay for) the application of chemicals (chemabrasion) or sand-paper-like procedures (dermabrasion) to remove numerous, apparently undesirable, layers of facial skin; or place themselves willingly under the plastic surgeon’s scalpel for rhinoplasty ("nose job"), blepharoplasty ("eye job"), mammoplasty ("breast job") or abdominoplasty ("tummy tuck"): all to achieve our socially constructed appearance of beauty. 27

Popular literary examples may perpetuate these attitudes. Lawrence’s (1960) Lady Chatterley’s Lover (described in Battye, 1974: 93-94) demonstrated societal mistrust, pity and disdain towards ‘cripples’; Kesey’s (1962/1973) One Flew Over the Cuckoo’s Nest illustrated institutionalisation and maltreatment of those who don’t fit in; Biblical references describe the need to expel ‘unclean people’ (Good News Bible, 1976: The Old Testament: Numbers 5.1-4); American comedian Paul Reiser suggested that we idolise the cute and penalise the unattractive: ‘We get all upset when dolphins get caught in tuna nets, but no one cares about

27 For more examples of the medical profession reinforcing this social intolerance of the unusual through performance of cosmetic “miracles”, refer to Finkelstein (1991: 92-99). The dominant postwar symbol is a healthy and sexy body, achieved at great cost (physical, emotional and financial) to the individual (Siebers, 1994: 30). ‘The recent penchant for commodification of the body ‘to display power, prestige and status’ (Finkelstein, 1991: 4) is used to great advantage by a medical profession who are ready, and armed, with the appropriate remedies.
the 10,000 dead tunas on the same boat. Little ugly tunas, one on top of the other, screaming for help’ (Reiser, 1994: 292-293). The mass media perpetuate negative perceptions (Safilios-Rothschild, 1970: 11): Wang (1992: 1093-1102) reported the problems of stigma generation arising from health promotion campaigns run to prevent drink driving. Targeted groups reported that they would rather die 'than end up in a wheelchair'. The able-bodied find it inconceivable that someone who is paralysed can experience a life worth living (Morris, 1995: 108) and it has been suggested that some social efforts to help the disabled could be construed as trying to make disabled people "normal" (for example, through technology usage) in order to result in less discomfort for the able-bodied around them (Galbally, 1988: 8). What evolve, and are confirmed, are negative stereotypes about those who don't adhere to the socially constructed norms of health, youth and beauty.

Out of this plethora of negativity arise many erroneous beliefs about illness and disability. Unfortunately, beliefs may become certainties and the basis of wrong premises, ambiguities, errors and action through 'framing' events (Goffman, 1974b: 308) leading to attributions of deviance, labelling and stigma, and likely discrimination and prejudice.

*What is "Normal"? What is "Deviant"?*

A discussion on deviance and its incumbent problems is suggestive of the need to benchmark normality. Does health equate to normality? Certainly our ideological and cultural representations indicate that health is desirable and normal. However, there are recognised difficulties in defining what is regarded as "normal" (Margolis, 1981; Maslow and Mittleman, 1981); maintaining an appearance of "normal" is recognised to be hard work (De Swaan, 1990: 1). La Bier (1986: 137) suggested that normal is 'really a constellation of attitudes,
values and behaviour of the dominant social character orientation, which we all share or are influenced by, to some degree. In terms of health, what is perceived to be "normal" may be statistically improbable, difficult to achieve and hard to live up to. For example, healthy teeth may require 32 perfect, white teeth; unlikely for most of us. The healthy individual may be regarded as one who never gets sick, an absence of disease (Blaxter, 1995: 28). Health may also include an component of spiritual and emotional well-being or of functioning in a manner acceptable to himself and to the group of which he is a part (Dubos, 1995: 9). Normality may also incorporate various manifestations of psychological health, including adequate feelings of security, adequate self-evaluation, efficient contact with reality, adequate bodily desires and an ability to gratify them, adequate life goals, an ability to satisfy the requirements of the group, as well as sufficient emancipation from the group (Maslow and Mittlemann, 1981: 49-50).

A review of the traditional literature on deviance emphasises the behavioural dimension of deviance: deviance is about breaking the rules; a motivated choice to deviate from conformity (Parsons, 1951: 206; Becker, 1963: 3; Kaplan, 1980). Underpinning such a definition is the element of choice in the determination of the individual to break the normative behavioural code in society: deviants choose to become criminals; deviants choose to smoke marijuana; deviants choose to behave in socially unacceptable ways. When this kind of deviance occurs, society is bound to correct or control it in order to prevent change or the disintegration of the norms and expectations that exist (Parsons, 1951: 206).

Despite the Western predilection for apportioning blame to sick people, frequently no choice...
exists for the person who becomes sick or disabled. The need to differentiate various forms of social deviance then becomes mandatory: differentiation of social deviance does take place in society and yet illness is negatively viewed along with criminals, the possessed and religious fanatics, although this may not always be for the same reasons (Veatch, 1981: 528). Fabrega (1981b: 138) made this important delineation between illness deviance and non-illness deviance.

Many people who are chronically ill and disabled are not necessarily able to choose a non-deviant behaviour, given their circumstances. For example, ambulation is a norm of behaviour in society. A wheelchair user who wants to participate in life needs to use a "deviant" mode of ambulation; the use of the wheelchair necessarily promotes his or her deviancy. However, for PwICI, we see that more choices are available: PwICI are able, in many cases, to choose normative behaviours in order to conform to societal expectations; choices that may be at the expense of their well-being.

Illness and Deviance: Labelling and Stigma

The Lord said to Moses, "Command the people of Israel to expel from the camp everyone with a dreaded skin disease or a bodily discharge and everyone who is unclean by contact with a corpse. Send all these ritually unclean people out, so that they will not defile the camp, where I live among my people."

The Israelites obeyed and expelled them all from the camp (Good News Bible, 1976, The Old Testament: Numbers 5.1-4).

Susman (1994: 16) described "stigma" as 'any persistent trait of an individual or group which
evokes negative or punitive responses.’ In nature, diseased members of the group are generally shunned if they are unable to keep up with the group since they attract predators (Fabrega, 1981b: 134). Stigma is ‘an attribute that is deeply discrediting’ (Goffman, 1974a: 80): ‘a formal concept which captures a relationship of devaluation rather than a fixed attribute’ (Marshall, 1994: 512). Unfortunately, for both visible and invisible conditions, it is ‘not the functional limitations of impairment which constitute the greatest problems faced by disabled individuals, but rather societal and social responses to it’ (Susman, 1994: 16).

Goffman (1974a: 79) described the origins of stigma as being from the ancient Greeks who cut or burned marks into the unfortunates: the origins of stigma are visible marks of shame. Goffman (1963; 1974a: 80) also made the important distinction between visible and invisible stigma, known and unknown stigma (Goffman, 1974a: 80). The results of stigma were, and are, both collective and individual: vilification, discrimination, ostracism — the Bible tells us so. Whether stigma is applied to visible or invisible conditions ‘in recent years, stigma has tended to define the bearer, rather than the sign carried by the bearer, and the bearer becomes known by the disease itself’ (Goldin, 1994: 1360). Three useful approaches to stigma interpretation:

From the point of view of the outside observer, (a) attention may be directed at psychological, interpersonal, sociological, economic and/or political effects on persons who possess certain characteristics. Alternatively, (b) stigma may be understood as metaphors about social order and the body politic; the focus of attention may shift to those who identify themselves as not possessing the specified traits. Or, (c) stigma may be understood from an interactionist
perspective as the language of relationships, as the product of, and inherent in,
a relationship between the 'normal' and the 'other' (Goldin, 1994: 1359,
emphasis in the original).

Stigma is not just an obvious, visually observable trait, but a general sense of moral
inferiority, culpability, depravity (Scott, 1974: 109) with four sets of forces that affect the
meaning of stigma within a society: cultural values; professionalism and the construction of
expert meanings of stigma; bureaucratic processes and the content of expert meanings of
stigma; and clientele (Scott, 1974: 112-118). The response of normals to the stigmatised
individual varies with the stigma and the person’s past conditions, and leads to devaluation,
stereotyping and labelling (Saylor, 1990: 74). 'Whenever a stigma is present, the devaluing
characteristic is so powerful that it overshadows other traits and becomes the focus of personal
evaluations' (Saylor, 1990: 67).

The literature denotes varying types of stigma: the stigma of physical deformity; stigma of
character blemishes, such as rigid beliefs, dishonesty, alcoholism; or tribal stigma, called
prejudice, for example, through race or religion (Goffman, 1963; Saylor, 1990: 68).
Additionally, Mankoff (1971; cited in Scambler, 1984: 204) distinguished 'achieved' and
'ascribed' stigma: achieved stigma is stigma “earned” by the person through chosen or
deliberate actions taken that violate the norms of society. Others have described this
previously as behavioural deviance (Becker, 1963; Berger and Luckmann, 1966), deviant
conduct (Erikson, 1964: 10-11) or non-illness deviance (Fabra, 1981a). It is a property
‘conferred upon’ the person by the social audience (Erikson, 1964: 11) as a result of chosen
activity that is deemed unacceptable. Traditional examples of achieved stigma would include
criminal activities, promiscuity, drug use.29

Conversely, ascribed stigma is attributed to a person because of how they are: 'the nature of his or her "offence" is perhaps best characterised as ontological' (Scambler, 1984: 208). Examples of ICIs with ascribed stigma may include epilepsy and MS; conditions which have occurred through no "fault" of the bearer but are still highly stigmatised. For example, Scambler (1984), in a study of individuals with epilepsy, described some of the problems associated with stigma, including its threat to social order and problems associated with perceiving and coping with stigmatising conditions.

Scambler (1984) and, more recently, Jacoby (1994: 270) have noted the difference between 'felt' and 'enacted' stigma: 'Felt stigma refers, first, to the shame associated with being epileptic. People felt ashamed fundamentally because they see "being epileptic" as amounting to an infringement against norms relating to "identity or being"' (Scambler, 1984: 215). This is the stigma felt by the individual (Scambler, 1984; Jacoby, 1994: 270; Nijhof, 1995: 201) and may be explained, in part, by the psychology of impression management (Forgas, 1985), the playing of social roles (including hiding the self or staging a presentation) (Wilmot, 1975: 50) or 'persona presentation' (Harré et al, 1985: 144) which demonstrates the importance of 'how to appear in public, how to put on the best show, to demonstrate the best persona, to

29The author has elsewhere argued (Vickers, 1996b) that many ICIs also attract achieved stigma. For example, the PwFCI may be judged harshly for bringing the condition upon themselves: by not eating properly; by smoking and drinking; by engaging in socially deviant sexual behaviour; by not adhering to an exercise regimen; by not seeking medical help; or by not following medical advice closely. Examples include the contraction of HIV or AIDS (Cacioppo, 1988; Small, 1995) or the perceived character blemish of alcoholism (Guffman, 1974a: 80; Saylor, 1990: 68). The individual is held responsible, with a natural implication of culpability for those who infect others with AIDS (Goldin, 1994: 1360). Illnesses attracting achieved stigma, such as HIV, lung cancer or cirrhosis of the liver, are frequently believed to be 'God's punishment', a form of instruction to the soul and deserved by the bearer (Scott, 1974: 108; Sontag, 1977: 46; 1988: 25; Turner, 1987: 21; Saylor, 1990: 66).
be ascribed the right kind of personality’ (Harré et al., 1985: 144). People feel an almost desperate need to 'pass' as normal (Goffman, 1963; Kleinman, 1988: 161) and nothing exists to protect people from the shame of a stigmatising condition (Kleinman, 1988: 168).

Labelling contributes to the attribution of stigma:

Labelling theory contains three central propositions. The first is that deviant behaviour has no consistent unitary content or essence; it is merely behaviour which is labelled as deviant by powerful, influential or significant social groups which are important in shaping public opinion. Secondly, people who are labelled as deviant suffer stigmatization which excludes them from normal interactions and thus converts their behaviour into a distinctive career of deviance. Thirdly, behaviour which is stigmatised by social labelling becomes amplified because alternative lifestyles and careers are no longer available for the deviant. The paradox is that social intervention by agents of social control produces deviance and amplifies it (Turner, 1987: 73).

Turner’s (1987) comments on the amplification of deviance by agents of social control are mirrored by Szasz’s (1970) comparison of the labelling and persecution of "witches" during the Inquisition to modern psychiatric practice. Szasz (1980) later analysed sexual "deviancy" and the human preoccupation with sexuality: the need to control it, regulate it, define what is normal and what is not - a need to dominate and control through the assignment of deviant status.
'Enacted' stigma (Scambler, 1984: 215), or discrimination, has been well documented against those with *visible* disabilities (for example, Treves, 1923/1980; Safilios-Rothschild, 1970; Northdurft and Astor, 1986; Cacioppe, 1988; Noel, 1990; Kerr, 1992; Rayner, 1992; Dean, 1993; Singer, 1993; Klimoski, 1994; Jones and Stone, 1994). According to Nijhof (1995: 193), the results of enacted stigma are twofold: the first response may be a split in the stigmatised person's lifeworld leading to identification of a private realm, where the actor may feel safe from prying eyes and a public world fraught with humiliation and fear; the second response being to retreat from the public domain altogether.

However, it should be acknowledged that it is not only people who are visibly sick and disabled who are stigmatised. Enacted stigma (discrimination) exists against those with ICI also (Safilios-Rothschild, 1970; Scambler, 1984; Jacoby, 1994): there exists, broadly, the problem of the discreditable person becoming discredited (Goffman, 1963; Freedman and Doob, 1968: 48). More specifically, discrimination has been reported against those invisible conditions such as AIDS and/or HIV (Cacioppe, 1988; Stone, 1994: 55; Small, 1995), MS (Kantor, 1991), schizophrenia\(^3\) (Leonard et al, 1989) and epilepsy (Scambler, 1984; Jacoby, 1994).

Unfortunately, from labelling, stigmatisation and deviance, come prejudice and discrimination: 'cognitive' (or epistemic) prejudice (Sun, 1993: 1152) 'involves cognitive distortions of the social reality', including erroneous generalisation, oversimplification, stereotypical judgements, a lack of appreciation of the situational constraints faced by a marginalised group and other

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\(^3\)This section is written following the Port Arthur Massacre in the quiet island state of Australia: Tasmania. The author shudders whilst contemplating the stigma that will be consequently attached to those diagnosed with schizophrenia in this country given that the alleged murderer was a diagnosed schizophrenic.
inaccuracies in categorising, evaluating and explaining social entities (Sun, 1993: 1152). Additionally, 'moral prejudice' can be conceptualised as 'social perceptions or attitudes that deviate from a normative standard or moral value, such as the principle of fairness, equity, equality or need' (Sun, 1993: 1152). Both are, unfortunately, relevant here.

"Entities" of Influence: The Medical Profession

Lay Concepts of Health and Illness

Before delving into the impact of the medical profession, it is important to note the existence of lay 'constructions of illness' (Freidson, 1970: 278), lay 'beliefs' about illness (Freidson, 1970: 283; Fitzpatrick, 1984: 17; Kleinman, 1988; Thorogood, 1992: 48; Klonoff and Landrine, 1994: 408; Archer, 1995: 89; Helman, 1995: 18; Nettleton, 1995: 39), lay 'concepts' (Fitzpatrick, 1984: 11), 'folk understandings' (Fabrega, 1981b: 139; Helman, 1995: 18), 'folk epistemology' (Good, 1994: 116) or 'commonsense beliefs' (Klonoff and Landrine, 1994) about illness, which serve as a nonprofessional basis for understanding and action toward illness. These may include names, causes, remedies, routines for home treatment and the body of rules and expectations surrounding illness, for both those who are ill and for those who come into contact with sick people (Fabrega, 1981b: 139). These 'beliefs' about illness greatly affect individual response to illness, including the use of medical services (Freidson, 1970: 286) and perceptions as to their efficacy or otherwise (Archer, 1995: 89). They are heavily ethnically and culturally influenced (Fitzpatrick, 1984: 11-12; Turner, 1987: 54; Kleinman, 1988: 100-120; Helman, 1990: 117; Klonoff and Landrine, 1994: 408), gender

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31 The distinction is made here between medicine in Western and non-Western cultures deliberately. Non-Western medicine has a unique range of properties, treatments and cultural ethics (Foster and Anderson, 1978: 123-141).
influenced (Helman, 1990: 130), socially and ideologically influenced (Nettleton, 1995: 46) and may be very complex, multifactorial (Fitzpatrick, 1984: 17) and frequently problematic, illogical, inconsistent, seldom formalised and syncretic in origin (Fitzpatrick, 1984: 17-18). They may also be adjusted according to the current concerns of the individual (Fitzpatrick, 1984: 18) and affect health behaviour (Nettleton, 1995: 39), health maintenance and disease prevention behaviours (Nettleton, 1995: 44), especially lifestyle (Nettleton, 1995: 49). These beliefs about health and illness were apparent in the stories reported in this volume and may even contribute to the ability of the respondent to 'active sense-making' (Fitzpatrick, 1984: 25) and, perhaps, to "decomplexify" and "decrisisify" their situation. Finally, they may also contribute to the problems experienced by Pw|CI, especially through others' illness ignorance: 'within consumer culture the body becomes both a site of pleasure and a representation of happiness and success. The appearance of the body reflects the inner self -- to look good is to feel good' (Nettleton, 1995: 50, emphasis in the original).

*Medicine: The "Doyen" of Professions*

The influence of the medical profession cannot be underestimated in a study involving Pw|CI. The entity of the medical profession is one including the professionals that undertake to treat sick people; the professional mystique that surrounds them; the "scientific" approach to medical treatment and diagnosis; and the subsequent dominance such a group hold over thought and behaviour.

Medicine has long been regarded as the "doyen" of professions; the medical practitioner traditionally regarded as being beyond materiality and capitalistic gratification: 'A person motivated neither by personal interests nor simply by the desire for economic rewards'
(Turner, 1987: 131). The medical profession is deemed by many to be *par excellence*; a calling to serve others in the absence of material reward (Turner, 1987: 131). Parsons (1951) and Freidson (1970) challenged this notion, placing *stress on the role of power in the medical division of labour* noting *that the monopolistic power of the medical profession was such that it could subordinate adjacent and related occupations* (Turner, 1987: 132). The concept, and dimensions, of professionalisation are used as a strategy of occupational monopoly and control. The body of knowledge is sustained through a formal university education; the clientele is maintained through various exclusionary practices in the market, including legislation, to maintain the professional monopoly; and the professional group seeks to maintain certain privileges in service delivery, *namely to maintain autonomy over the delivery of skills and the relationship with the client* (Turner, 1987: 140).

Occupational monopoly is of interest here when one sees the importance of *diagnosis* in Western culture. Sick individuals are unable to take on the "advantages" of the 'sick role' (Parsons, 1951; Mechanic, 1981; Falvo et al, 1982: 5; Becker and Rosenstock, 1984; Harrison, 1984; Yelin, 1986: 623-624; Lambert and Lambert, 1979; Lubkin, 1990: 53; Morse and Johnson, 1991: 2; Ford, 1992: 338) until their disease has been ratified by a medical professional. In the West, there is *no other* recognised mode of illness validation. The medical professional's expertise is firmly grounded in "scientific" principles, creating

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32 James (1869/1950; cited in Goffman, 1974b: 2) asked *'Under what circumstances do we think things are real?'* This author asks: Under what circumstances do we think *illness is real?* Western perceptions of the "reality" of illness seem totally dependent on the sanction of the medical profession and their inherently positivist approach to illness definition: if it is not diagnosed, it does not exist. The medical profession's ability to "see" (read diagnose) illness is limited to current medical "knowledge", diagnostic efficacy and medical technology. If physicians cannot "see" illness, having performed the battery of currently available tests, then it is presumed non-existent. This provides an interesting parallel with the starting point for this thesis: both medical and social "diagnoses" rely on one's ability to "see" illness. If one cannot "see" illness, it does not exist. In the case of medical diagnosis (as opposed to "social diagnosis") the medical practitioner's sense of "sight" is merely extended through the use of current technology.
specialised knowledge and a basis for prestige and social distance between the expert (doctor) and client (patient). This special, and systematic, body of scientific knowledge also provides the basis for external intervention and social control (Turner, 1987: 135). This same 'breed of men' (physicians and scientists) wish to continue with the dominance of their craft in society and are assisted in this end (Adorno, 1951: 123).

Whilst the public view of medicine has transformed during the nineteenth century from suspicion to trust, many societal members today are increasingly embracing "alternative" treatments as a safer, less invasive approach to health care and maintenance (Gould, 1985: ix; Calnan and Williams, 1992: 250). Some of the views suggested by Parsons (1951) and Illich (1975), 'that the public accepts that modern medicine is effective and thus has complete faith in the value of scientific medical knowledge', have transformed somewhat in the past twenty years or so (Calnan and Williams, 1992: 233). Recent arguments suggest that the "blanket" dependence model portrayed by, for example Illich (1975), is too simplistic.

Remaining, though, is the popular and widely encouraged view of the medical community metaphorically "waging a war" against the "evils of disease". For example, AIDS is referred to variously as the plague, an invisible contagion, a moral punishment, an invader or a primitive or presocial entity (Helman, 1990: 100-101). However, the metaphor illustrative of a war between "good" (medical professional) and "evil" (disease) neither represents a balanced view of medical services nor an accurate one. Reliance on metaphor may result in less than accurate understanding of "truth" (Carr and Leivesley, 1995: 58), serving to re-vivify the unexamined assumptions of positivism (Carr and Leivesley, 1995: 63). There is a public need for miracle "cures" and a fascination with high-technology care: 'high-technology
medicine is the most solemn element in a ritual celebrating and reinforcing the myth that doctors struggle heroically against death' (Illich, 1975: 52). It may also be argued that the symbolism and mythology surrounding medical progress has far outreached the actuality of progress. Attempts to manage all diseases by engineering interventions has, paradoxically, focused more attention on the symbolic and non-technical functions: 'white coats, antiseptic environments, ambulances and insurance came to serve magical and symbolic functions influencing health' (Illich, 1975: 53). An increasingly secular social emphasis is resulting in the medical practitioner's role taking on more "priestly" overtones, with religious rites being increasingly replaced by scientific ones (Gould, 1985: 33; Calnan and Williams, 1992: 251).

The current notion of an "unhealthy lifestyle" leading to illness has replaced the earlier religious concepts of "sinful behaviour" leading to divine retribution (Helman, 1990: 138).

The language of medicine adds to the mystique. Some may argue that medical professionals are simply using the technical jargon of their trade. Whilst this may be necessary when talking to fellow professionals, when talking to the lay person ("patient") it serves to intensify the imbued mystical qualities of the "healer" and further deepen the dependence relationship.

The lay person may be erroneously led to believe that such scientific "mumbo-jumbo" may be proof of the expertise of the physician. This may not always be the case, for example:

They had holes bored each side of the skull, just above the temple, through which a knife was inserted and waggled around to destroy the millions of fibres presumed to be carrying disruptive and inappropriate signals, and thus, as one eminent British neurosurgeon later put the matter, "to break a vicious circuit of tension", a concept as vague and unsubstantiated as dear old
Arbuthnot Lane’s poison-absorbing colons (Gould, 1985: 141).

As scientists, the medical profession speak "objectively" of lesions, organs, functions; yet, as social members, they are inclined to speak more subjectively and emotively about illness, suffering, recovery, incapacitation (Margolis, 1981: 564). One must ask how "objective" is the language of lesions and organs, and what information is actually conveyed with such language? More fundamentally, how certain is medical science? Historically, one must question past "scientific" treatments, for example, "consolidation", "purification", "immersion" and "regulation of movement" were used to cure mental illness (Foucault, 1961) and sexuality was regarded as a disease to be treated, controlled and regulated (Szasz, 1980). In 1997, much in medicine is still uncertain, unknown. It is acknowledged here that, in some areas, strides have been made in ameliorating suffering and preventing premature death, for example, antiseptic surgery practices, penicillin, hip replacements, heart valve replacement and reduced infant mortality (Gould, 1985). However, extrapolation of these successes to all areas of medicine is dangerous and naive.

The Medical Model

Western medicine is based on the medical model (Veatch, 1981; Helman 1990: 86). The medical model and its aetiological categories reflect the underlying assumptions of capitalism in which health is a commodity and responsibility for illness is increasingly seen to be the individual’s problem. The distribution of health resources also reflects the medical dominance enjoyed by professional medicine as a section of the dominant class (Turner, 1987: 193-194). Diagnosis of illness today is very much the focus of medical practice (Bates and Lapsley, 1985: 208) as is the use of technology to support and maintain medical dominance (Nettleton,
1995: 26). 'Views differ on the relative merits of modern medical technology according to which specific form of technological intervention is being considered (antibiotics, tranquillisers, hip operations, heart transplants), and also in terms of the socio-demographic characteristics of the lay populace (age, gender, class, educational status, health status)' (Calnan and Williams, 1992: 248-249).

It has been argued that the medical profession assumes a positivist approach to recognition, diagnosis and treatment of disease, but one should also consider that all disease has been labelled, categorised and studied from this position historically. Current knowledge is based on past developments, past failures; a modern historicist understanding. For example, clinical evidence that can be confirmed by an examining physician is called a 'sign' of disease. Signs of disease are regarded as "objective" indicators of disease. For example, signs of MS (that the bearer may or may not be aware of) may include abnormal reflexes or nystagmus (Poser and Aisen, 1987: 25). Conversely, "subjective" indicators of disease are those experienced by the bearer but not necessarily evident to an examining physician: diminished or abnormal sensation, weakness of a body part, a decrease in vision or clumsiness (Poser and Aisen, 1987: 25). They are, also, naturally more difficult to measure or compare between patients. Symptoms, then, are largely "invisible" requiring (another) distinction to be made between what "seems" and what "really is", between "appearance" and "reality" (King, 1981: 110).

The medical model has its limitations: there remains some 'ambivalence' about modern scientific medicine expressed by the lay populace (Calnan and Williams, 1992: 250). 'Scientists are no longer the gods that they were twenty years ago and there is some evidence of disunity in the scientific community although perhaps less so amongst the more tightly knit
medical profession. The demystification of science and scientific medicine may, partly, have been brought about due to the role of the mass media in society’ (Calnan and Williams, 1992: 250). However, the medical model is still a force of influence for PwCI, especially in the organisational context. Although they may be, as individuals, more questioning and less complacent with their own medical care, reliance remains on the medical profession in diagnosing and, thus, validating illness that will affect the person in their workplace.

*Iatrogenic Illness*

*Iatrogenic* disease or illness (Illich, 1975; Gould, 1985; Archer, 1995: 28; Garrett, 1995: 447-448), a term first coined by Ivan Illich (1975), is disease *resulting* from treatment, either as an unforeseen or an inevitable side-effect (Martin, 1990: 341): this, when the “first commandment” of Western medicine is *Primum non nocere* (First, do no harm) (Szasz, 1977/1988: 1). Medicine has become one of the greatest sources of suffering (Szasz, 1977/1988: xviii). For example, the continued use of dubious treatments such as electroconvulsive therapy (ECT) is confounding:

Even after 50 years of widespread use we have no idea why disrupting brain circuits with the electrical equivalent of a coup should restore the disordered mind, or indeed whether it ever actually does so. . . . We may not know much about the mechanisms of the mind, but we do know that they are far more complex than the circuitry of the most sophisticated computers or artificial intelligence machines. An electronics expert would hardly imagine that a malfunctioning black box could be "cured" by identifying one of the components in the circuits involved, and then destroying it with a red hot
soldering iron, and without ever knowing whether the part attacked was faulty.

It is naive, almost to the point of irresponsibility, to suppose that the brain should respond favourably to such crude and illogical interference (Gould, 1985: 138-143, emphasis in the original).

Historically, science (medicine) has inflicted much harm: 'Louis XIII is said to have suffered 212 enemas, 215 purgations and 47 bleedings in the course of a single year' (Gould, 1985: 27) and yet these treatments, whilst unpleasant, were considerably less harmful than the many available today. Scientific progress has equipped medical science with 'a huge armamentarium of remedies' (Gould, 1985: 34, emphasis added) so that over-treatment, or inappropriate treatment, are increasingly problematic. 'Therapeutism' has achieved a power so far unchecked by any effective countervailing force (Szasz, 1977/1988: xviii).

The Medical Profession: Dominance and Patriarchy, Surveillance and Control.

Even if they show themselves, outside their official capacity, to be quite human and sensible beings they are paralysed by pathetic stupidity the moment they begin to think professionally. . . . They hit out at speculation and in it kill common sense. The more intelligent of them suspect the sickness of their intellectual powers . . . Many wait in fear and shame for their defect to be discovered (Adorno, 1951: 124).

Medical dominance (Turner, 1987: 141) may include violations of freedom (Szasz, 1977/1988: xxi), a fundamental tendency to infantilise the sick person (Szasz, 1977/1988: 19), even outrageous and blanket withholding of diagnostic information from the sick person (Szasz,
1977/1988: 20; Elian and Dean, 1985; Konner, 1993: 5). The medical profession have historically held power: the directors of the *Hôpital Général* in the mid-seventeenth century in France had ubiquitous power, clearly beyond the curative:

From the very start, one thing is clear: The *Hôpital Général* is not a medical establishment. It is rather a sort of semijudicial structure, an administrative entity which, along with the already constituted powers, and outside of the courts, decides, judges, and executes. "The directors having for these purposes stakes, irons, prisons, and dungeons in the said *Hôpital Général* and the places thereto appertaining so much as they deem necessary, no appeal will be accepted from the regulations they establish within the said hospital; and as for such regulations as intervene from without, they will be executed according to their form and tenor, notwithstanding opposition or whatsoever appeal made or to be made, and without prejudice to these, and for which, notwithstanding all defence or suits for justice, no distinction will be made" (Foucault, 1961: 40; including a quote from the *lettres de cachet* of 1656, emphasis added).

The treatment of the insane during the sixteenth century has been described as *correcting the animalism* in the demented person with brutality and force (Foucault, 1961: 74-75). The literature depicts examples of "treatment" of modern psychiatric patients and, later, the preoccupation of medical science in controlling the "disease" of sexual behaviour (Szasz, 1970; 1980). Illness and medical care have long been institutionalised (Freidson, 1970: 303), with institutional care studied for its 'social efficiency' (Georgopoulos, 1972: 24). The medical profession have notably controlled others (patients) with physical means and
inappropriate behaviour (Parsonson, 1989: 215) and with less than humane consideration. Sir Frederick Treves, who first published the plight of John Merrick (The "Elephant Man"), was the Lecturer on Anatomy at the local Medical College when he initially met Merrick. He reported, 'I was anxious to examine him in detail and to prepare an account of his abnormalities' (Treves, 1923/1980: 10) - this, after describing the disgusting and inhumane circumstances in which Merrick was living (Treves, 1923/1980: 8-9). There was no mention made of the need to investigate Merrick's living standards or mental health, merely a pressing urgency for Treves' to publish his findings (which were subsequently published in The British Medical Journal, December 1886 and April 1890). Unfortunately, the public record is littered with similar examples of pernicious inhumanity at the hands of the medical community; too numerous to describe here (for example, Treves, 1923/1980; Brown, 1954; Foucault, 1961; Goffman, 1961; Szasz, 1970; 1980; Illich, 1975; Gould, 1985; Helman, 1990; Ferguson, 1991; Konner, 1993; Archer, 1995). This detachment may be a result of the loss of idealism and increased cynicism during medical training, perhaps arising from constantly needing to cope with death and suffering (Foster and Anderson, 1978: 181). Fortunately, evidence of increasing social concern coincides with a growth of social and behavioural science courses in medicine in more recent years (Perricone, 1974; cited in Foster and Anderson, 1978: 181) although, as the stories will later confirm, there is still some distance to travel.

Adorno (1951: 63) wrote of the psycho-analysis who prided themselves on their abilities to restore the happiness of the sick person: it is "happiness" that is forced on the person, in the same way an angry parent demands a child love them. The mechanism of domination is one which forbids the recognition of suffering. The theme of domination is exacerbated by the application of technical knowledge: "The medical profession has not achieved its dominant
position within the health-care division of labour because of its inherently superior expertise, but because it has managed to create and maintain the control over certain technological procedures and practices' (Nettleton, 1995: 26). Foucault (1973; cited in Calnan and Williams, 1992: 233-234) suggested that 'power lies in control over knowledge and the structures and practices which sustain it' and 'the body is a product of a subtle play of power which is constituted by the clinical gaze.'

The professional-patient relationship demonstrates similar themes of domination. Health professionals have often neglected to take the patient's view seriously (Nettleton, 1995: 131) and whilst the relationship is a reciprocal one, it is not equal (Nettleton, 1995: 133). For example, it is common practice that the patient call the physician "Doctor", however, physicians rarely address patients other than by first names (Szasz, 1991: 14). It is almost indicative of an adult-child relationship: 'The one dominant, intelligent and important, the other submissive, unintelligent, and unimportant' (Szasz, 1991: 14). Special privileges are extended to the physician through this relationship. For example, the assumption generally exists (by both parties) that it is acceptable for medical professionals to approach the human body (Goffman, 1974b: 35). Goffman (1974b) pointed out that the social role of "healer" or physician in our society appears to allow familiarity that would not normally be condoned. The fact that the vast majority will disrobe perfunctorily at a medical examination is symbolic of the relational power imbalance.

The 'code of silence' (Konner, 1993: 5) is still widely used by medical practitioners: this involves the withholding of diagnostic or prognostic information from the patient. 'What could be more threatening to a person's rights than not knowing things at once so personal
and momentous? Yet, until very recently, Western physicians concealed the facts from patients as long as they could, often whispering the truth to the next of kin' (Konner, 1993: 5). Elian and Dean (1985: 27) confirmed this fear of open discourse about illness in their article entitled *To Tell or Not to Tell the Diagnosis of Multiple Sclerosis*: 'When [they] approached neurologists for permission to interview their patients [with MS], most consented with one proviso—that under no circumstances must the patients find out that they have MS. Some added that this was in the patients' best interests' (my emphasis). The professional-patient relationship, thus, reflects and reinforces wider social relations and social inequalities, especially those involving gender, ethnicity or social class (Nettleton, 1995: 131) and, yet,

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32 It would be preferable to think that this infuriating practice has come to an end but this author remains unsure that it has. From my own experience, a suspected diagnosis of MS, although unconfirmed medically, was withheld from me for about eight years during which time I could have used this essential (albeit unconfirmed) information to have influenced career, health and lifestyle choices, which may (or may not) have altered the course of the disease or my quality of life, then and now. Unfortunately, these choices were effectively and completely taken from me by those closest to me - my parents.

In trying to understand the motives for this behaviour and my response to it, an unusual and perhaps unique situation became apparent. The author's parents were, also, both practicing medical practitioners and, as such, were necessarily imbued with the doctrines and ideology of their profession. I remain certain that at the time they believed that they were doing the 'right' thing for their daughter, having had, presumably, much experience in upholding the medical profession's 'code of silence' (Konner, 1993: 5) for the 'benefit' of others. The extraordinary situation existed where, at age 21, a patient was effectively separated from their doctor as an information source and, thus, from any efficacious decision-making capability. My recollection (however accurate this may be) is that all diagnostic information was relayed through my parents (colleagues of the neurologist) who took it upon themselves (probably unconsciously) to act as a "filter" on my behalf and, presumably, in my best interests. One must add that, as an adult, it seems extraordinary that I allowed this to happen.

There must be, then, some reference made here to Freud's Oedipus complex (Freud, 1963/1974; Klein, 1984: 10; Simon and Blass, 1991: 161). The author refers specifically to the complex associated 'with the entire range of feelings the child may experience in relation to his parents and interactions he or she may have with them' (Simon and Blass, 1991: 161); what has been generally agreed to be the complex relationship of a child with both parents, the developmental history of that relationship and the complex array of feelings in the child towards their parents, as well as the feelings in both the parents, individually and as a dyad (Simon and Blass, 1991: 173). Unfortunately, as the child devotes themselves to the great task of detaching themselves from their parents (Freud, 1963/1974: 380), as one moves with maturity and understanding, from a "parent-child" relationship to one of "adult-to-adult", it is argued here that when the crisis of illness confronts the actors involved, the 'daddy-mommy-one triangle' (Deleuze and Guattari, 1984: 51) may re-emerge.

The two people apparently motivated by parental anguish, professional ideology, Freudian defence mechanisms (repression or denial) and whatever else, have long-since been forgiven. Even when the spectre of illness arises we strive now to approach these challenges with an "adult togetherness" rather than a "parent-child" distance.
clients (patients) are encouraged to trust them as experts in much the same way as we would our accountants (Brewin, 1995: 328). Women, in particular, are subject to sexist ideologies that underpin medical science and medical practice (Nettleton, 1995: 140) as evidenced by the medicalisation of childbirth and the notion that 'doctor knows best' about a condition (pregnancy) which is treated so readily as an illness (Oakley, 1995: 332; Nettleton, 1995: 152). Unfortunately, 'women who have attempted to resist medical control have found that they have had to contend with defensive, and often hostile, responses' (Nettleton, 1995: 141). The attitudes of the male-dominated medical profession towards patients, particularly women ("neurotic, nerve cases"), is evident in a note penned from one physician to another:

It began, "My dear Harry," and contained a great deal about their respective handicaps at golf and their plans for the summer. The kind doctor ended . . . in a postscript: "The lady who brings this is Mrs.---. She is a terrible woman, a deplorable neurotic. I need say no more about her, but I hope you won't mind my burdening you with her, for she is the kind of tedious person who bores me to death. However, she pays her fees" (Treves, 1923/1980: 53).

Many treatments may be regarded as patronising, paternalistic, even humiliating; seemingly 'benign fabrications' (Goffman, 1974b: 163); harmless fabrications that can be exploited in order to wield power over people, punish them, incarcerate them and discriminate against them. Medical treatment is often given to assist with individual social acceptability and is indicative of a fundamental paternalism: the medical profession may judge what is socially acceptable and are empowered to act upon such judgements to "help" others. The quintessential "successes" of psychiatric practice have been as 'medical police' (Szasz,
1977/1988); to "help" others improve behavioural acceptability (Szasz, 1970), even correcting "deviant" sexual behaviour (Szasz, 1980). Even the correction of appearances and, thus, social acceptability through numerous cosmetic surgery options, is now available (Finkelstein, 1991: 81).

Finally, consider organisational life. Organisations strongly rely on the medical model. Goffman's (1974b: 303) exploration of frame analysis suggested that a specialist is often called to clear the ambiguity in a frame: the medical practitioner is called to clear the ambiguity of illness "reality". What sickness, how sick and the impact on (current and future) functionality; all are defined according to medical testimony. For example, people with AIDS are only able to continue working within an organisation for as long as the medical profession say so (Stone, 1994: 63). Educational institutions rely on evidence from a physician (medical certificate) to validate a student's claim of illness to miss an exam (Robertson, 1993). Insurance companies rely on their own troupe of medical professionals to validate illness claims with this being potentially problematic for someone with an invisible, and scientifically unrecognised, illness such as chronic fatigue syndrome:

Insurance companies and their physicians were even more exasperating.

Insurance companies are reluctant to accept claims for illness that do not have neat labels, neat causes, neat cures and long histories (Blake, 1993b: 32).

Finally, negative social values about illness and disability are similarly held by the medical profession: 'Health care professionals share the values and expectations of their society. Most nurses, physical therapists and allied health workers share the American dream of
achievement, attractiveness, and a cohesive, healthy family. These values influence perceptions of individuals who are disabled, impaired or otherwise less than "normal" (Saylor, 1990: 74).

"Entities" of Influence: "Invisible" Chronic Illness

Individual Response

Many studies have confirmed the profound psychological impact of illness on the individual. Kaplan (1980: 3) reported the importance of self-feelings or self-attitudes in response to illness. Varying psychological responses to illness are reported: anxiety; denial; questioning; ambivalence; suspicion; hostility; regression; loneliness and rejection; depression and withdrawal (Lambert and Lambert, 1979: 5-15). Additionally, self-doubt and self-loathing, self-dislike, uncertainty, interpersonal insecurity, loss of self-esteem and guilt are reported (Donoghue and Siegel, 1992: 29-36). Finally, and of particular note here, similarities in emotional response were observed where there were varying chronic disorders (for example, comparing genital herpes, MS, cerebrovascular accidents and epilepsy) which included denial, fear, depression and anger (Parsonson, 1989: 213-214).

Psychological responses may vary depending on the individual personality, cultural milieu and illness specificity: 'The degree of mental anguish that an individual will suffer from his illness, as well as the amount of care, trust, respect and compassion he will receive is dependent upon three factors outside himself: the social acceptability of the illness; the clarity of diagnosis; the potential severity of the illness' (Donoghue and Siegel, 1992: 40). 'How individuals react to their illness may depend upon their perceptions of themselves, their body
images and how they feel significant others and society view them and their illness’ (Mead, 1955; cited in Lambert and Lambert, 1979: 2). The presence of disease (with or without symptoms) may invoke a change in the personal identity of the bearer (Fabrega, 1981a: 511). Susman (1994: 18) confirmed, in a discussion of the psychological underpinnings of stigma and deviance, that the illness or disability may overshadow the individual’s personal identity, with impairment in Western society being 'considered the worst thing that can happen to a person' (Susman, 1994: 19).

Psychological and social factors clearly encourage non-disclosure of an ICI. People will conceal their deviancy to protect themselves from mistreatment (Freedman and Doob, 1968: 48). Jourard (1971: 6) described the paradox subsumed in the Western expectation of disclosure and yet the truth of penalty upon doing so: 'Impossible concepts of how man ought to be--which are often handed down from the pulpit--make man so ashamed of his true being that he feels obliged to seem different, if for no other reason than to protect his job'. This penalty is enacted stigma (Scambler, 1984: 215) (or discrimination) and has two perspectives; the socially determined and the personally accepted: 'Stigma is not solely the outcome of societal devaluations of differentness; in order for stigma to exist, individuals possessing such differentness must also accept this devaluation' (Jacoby, 1994: 269).

"Invisible" Chronic Illness: A Social Construction

The social construction of disease categories, the emergence of institutions responsible for the deviant, the classification and regulation of deviants and the concept of the 'sick role' (Turner, 1987: 4) are all part of illness construction. Different cultures socialise the sick person to respond to their illness in different ways. Different "languages of distress" have
been described by different socio-cultural groups. For example, the stoical Irish who are inclined to understate their complaints, have been compared to the more dramatic Italian-Americans who are voluble and effusive when describing their complaints to the medical practitioners (Helman, 1990: 117). Gender cultures arise in response to illness, with men tending to stoicism and a high threshold for medical consultation (avoiding it where possible) and women being socialised to have a low threshold for consultation and more inclined to seek medical assistance earlier (Helman, 1990: 143-145). Beliefs about tranquillisers are affected by age, gender, social class, educational and health status (Calman and Williams, 1992: 240) as are the medical practitioner's response to culture, gender and social status: the response of the male medical practitioner to a female patient is more likely to be a misdiagnosis of 'hysteria' or 'hypochondria' (Helman, 1990: 145). Conversely, the response to male stoicism and lack of complaint may be an underestimation of the seriousness of the disease (Helman, 1990: 143-14). Social culture constructs what is socially acceptable; what is legitimate. Whilst Western culture may trivialise a women's complaints (for example, when under the effects of PMS) as being hormonal, other cultures' response may be more drastic: for example, segregation of women to a "menstrual hut" during the offending time of the month may be regarded as routine to avoid contaminating others (men) in the camp or ruining the coming harvest (Helman, 1990: 141).

The constructed categories of "disease", "sickness" and "illness" are distinguished here and discussed below: 'Whereas disease is a concept which describes malfunctions of a physiological and biological character, illness refers to the individual's subjective awareness of the disorder and sickness designates appropriate social roles' (Susser and Watson, 1971; cited in Turner, 1987: 2, emphasis added).
"Disease"

The notion of disease as a physiological, biological phenomenon is central to the discipline of medicine (Nettleton, 1995: 24). Biomedical "disease" may be especially relevant for explanations about biologic evolution (Fabrega, 1981b: 135), although the biological sciences do not try to distinguish between health and disease, being more concerned with the interaction between living organisms and their environment (King, 1981: 107). The 'organismic' view of disease (Fabrega, 1981a: 510) or the 'biomedical' or 'medical model' (Mechanic, 1978; Dudgeon, 1992; Thorogood, 1992: 47; Blaxter, 1995: 26; Nettleton, 1995: 3-5) gives salience to biological issues. It is, equally, a socially constructed reality (Veatch, 1981) and one that views the individual seeking help as a 'changed organism' (Fabrega, 1981a: 510) - a body with abnormalities. 'What assumes importance now are his complaints, his pains, his physical limitations and his habits as they may pertain to his medical (bodily) condition' (Fabrega, 1981a: 510).

Disease is a physiological, "unhealthy" condition (Boorse, 1981: 546) whilst it appears that "normal" or "undiseased" is the aspired to "natural" or "healthy" state. Disease is often seen as the antithesis of "health" - with health being regarded as "good" and disease as "bad" (Boorse, 1981: 548). Western culture brings with it beliefs and assumptions about disease, for example, that people should "know" if they have a disease and that those symptoms should propel them quickly to the nearest physician (Fabrega, 1981a: 508). Disease is collectively judged by the social group (Gregory, 1968: 32; cited in Margolis, 1981: 561) and is 'the aggregate of those conditions which, judged by the prevailing culture, are deemed painful or

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34 Of course this doesn't always follow: Becker and Rosenstock (1984) confirmed that the sick person may do nothing, self-medicate or seek medical advice, based on varying situational or structural characteristics, their beliefs about illness or their cultural background.
disabling and which, at the same time, deviate from either the statistical norm or from some idealised status' (King, 1981: 112). Health, the opposite, is the state of well-being conforming to the ideals of the prevailing culture or the statistical norm (King, 1981: 112). Western culture assumes that a person free of disease is "normal" and "good" (Boorse, 1981: 548). Disease is seen as a deviation from two social norms: personal norms, those set by the individual; and group norms, those set by a relevant group to which the person belongs, for example, the workplace group (Fabrega, 1981b: 131).

Disease categories are themselves social constructions. Some assumptions about disease include the organism being discrete; disease being a qualitative state (usually perceived negatively) and thus discontinuous or temporally bounded\(^{35}\); and disease being undesirable in that it constitutes a deviation and can be a source of human misery and suffering (Fabrega, 1981a: 507). Disease is assessed on the basis of verbal reports (for example, pain), the observations of others and/or by means of various procedures applied to the person (Fabrega, 1981b: 131). The difficulty of determining "normality" in terms of disease and disease classification is underscored: 'To call a set of symptoms "bronchitis" does not mean that a discrete disease exists as an entity independently of social context, but that is how medical science, in a given time and place, with the aid of laboratory tests and theories, has come to define it' (Nettleton, 1995: 20). 'Disease categories are not simply a product of scientific analysis but also the outcome of social and political struggles' (Nettleton, 1995: 25). 'Facts' about disease are, similarly, socially constructed (Nettleton, 1995: 21), with disease categories being used to reinforce existing social structures and the language of disease being assumed.

\(^{35}\) Note the problematic nature of chronic disease fitting with these assumptions: chronic disease endures and is not necessarily temporally bounded or discontinuous.

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to be objective (Nettleton, 1995: 24). For example, 'there are diseases that are lethal but
there are no diseases that are classified as such merely because they result in death. On the
contrary, the most interesting general feature about disease is that it is a disorder or the cause
of disorder of a certain sort within the functional range of ongoing life' (Margolis, 1981: 570,
italics in the original).

Negative connotations are commonly associated with disease. Value judgements may be made;
disease being seen as some kind of lapse with respect to social norms of health; something
undesirable to be overcome - a deviance or abnormality (Margolis, 1981: 562) - and 'a
morbid or abnormal state of some sort, a state effective or deranged with respect to some
condition of healthy functioning' (Margolis, 1981: 566). Disease is viewed as a negative
deviation in the condition of a person (Fabrega, 1981b: 131). However, this may be
unrealistic, as is the case with lanthanic\(^{36}\) disease: 'On whatever professional criteria may be
admitted, the palpable onset of some disease, as among the cancers, need not by synchronic
with any determinate malfunctioning' (Margolis, 1981: 566). Boorse argued that a disease
only becomes an illness if it is serious enough to become incapacitating. If this happens it
becomes undesirable for the bearer, a title to special treatment and a valid excuse for normally
criticisable behaviour (Boorse, 1981: 555). However, the strength and influence of functional
norms in society on this 'the essential puzzle' (Margolis, 1981) of disease and functionality
are frequently not questioned, either professionally or philosophically.

\(^{36}\) Lanthanic diseases are diseases that are clinically evident but undetected by the patient (Margolis,
"Sickness"

Sickness refers to the social representation of illness and disease. It incorporates what is meant by sickness, the role undertaken by the bearer and the impact of the sickness on the individual within the collective. Negativity attributed to sickness (or illness or disease) comes largely from the collective. The role of the sick person, what Parsons (1951) defined as the 'sick role' (Parsons, 1951; Mechanic, 1978; 1981: 486; Lambert and Lambert, 1979: 2; Fabrega, 1981a; Becker and Rosenstock, 1984: 186; Harrison, 1984; Yelin, 1986: 623; Turner, 1987: 45-46; Curtin and Lubkin, 1990: 13; Morse and Johnson, 1991: 2; Nettleton, 1995: 70), can be viewed as the role prescribed and enforced by society; the set of societal expectations of the individual in this role and the set of norms associated with the role:37

According to Parsons' analysis, when a person's illness has been legitimized by medical sanction, or that of intimates and/or persons having influence over him, the person occupies a special role in society. During the time of the illness, he may be relieved of usual demands and obligations and his "sick role" takes priority over other social roles (eg occupational, familial etc). Moreover, the person is expected to seek help in restoring his full energies and to co-operate in the treatment process. Persons may be motivated to adopt the sick role to obtain release from various kind of responsibilities; but there are also others who fear the dependence of the sick role or who are suspicious of physicians and avoid seeking medical advice even when serious symptoms appear (Mechanic, 1981: 486).

37 The role of the sick person can also be considered from a second perspective, that of the individual's behavioural response to illness. "Illness behaviour" will be dealt with in the next section.
Note the importance, and expectation, of seeking professional help to restore functionality and to justify relief from general obligations. The sick role, then, involves a set of behaviours and dispositions adopted by the sick person and sanctioned by others (Fabrega, 1981a: 512). Society assigns the sick role to those who have been evaluated as having the aberrant or "bad" characteristics associated with being sick (Veatch, 1981: 526). The sick role includes two exemptions from social responsibilities: normal social responsibilities, and responsibility for the condition and the inability to decide to get well (Veatch, 1981: 526). It imposes two obligations upon the sick person: they should want to get well and they should seek technically competent help (Veatch, 1981: 527). Importantly, the individual is not deemed "sick" until the appropriate social judgement has been made (Veatch, 1981: 527). The sick role is regarded by some as a useful adaptive measure (Fabrega, 1981a: 512).

The "sick" person may decide not to embrace the sick role. This can depend on many factors: cultural or racial background; attitudes and beliefs; the socio-economic status of the individual; and, the individual’s previous experiences with illness (Mechanic, 1981: 485-488). Finally, the sick role does not necessarily take into account chronic illness (Turner, 1987: 54; Curtin and Lubkin, 1990: 13; Lubkin, 1990: 48) and, especially, not the complexities

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In fact, some clearly view illness in others and themselves as a useful opportunity to abdicate responsibility. The belief exists, for some, that the disease or sickness must somehow be within the control of the sick person. For example:

Illness is an option. It may not be perfect, like the old car, but if it saves us from doing things we find more scary or unpleasant, like asking our wife if she loves us, or walking to and from work, then we are benefiting from it... Illness is a way to obtain love, to get out of work. It confirms the world as slightly unhappy or perhaps downright miserable, confirms our belief in fate, provides a reason for being less successful than we hoped or provides a drive for success (Harrison, 1984: 185).

There is, of course, another view of illness: that it is downright inconvenient, scary and unpleasant - a means of making work much more difficult, a way to lose love, defeat the drive for success and, perhaps, prevent one from walking to work or anywhere else, ever again.
associated with "invisible" chronic illness:

The major deficiency of the sick role model is that it is based on acute episodic illness. Consequently, it overlooks chronic illness characteristics: the long-term rather than temporary nature of the illness, the reality that full recovery is not a reasonable expectation, and acknowledgment that management is often the responsibility of the client or family and, therefore, that the individual must adjust to a permanent change (Lubkin, 1990: 48).

Whilst the sick role does allow for some respite from social obligations (Turner, 1987: 55), for PwI CI this may be dependent upon the perceived "seriousness" of the condition and its observability by others. This situation is further complicated by the fact that the state of permanent change referred to above is usually subject to further, deleterious changes requiring continual adjustment and adaptation. Despite the prevalence of chronic illness and the fact that it is increasingly evident, society does not provide a clear and acceptable role for this group (Segall, 1976; cited by Lubkin, 1990: 49). The notion of an 'impaired role' (Curtin and Lubkin, 1990: 13; Lubkin 1990: 47) may provide a more reasonable conceptual framework.

"Illness"

The idea of disease as "illness" may be used to signify purely behavioural changes. In a general anthropological sense, it is a set of behaviours, judged as undesirable and unwanted in a culture, which is considered as having medical relevance (Fabrega, 1981b: 134).
Social-medical "illness" seems relevant for explanations about the complementary process of social evolution (Fabrega, 1981b: 135), as opposed to biological evolution. Illness is a social construction of deviance - the label of "illness" a social process (Veatch, 1981: 524). Illness is a socially assigned category given meaning through social interpretation and evaluation of biological abnormal characteristics (Veatch, 1981: 524) and involves human, and therefore social, evaluation of what is normal, proper and desirable, in much the same way as notions of morality (Veatch, 1981).

Illness behaviour is 'the way in which given symptoms may be differentially perceived, evaluated and acted (or not acted) upon by different kinds of persons' (Mechanic, 1981: 485) and may constitute the person being able to take one of the following courses of actions when symptoms or knowledge of disease is present: they may do nothing, self medicate or seek professional help (Becker and Rosenstock, 1984: 183). What action the person takes, and the timing of these decisions, are also aspects of illness behaviour (Becker and Rosenstock, 1984). Mechanic (1981) recognised four illness dimensions that can be conceptualised from two perspectives. The first perspective, illness recognition, refers to two characteristics: the frequency of occurrence of an illness and the relative familiarity of symptoms experienced. The second perspective, illness danger, refers to two different dimensions: the relative predictability of the outcome of the illness and the amount of threat or loss likely to result from the illness (Mechanic, 1981: 489). Thus, using Mechanic's analysis, the common cold is not perceived as a problem in society as it is "common"; that is, the symptoms are familiar, its course is predictable (if somewhat unpleasant) and the threat or loss likely to result is minimal - a condition classed by Mechanic (1981: 489) as a 'routine' illness. Conversely, AIDS would be classed as 'non-routine', being less common, less familiar, less predictable
and far more threatening.

Illness behaviour is influenced by situational or structural factors which affect the seeking of, and access to, health care including the resources available to the person (such as money, transportation and health insurance) (Becker and Rosenstock, 1984: 185). Cultural factors result in variation in interpretation of symptoms, the manner in which symptoms are expressed and a differential preparedness to act on symptoms (Becker and Rosenstock, 1984: 185). The sick role (and subsequently defined illness behaviour) is a legitimate and recognised role, but not necessarily socially approved (Veatch, 1981: 541). Illness is not socially approved because the desired normative state is "health" with its attendant functionality. Groups provide a social approach to illness through knowledge, tradition, guidelines and the values of the group which allow the group some indirect control over the illness (Fabrega, 1981b: 140).

"Entities" of Influence: The Modern, "Sick" Organisation

Society shapes the views of organisational members - the culture of the organisation is strongly influenced by the society that surrounds it and the individuals within it, particularly those in power. Themes of culture and power in modern organisations, and of "sick" organisational settings, will be the foci of the final sections of this chapter.

Modern Organisations: A Culture Intolerant of Illness

The earlier sections have highlighted the role of capitalism on PwICl. Modern organisations similarly construct an attitude of negativity and intolerance toward people with illness and
disability. As with social values, modern organisational culture is similarly influenced by a capitalist, individualist ideology. Organisational culture (Schein, 1981: 64; cited in Ivancevich and Matteson, 1990: 37-38) is described:

Layer 1 includes artifacts and creations which are visible but often not interpretable. An annual report, a newsletter, wall dividers between workers, and furnishings are examples of artifacts and creations [as are policies and procedures regarding sickness and disability in the workplace]. At Layer 2 are values or the things that are important to people. Values are conscious, affective desires or wants. In Layer 3 are the basic assumptions people make that guide behaviour. Included in this layer are assumptions that tell individuals how to perceive, think about, and feel about work, performance goals, human relationships, and the performance of colleagues.

'Agents... are "enculturated"... Agents not only draw on cultural beliefs, rules, and values to form their intentions and enact their projects, but through their activity culture itself is reconstituted. That is, culture is not only the ground of human activity but is the outcome of this activity as well' (Fay, 1996: 57). Culture is regarded as 'mental programming' (Hofstede, 1991: 4) - it is learned (Hofstede, 1991: 5) - and it is 'always a collective phenomenon' (Hofstede, 1991: 5). Organisation culture is normative; it provides standards of conduct for members to follow (Horton and Hunt, 1972: 49). Norms are the 'unwritten rules' (Sims et al, 1993: 24) guiding and shaping behaviour; mores are beliefs in the rightness or wrongness of acts that emerge over time and become self-validating and self-perpetuating (Horton and Hunt, 1972: 51). Normalising judgements may be regarded as instruments of
power (Nettleton, 1995: 114): actions or attributes of individuals are compared with the actions of others by 'judges of normality' who, according to Foucault (1979: 304; cited in Nettleton, 1995: 114), are to be found everywhere. Managers in organisations would be prime examples. Stigma is, consequently, culturally defined and constructed within the organisational context: different experts have constructed different meanings for stigmatising conditions; such differences are not random but 'seem to be related to such things as core cultural values, the experts' professional training and the institutional settings in which they are practised' (Scott, 1974: 111). 'Instrumental reason dominates' (Alvesson, 1993: 27). Formal technical rules 'underpin the single-minded pursuit of efficiency that characterises many organisations' (Sims et al, 1993: 27). They are often impersonal, inflexible and apply to all (Sims et al, 1993: 26) regardless of the individual capacity to comply. For PwICl, the strictures of culture, normalisation and attendant judgements within the organisational environment may present many problems.

Group behaviour relates to those roles, norms and normalisation: 'A role is the organised system of participation of an individual in a social system, with special reference to the organisation of that social system as a collectivity. Roles, looked at in this way, constitute the primary focus of the articulation and hence interpenetration between personalities and social systems' (Parsons, 1981: 59-60). The role is at the heart of social function; it is also the nexus of psychological and sociological influences: the psychological health of the individual requires that person to have an 'ability to satisfy the requirements of the group' (Maslow and Mittlemann, 1981: 49-50). That person must be:

(a) not too unlike the other members of his group in ways that the group
considers important; (b) adequately informed and essentially accepting of the folkways of his group; (c) willing and able to inhibit the drives and desires tabooed by his group; (d) able to show the fundamental strivings expected by his group: ambition, promptness, friendliness, sense of responsibility and loyalty; (e) interested in the recreational activities favored by his group (Maslow and Mittlemann, 1981: 50).  

For the person who is chronically ill or disabled, group conformity via normative behaviour is not always easy, even if that illness or disability is invisible. In organisational life, managers and colleagues become the 'judges of normality' Foucault (1979: 304; cited in Nettleton, 1995: 114) has nominated. They do this with confidence and with incomplete knowledge about illness. They also do this with the socially predetermined negative attitudes towards illness and disease, and the attendant assumptions of reduced functionality for the individual. Standard, normative modes of "getting the job done" may be inappropriate for PwCI to conform to. For example, the expectation of people arriving at the office early and leaving late may leave the PwCI exhausted and ineffective. The same person, encouraged to work from home for several hours per day or several days per week, may be far more productive and comfortable being able to incorporate rest periods throughout the day or work in the evenings after resting.

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39 Conversely, psychological health also requires 'adequate emancipation from the group or culture', requiring the individual to be original, independent, non-reliant on excessive group-approval and tolerance of cultural differences (Maslow and Mittlemann, 1981: 49-50). This apparent tension introduces the notion of ambiguity, conflict and contradiction, even for the "healthy" individual, a theme that will emerge later.
"Rabid" Managerialism

Managerialist tendencies in organisations may also present problems for those with illness and disability. One of the main claims made about the managerialist ideology is that efficient management can solve almost any problem (Rees, 1995a: 15); that management "knows best" (Rees, 1995b: 198). Management 'recipes' (such as re-structuring, re-engineering and outsourcing) become irresistible. Indeed, the metaphor of 'culture as manager-controlled rites' (Alvesson, 1993: 20) depicts 'managers . . . standing "above" culture and controlling it' (Alvesson, 1993: 21) and portrays managers 'as (potentially) in control of culture while employees respond passively to their dictates' (Alvesson, 1993: 26). The 'new role of managers' emphasises functionalist approaches which 'seek to base an explanation of the increasing authority of managers upon objective definitions of the manager's job description' (Considine, 1994: 224) which, unfortunately, are often ill-defined and euphemistic (Considine, 1994: 224). Vague titles as "entrepreneur", "figurehead" and "leader" (Considine, 1994: 224) imply the existence of modern managers able to handle all that may come their way by utilising an enthusiastic embrace of efficiency.

Another of the implications of the 'new managerialism' (Considine, 1994: 232) is the politicised role of senior management (Considine, 1994: 232) where purposive, rather than purely administrative, functions are expected of management (Considine, 1994: 231). Especially in public administration, a 'new commodified approach' emerges where administrators are expected to emphasise 'means rather than ends' and professional "neutrality" (Davis et al, 1993: 43). 'This has the effect both of privatising the internal life of public organisations and subjecting formerly private decisions about training and investment to social norms and demands' (Considine, 1994: 231-232); that is, to subject even public
organisations (and their members) to the rigours of resource constraints 'and a desire to impose greater political and managerial control' (Davis et al, 1993: 43).

The recent economic rationalist backdrop of Anglo-American managerial praxis (Kouzmin et al, 1997: 31) nurtures the managerialist ideology (Rees, 1995a: 16) and, yet, the economic basis of managerialism is one of its major criticisms (Hughes, 1994: 77). It has been argued that organisational theorising has been, thus far, unable to adequately confront the contemporary hegemony of economic rationalism (Kouzmin et al, 1997: 21). One of the interesting metaphors of the managerialist ideology is the strong person taking 'tough decisions' and being rational and/or scientific whilst doing so (Rees, 1995a: 16); of doing 'more with less' (Considine, 1994: 226; Hughes, 1994: 69; Rees, 1995b: 197); an emphasis on results rather than procedures (Hughes, 1994: 69); a focus on outputs (Hughes, 1994: 69); an achievement of results and of taking individual responsibility for their achievement (Hughes, 1994: 77) - 'the obsession focuses upon means and obscures ends' (Kouzmin et al, 1997: 30). Economic rationalism is, arguably, a paradigm for the functionalists concerned with "how to" and "best approaches" implemented by professional managers indoctrinated with the traditional coercive management theory (Kouzmin et al, 1997: 31). The corollary to this is a corporatised focus 'dealing with one-another on an "arms-length" basis' (Hughes, 1994: 69) and appearing tough about the outcomes (Rees, 1995b: 197). Managerialism is about 'homogenising the organisation and its subunits through an application of standardised budget, planning and training systems' (Considine, 1994: 232); approaches that lead ultimately to increased control (Davis et al, 1993: 105; Considine, 1994: 226; Hughes, 1994: 68) and reduced diversity whilst narrowing 'the band of action to those things best able to be controlled' (Considine, 1994: 226). It is claimed to be a return to the scientific management
ideas of Frederick Taylor - "Neo-Taylorism" (Hughes, 1994: 80) - through the emphasis on performance measurement, incentive structures and easier avenues for dismissal of staff (Hughes, 1994: 81). It encourages the exercise of control over work-related behaviour and a continuing capacity to impose work related sanctions (Kouzmin, 1980: 132): 'Both control over the product and control over the work process by managerial authority provides a division of labour characterized by a high routinization of tasks. To routinize is to control and as a strategy for task allocation, comes to be the cornerstone in the evolution of a managerial ideology within which the question of power is paramount, but infrequently addressed' (Kouzmin, 1980: 133). Routinisation and standardisation of task and task performance may be problematic for one unable to easily conform to expectations.

Managerialist changes in the public sector are associated with distinct values: 'neutrality, anonymity, a career structure and an acceptance of the need for processes to be fair, equitable and proper' (Davis et al, 1993: 104-105). Unfortunately, the rise of managerialism does not address the "human costs" - these are 'not allowed to cloud the efficiency equation' (Rees, 1995a: 24). An ideology to justify callousness is provided by the economists (Wheelwright, 1995: 30) and is one that seems to condone economic and social inequality (Rees, 1995b: 197) even whilst espousing the need for fairness and equity (Davis et al, 1993: 105). The "neo-Taylorian" approaches employed by the new managerialism are, in many respects, contrary to the wisdom of the human relations school (Hughes, 1994: 80). 'As instrumental criteria, efficiency and effectiveness serve as measures of accountability for organisational action. This probably explains much of their appeal in that they seem, at least, to provide standards of correct action' (Harmon and Mayer, 1986: 384, emphasis in the original). However, the rational model may only make instrumental, as opposed to expressive, statements: there is no
comment on the meaning or value of human action (Denhardt, 1981: 26, emphasis in the original). Issues such as fairness, justice, representation or participation may be treated as constraints whilst striving for ever greater levels of efficiency (Hughes, 1994: 82). 'Indeed, a major justification of organization in the beginning is that it can help eliminate those bothersome, inefficient human qualities, such as feelings, that interfere with rational endeavor' (Denhardt, 1981: 28). Illness may be similarly regarded as a "bothersome", "human" inadequacy detracting from the "efficient" processes of organisational life.

Nor does managerialist ideology address the problem of making simplistic, rationally-prescribed decisions, relating to indefinable, often insoluble, problems: 'The moral fiction' is that 'many of the claims of managerialism are a fiction' (Rees, 1995a: 23-24) involving a preoccupation with management panaceas (Rees, 1995a: 24); management 'recipes' (Kouzmin et al, 1997: 20) where management praxis is applauded as a means of increasing productivity (Kouzmin et al, 1997: 31); a pathological embrace of faddish management practices or 'tool tropism' (Jun, 1996: 109) and their application to difficult (or even simple) organisational problems. It is inconceivable to many that some of these recipes may be inappropriate (Kouzmin et al, 1997: 30). The mythology is perpetuated - if the suitably prescribed solutions do not work, it is in some way the organisation's fault (Rees, 1995a: 24) or the failure of the people involved to work hard enough or be smart enough.

The rise of the generalist manager, that is, the manager who can easily and competently manage any private or public agency (Easton, 1995: 39) perpetuates the mythology that these "super-managers" of efficiency can also handle any issues; including delicate and sensitive ones (such as those possibly provided by PwICl). The predominance of the managerialist
ideology and its relationship to loss of morale and sickness (Rees, 1995a: 15), including the narrow, reductionist managerialist interpretations of terms such as 'efficiency' and 'excellence' (Solondz, 1995: 212), are issues that potentially may make life and work even more complex for PwIcI.\footnote{The preponderance of managerialism and associated problems for PwIcI emerges in the narratives in Chapters Five and Six.}

Managers who are inconsiderate of other members of the organisation, through ignorance or the chasing of efficiency objectives, may feel exempt from responsibility. Organisations are human creations and 'replete with impersonal rules, roles and procedures - they seem to take on a life and legitimacy of their own in the minds of those who work in them and are affected by them' (Harmon and Mayer, 1986: 14). "Rational action" has come to be identified almost solely with what one does within an organizational setting and especially with what one does to further the goals and objectives of that organization" (Harmon and Mayer, 1986: 15). Unfortunately, this action does not always correlate with consideration and concern for others. The common meaning of "efficiency" is the measure of how well action is instrumental in achieving the ends of the organisation (Harmon and Mayer, 1986: 15). However, and unfortunately,

Claims to innocence, whether grounded in unconnectedness or inadvertence, raise a special problem regarding frame limits; namely, how far can the plea of essential innocence be pressed -- apart, that is, from the issue of how far it can be pressed convincingly. The answer . . . seems to be: very far indeed (Goffman, 1974b: 330).
Some of the "human costs" of managerialist ideology are emerging in the literature: greed and bullying (Rees, 1995b: 197); the dehumanising nature of organisational, capitalist-based "success" (Rees, 1995b: 204); 'creeping crisis' effects (Jarman and Kouzmin, 1994; Korac-Boisvert and Kouzmin, 1994; Kouzmin et al, 1996; Kouzmin et al, 1997: 20); a loss of social conscience (Rees, 1995b: 206); feelings of betrayal in organisational life (Solondz, 1995: 212; Temby et al, 1996; Morrison and Robinson, 1997); loss of trust in organisations (Britton, 1995: 225; Morrison and Robinson, 1997: 227); a focus on instrumental, as opposed to noninstrumental, ethics in business (Quinn and Jones, 1995: 23-25); cronyism (Rees, 1995b: 207); unemployment (Rees, 1995b: 209; Temby et al, 1996); job insecurity (Rees, 1995b: 209; Solondz, 1995: 218); a persistent sense of powerlessness (Rees, 1995b: 209); and problems of stress, fatigue and anxiety at work (Britton, 1995: 221; Rees, 1995b: 209). All of these add to the difficulties already faced by PwICl in organisational life.

There may exist a mythical and negative view of the sick worker; one which may work against that individual given the managerialist scenario depicted above. The (often erroneous) belief is that people choose to stop work due to illness and gain sanction from the 'sick role' (Yelin, 1986: 623-624); that the chronically ill are malingerers (Goffman, 1974b: 191; Yelin, 1986: 624); or that people choose disability rather than work (Yelin, 1986: 625). It has been suggested that there is some difficulty attached to telling apart two different forms of 'feigned incapacity' (Goffman, 1974b: 192): those who are 'malingering' (Goffman, 1974b: 191), and those with 'hysterical illness' or 'conversion reaction' who delude themselves about their

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41 According to Yelin's (1986) study, this is not the case. The social characteristics of work and, especially, levels of autonomy, the nature of work and certain demographic characteristics have the most profound impact on people with impairment leaving work. For example, for those with impairment, individuals in jobs with high levels of discretion are more than 20 times as likely to be working as those with less autonomy, despite their limitations (Yelin, 1986: 644).
malfunctioning (Goffman, 1974b: 192). Rather than uncritically embracing the view that sick people are "hysterical", "malingers" or just plain lazy and in need of some positive self-talk, perhaps, instead, it is the world of work which requires some scrutiny:

Instead of focusing on the nature of illness, public policy would do well to emphasize the world of the work place. Altering the characteristics of jobs can reduce the probability of work loss dramatically, even among those with activity limitations. This can be done by modifying the fit between the individual and the job, both in the interaction between the physical limitations and physical requirements of work and in the discretion granted the individual to do a job in the ways and at the pace consonant with capacities (Yelin, 1986: 647).

*Modern Organisations: Mechanisms of Social Control*

A mechanism of social control, then, is a motivational process in one or more individual actors which tends to counteract a tendency to deviance from the fulfilment of role-expectations, in himself or in one or more others. It is a re-equilibrating mechanism (Parsons, 1951: 206, emphasis in the original).

'Organized systems are inherently based around notions of regulation and control' (Denhardt, 1981: 8). The 'rational model of organization' (Denhardt, 1981: 15) is ascending rapidly - a functional organisation that purports a relationship with people that is value-free (Kouzmin, 1983: 235). 'However, functionalist forms of explanations are dependent upon a view of society, and organization, as coercive systems' (Kouzmin, 1983: 235). Science and
organization espouse values of rationality and control to society and its members (Denhardt, 1981: 41). Foucault (1977: 28) made the connection between power and knowledge; control may be derived from hierarchical domination but expressed as technical or functional rationality (Kouzmin, 1980: 133). Conversely, it has been argued that organic organisations reliant on culture report a change in emphasis from control of behaviour and measurement of outputs, to control of employees' attitudes and commitment (Alvesson, 1993: 4). Whatever view is followed, not only are organisations vast and dominant, but organisations penetrate - they are pervasive in so many aspects of modern life (Denhardt, 1981: 16). 'Authority is always and everywhere a system of regulation' with techniques of control or co-ordination masking form but not effect (Considine, 1994: 64). Indeed, the making of policy involves an attempt to mobilise resources and direct human effort (Considine, 1994: 62) and is done through rules and legitimacy - and little consideration of flexibility. For a PwICl, this may be problematic as they may have difficulty adhering to rules, following policy and responding to authority as it is currently characterised in rational organisations.

It is with reference to the goals of the organisation that individual actions are regarded as rational - efficiency equates with rationality (Denhardt, 1981: 22-23). The modern organisation may be regarded as panopticist (Bentham; cited by Foucault, 1977) in that overt, corporal punishment has been replaced by surveillance; the watched don't know when they are being watched - and they are watched in the name of efficiency, under the guise of control. 'In keeping with the instrumental pursuit of organizational objectives, it is expected that the members of the organization will soon learn to behave in a way consistent with the organization's goals' (Denhardt, 1981: 24). The organisation, as pattern of social domination, emerges as a battleground over which the struggle between work and interaction, labour and
humanity is fought (Denhardt, 1981: 63).

It has been argued above that "illness" is regarded as deviant, especially in a capitalist, functionalist, individualist society and prone to callous disregard in an instrumental, managerialist, efficiency-seeking organisation. In modern workplaces, it is not just the psychiatrist or the medical practitioner who decides who is normal in the working organisation: modern managers embrace the task of "judging" normal behaviour using their positional power. The strongest sources of authority are those which involve consent. Actors may choose to submit to the directions of others to avoid internal upheaval (Considine, 1994: 64): 'At its strongest this form of permission becomes moral consent' (Considine, 1994: 64).
PwIC1, as free agents, may routinely mask (perceived or real) weakness, employing "keeping-up" behaviour to avoid potential internal upheaval. The managerialist ideology in a coercive institution is strengthened when the manager is relied upon for advice, trusted to "understand" (when they probably do not) or (perhaps mistakenly) believed to be morally concerned.

The "Sick" Person in the "Sick" Organisation

Whilst we may assume that the average workplace may potentially be a good source of social support for the individual (Turner, 1987: 77), capitalism may incite an "unhealthy" desire to conform, to progress, to succeed, making the mutual trust and honesty required for social support difficult. The 'insanity' of capitalism and the 'sick society' was first described by Eric Fromm (1956: 12) as a 'pathology of normalcy'. One aspect of this 'insanity' involved a suppression of spontaneous feelings. The organisational culture may foster a tendency to conform (Fromm, 1942/1960: 208): 'Friendliness, cheerfulness and everything that a smile is supposed to express, become automatic responses which one turns on and off like an
electric switch' (Fromm, 1942/1960: 210). The 'ethic of organization' (Denhardt, 1981: vii) similarly requires that 'the expression of certain functions is rewarded while other functions are repressed' (Denhardt, 1981: 52) - functions of intuition and feeling are neglected in preference to the "machine-like" sensing-thinking Jungian combination (Denhardt, 1981: 52). Emotions are generally discouraged, with the term "emotional" having negative connotations associated with a person who is unbalanced, unsound (Fromm, 1942/1960: 211). The "normal" person, thus, is one who is 'never too sad, too angry or too excited' (Fromm, 1942/1960: 212).

Notions of individualism suggest a freedom to think and act. "The right to express our thoughts, however, means something only if we are able to have thoughts of our own' (Fromm, 1942/1960: 207). Individualism becomes, then, an 'illusion of individuality' (Fromm, 1942/1960: 207) and of freedom. The ubiquity and strength of conformist behaviour in organisational life confirms this. A well cited example is Janis' notion of 'groupthink' (Janis, 1971/1989: 268; Forgas, 1985: 299; Sims et al, 1993: 254; Korac-Boisvert and Kouzmin, 1994: 68). Unfortunately, whilst the policy design effects of group-thinking can be operationally devastating ('t Hart, 1990; cited in Korac-Boisvert and Kouzmin, 1994: 68) group-thinking also represents the extreme or dark-side of social networks (Korac-Boisvert and Kouzmin, 1994: 68). Whilst group-thinking has been argued to be an inevitable recipe for both analytical and institutional disasters (Jarman and Kouzmin, 1994; Korac-Boisvert and Kouzmin, 1994: 68), representing the pathologies of all the other decision-making forms (Jarman and Kouzmin, 1994; Korac-Boisvert and Kouzmin, 1994: 68), it is also one that may invite disaster at a more personal level. Individuals censor themselves and keep their behaviour under surveillance so it resembles what is widely believed to constitute 'normality'
Williams, 1992: 34), disciplining themselves to secure the recognition of significant others
(Williams, 1992: 34). La Bier's (1986) Modern Madness extends the discussion of the
problems of insistence upon conformity: modern organisations foster emotionally "unhealthy"
individuals. The modern careerist in the modern (sick) organisation is described:

The Working Wounded are men and women in the career professional class
who suffer from and try to deal with this psychological fallout from success.

... Because it is accepted as a given that the name of the game is to work
hard, be well-rewarded, acquire possessions of high quality, and be able to feel
tranquilized by them, it is assumed that if the person experiences a problem,
it must be rooted in some internal conflict that prevents the person from
functioning smoothly, without complaint, in his or her adult environment (La

Combining the physical, emotional and psychological burden of having to maintain a
smoothly functioning, careerist persona with a body that is constantly in pain, fatigued or ill-
functioning may result in a potential cocktail of misery for the PwIC. Not only will they be
unlikely to be 'tranquilled' by their success (La Bier, 1986: 71), they may very well pay a
dear price for it in physical decline, a decline unseen by others. La Bier's (1986: 52)
description of the modern careerist could easily be a PwIC:

Most are like Gary: highly successful at work and seemingly normal to others.
What they say and how they act are not too different from other people in their
situations - at least in their organisations. They have adapted themselves to
their workplace in ways which have been great for their career advancement but disastrous for their emotional health. And ultimately, for the organisations as well.

The paradox of 'modern madness' is that people appear sick but are normal, whilst others appear normal but are sick (Carr, 1993: 4). At the individual level, this is evidenced by the apparent promulgation of 'automatons' (Fromm, 1956: 16) or alexithymic individuals (Kets de Vries, 1993: 64) - colourless, dull and unimaginative individuals characterising the quintessential 'organization man' (Whyte, 1956/1963: 126; Kets de Vries, 1993: 61); the 'administrative man' (Simon, 1950: 82; cited in Denhardt, 1981: 25), an essentially calculating animal pursuing the necessities of organisational life (Denhardt, 1981: 27); problems of narcissism (Fromm, 1956: 35; Kets de Vries 1993: 154; 1995: 10); megalomania (Kets de Vries, 1995: 73); paranoia (Kets de Vries, 1995: 77); and 'the imposter syndrome' (Kets de Vries, 1993: 114). At the organisational level there is evidence of 'organisational neurosis' (Whyte, 1956/1963: 134) motivated by the protestant ethic; organisationally-based 'social neurosis' (Freud; cited by Fromm, 1956: 19); pathologies evident through organisational power abuse (Kets de Vries, 1993: 143); and organisational cultures that are 'compulsive' or 'depressive' (Kets de Vries, 1993: 76-77).

If this is what "healthy" people in organisations must endure, what is to become of those who are sick? A bizarre paradox emerges: PwICl who look "normal" but are sick, pretending to be "normal" so they can behave in a manner that is "sick", in organisations which regard such behaviour as "normal" and which, in turn, is likely to make them even more sick!
The difficulties associated with the decision of disclosure, given the problems articulated
above, should not be underestimated and comprise a major hurdle for many PwICl. For
those who choose to disclose the risks are many: patent disbelief; insensitivity; ignorance;
labels of malingerer or deviant; stigmatisation; discrimination; stereotyping; prejudice
(Vickers, 1996a; in press). Alternatively, at the broadest level, silence also becomes a
problem. For example:

Fears of the consequences of open discourse and self-identification have
created a silence that threatens all of us . . . . An understanding of how AIDS
stigmatisation affects research, diagnosis, treatment and prevention efforts is
critical for effective public health programs (Goldin, 1994: 1359).

Whether the conspiracy of silence emanates from social forces, personal psychodynamics or
both, there is no doubt that it exists in organisations: PwICl are unlikely to speak about
illness; employers don’t want to listen. For the person who chooses partial or total secrecy
as a policy, Goffman (1963: 57) has alerted us to the stresses associated with the fear of being
found out; to the constant tension of who may know and who does not; and how, where and
when to reveal the discrediting secret. For the PwICl, the organisation may indeed be a
dangerous place: stress associated with non-disclosure or other occupational stress may
precipitate an exacerbation of their condition. In the case of those with potentially life-
threatening conditions such as heart disease, diabetes or asthma, non-disclosure of such
conditions to colleagues may result in a serious threat to safety, with no-one knowing how

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42 A complete discussion of the dilemma of disclosure for PwICl is found in Vickers (1996a; in press).
The following paragraphs are extracted from the concluding section of that paper.

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to respond appropriately in an emergency.

Our preoccupation with efficiency encourages this conspiracy of silence, at great potential cost to the PwIC. Erikson's (1994: 238-239) poignant words are considered whilst contemplating the "sick" person in the "sick" organisation:

It can be profoundly painful when the people in charge of a company at the time of a severe mishap deny responsibility, offer no apology, express no regrets, and crouch out of sight behind that wall of lawyers and legalisms . . .

. . . But the real problem in the long run is that the inhumanity people experience comes to be seen as a natural feature of human life rather than as the bad manners of a particular corporation. They think their eyes are being opened to a larger and profoundly unsettling truth: that human institutions cannot be relied on.

It is increasingly unclear just what employees, and employers, owe one another in terms of fulfilment of tacit obligations surrounding the psychological contract (Morrison and Robinson, 1997: 226). What is clear is that violations, such as those mentioned by Erikson (1994), are increasingly occurring and, when they do, result in decreases in trust, job satisfaction, as well as any perceived obligations to the organisation and intentions to remain (Morrison and Robinson, 1997: 227). This feeling of 'violation' (Morrison and Robinson, 1997: 226), of betrayal, is a multifaceted blend of first order feelings: central to the experience are feelings of anger; resentment; bitterness; indignation; even outrage that comes from the perception of betrayal or mistreatment - a feeling experienced at a deep visceral level (Morrison and
Robinson, 1997: 231). Evidence of this suffering and sense of betrayal may be seen in later chapters. For PwICI, feelings of violation may, arguably, add to the melange of an already difficult working life.

Conclusion

This chapter has reviewed the literature comprising the conceptual framework underpinning this study. It has been argued, using a social constructionist guideline, that various aspects of Western life, the medical profession, issues surrounding the "invisible" chronic illness and aspects of modern organisational life all contribute to the negative experience of life and work with "invisible" chronic illness.
CHAPTER THREE

Research Methodology: Issues, Choices, Justification

The most admirable thinkers within the scholarly community . . . do not split their work from their lives . . . . What this means is that you must learn to use your life experiences in your intellectual work (Mills, 1959: 195-196; cited in Denzin, 1989: 26).

Introduction

This chapter, and the next, seeks to explain the eclectic methodological choices made for this qualitative study, including the process followed from the initial choice of qualitative or quantitative, through to the specifics of methodological choices, research design, data gathering and data analysis. Work commenced on this chapter from an ethnographic perspective, although the author was increasingly drawn to the phenomenological perspective (whilst still recognising the value of certain ethnographic characteristics pertaining to the proposed study). Data gathering followed the multiple-case study approach and data analysis was interpretive, critical, phenomenologically-based analysis of transcribed in-depth interviews, supported by the use of basic demographic characteristics gathered prior to interview and the theoretical framework developed in the previous chapter.

One way to judge whether a piece of research is of suitable quality is its "transparence"; 'that is, stating openly the course and elements of the research process’ (Sarantakos, 1993: 21).
Many authors have expressed the paramount importance of the researcher adequately explaining their chosen methodology and reasons for that choice (Sando, 1983: 34; Field and Morse, 1985: 12; Leonard, 1989: 41; Minichiello et al., 1990: 23; Baker et al., 1992; Cohen and Omery, 1994: 136; Dreher, 1994: 281; Stern, 1994; Koch, 1995: 827). Indeed, 'methodological options rarely remain merely questions of method; rather, they eventually come to constitute an epistemological terrain in which both the analyst and the subject matter are bounded by unrecognized commitments to both private and collective values and interests' (Kouzmin, 1983: 232). The aim of this chapter, then, is to make these methodological, philosophical choices and reasoning suitably transparent to the reader on the basis that through 'reflexive analysis, theorists may acquire insights into their own epistemological commitments and neutralise the worst of their effects' (Kouzmin, 1983: 232). The choice of methodology should be influenced by 'the appropriateness of the method for the theoretical goals; the adequacy of the method regarding the research object and the realisation of methodological rules which determine its structure, possibilities and limitations' (Sarantakos, 1993: 106).

Research Objectives Revisited

Chapter One outlined the primary reasons and goals for this research. These, the reader may recall, included pragmatic, epistemological and ethical/moral arguments. Looking to the title of the thesis and then to the research objectives, one can see the essence of what is sought in this study and the objectives reflected in the title of the thesis. It is important to focus on the theoretical objectives in order to develop an effective research design (Yin, 1993: 45). They are:
1. To explore the psychically and socially constructed workplace reality for PwI, as interpreted by individual actors;

2. To (hermeneutically) interpret these subjectively experienced phenomena; in particular, what is the lived experience of PwI, their response, and the experiences and issues of deepest concern to them;

3. To explore themes and build possible linkages and explanations about the subjective interpretations reported by PwI and their work-world through thematic analysis of multiple case-studies;

4. To aid in the amelioration of the working lives of PwI, including the empowerment and emancipation of PwI in organisations, by understanding more about life and work with I, recording the reported experiences, identifying what the issues of import may be, and attempting to explain why they may exist; and,

5. To assist organisation theorists and practitioners in understanding the issues and problems that exist for a sizeable proportion of the workforce.

An Exploratory Qualitative Study

It is important to justify the qualitative choice taken for this research. This choice was made considering several constituents: the research objectives to be met, the rights of informants
participating, the contextual sensitivities associated with illness and disability in the workplace, and the particularities of the researcher as an 'insider' or 'intimate' (Wilmot, 1975: 59) to the phenomena under review. With this in mind 'the question is no longer about whether the one methodology is better than the other; nor is it about their merits or deficiencies. It is rather about which methodology is most suitable for the project' (Sarantakos, 1993: 106).

The research was exploratory. Literature dealing with "invisible" chronic illness, especially in the workplace, was sparse, piecemeal: 'Exploratory studies are carried out when there is not sufficient information about the topic and, thus, the formulation of hypotheses and the operationalisation of the question are difficult or even impossible' (Sarantakos, 1993: 114). Exploratory work may be undertaken for a number of reasons: feasibility; familiarisation; new ideas; formulation of hypotheses; or, operationalisation (Sarantakos, 1993: 114). This was certainly one of feasibility; to demonstrate the importance (or non-importance) of phenomena uncovered and whether further investigation from management and organisational scholars was warranted. It was also one of familiarisation: of the sociological and psychological context of illness, and of the philosophy behind methods employed. This exploratory study was designed to uncover and generate new ideas, views and opinions, and bring an under-researched area into the spotlight for debate.

Finally, the outcomes of the study were the formulation of themes and concepts, a framework of understanding, if not some early hypotheses. This study encompassed a literature review and qualitative case study analysis (as did Seltiz et al., 1976; cited in Sarantakos, 1993: 115), as well as informal discussions with friends, colleagues, members of the medical fraternity and personal experience. There was no current theory to test, which would rule out the use
of more deductive quantitative methods (Sarantakos, 1993: 15). Qualitative research is inductive (Sarantakos, 1993: 15) which brings with it the benefits of developing new theory or, in this case, patterns, themes and conceptual discovery beginning from the reality of lived experience of PwICI. The qualitative process is one of data generation and verification (Sarantakos, 1993: 15), and the ultimate development of themes or theory for analysis is undertaken to allow 'analytic generalisation' or 'exemplar generalisation' (Yin, 1989; Sarantakos, 1993: 15) as opposed to the statistical generalisation used with quantitative methods.

When choosing qualitative methods, the researcher should be aware of possible weaknesses and pitfalls, for example, the laborious and highly labour-intensive nature of qualitative research, in addition to its capacity for generating stress in the researcher (Miles, 1983: 118) and, presumably, the informant. Qualitative data tend to 'overload the researcher badly at almost every point: the sheer range of phenomena to be observed, the recorded volume of notes, the time required for write-up, coding and analysis can all become overwhelming' (Miles, 1983: 118), with 'the most serious and central difficulty in the use of qualitative data [being] that methods of analysis are not well formulated' and that the analyst has 'very few guidelines for protection against self-delusion, let alone the presentation of "unreliable" or "invalid" conclusions to scientific or policy-making audiences' (Miles, 1983: 118). Problems encountered when reviewing qualitative research included the 'inappropriate use of qualitative and quantitative paradigms, inadequate plans for analysis, excessive reliance on verbal data, insufficient description of the research design or inadequate justification for the use of qualitative research strategies' (Dreher, 1994: 283). Finally, Miles (1983: 118) alerted this researcher to the possibility that these "earthly" and "serendipitous" findings could, in fact, be
With such Dantecan\textsuperscript{43} concerns uppermost, the author sought to examine some concerns for qualitative research: first, the notions of reliability and validity; secondly, the issues of representativeness and generalisability; and thirdly, ethical issues considered to be especially important in this research.

\textit{Reliability and Validity}

In selecting a qualitative approach, the researcher fundamentally rejected the notion of objectivity (Sarantakos, 1993: 20) as it is understood by traditional quantitative researchers. The essential element for objectivity is standardisation; this quality is missing in qualitative research. Standardisation is neither desirable nor possible in qualitative research (Sarantakos, 1993: 20); Rather than objectivity\textsuperscript{44}, then, validity and reliability were sought.

A study is defined as being reliable when 'it consistently gives the same result' (Minichiello et al, 1990: 45). Case study research is reliable 'if a later investigator followed exactly the same procedures as described by an earlier investigator and conducted the same case study all over again, the later investigator should arrive at the same findings and conclusions. (Note

\textsuperscript{43}The author is referring here to Dante Alighieri (1265-1321), the Italian poet, prose writer, literary theorist and moral philosopher famous for the epic poem \textit{La Divina Commedia} (The Divine Comedy), an allegorical account of his journey through Hell, Purgatory and Paradise (Wilkes, 1979: 377).

\textsuperscript{44}The views of Kvale (1994) are most interesting: rather than promoting the benefits of subjectivity as I have tended to do, Kvale's response to the common objection that qualitative research is not objective but merely subjective, was to demonstrate the fallacy of intersubjectivism; reporting that 'the sheer number of observers reporting the same phenomenon is no guarantee of truth' (1994: 152) and, indeed, that objectivity may also be measured in terms of truth, reality and goodness (1994: 153). Kvale (1994: 153) also suggested that qualitative research may be objective in terms of following the hermeneutic tradition of a dialogal conception of truth.
that the emphasis is on doing the *same* case over again, not on 'replicating' the results of one case by doing another case study' (Yin, 1989: 45, emphasis in the original). The investigator should make as many steps in the research process as operational as possible (Yin, 1989); the central aim of this chapter and the next. Reliability is not irrelevant in interpretive research as many novice qualitative researchers seem to think, but is 'achieved through an extended, trusting and confidential relationship between investigator and informants, rather than through the establishment of the psychometric properties of research instruments' (Dreher, 1994: 286). Additionally, reliability may be increased by asking expert colleagues to review transcripts, as Swanson-Kaufman (1986: 66) has done, 'to assist the informants in validly sharing their experience' (Swanson-Kaufman, 1986: 66). Yin (1989: 102-103) also proposed 'maintaining a chain of evidence' to increase reliability. Following this principle would allow an external observer 'to follow the derivation of any evidence from initial research questions to ultimate case study conclusions'; in fact, an external observer should be able to trace the logic in either direction; 'from conclusions back to initial research questions or from questions to conclusions' (Yin, 1989: 102).

A piece of research is determined to be valid 'if it really shows what it is supposed to show' (Minichiello et al., 1990: 45). Research design quality should be judged against the following validity criteria: *construct validity* (establishing correct operational measures for the concepts being studied); *internal validity* (establishing an internal causal relationship and, as such, not suitable for an exploratory study such as this one); and *external validity* (establishing the

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45The researcher endeavoured to make this possible, setting out as carefully as possible exactly what transpired. However, it should be recognised that unless it was this researcher, living through the same unique circumstances, it is doubtful that the research conclusions would be the same. Certainly the procedure could be followed though: the 'chain of evidence' (Yin, 1989: 102) is available for review in this chapter and the next.
domain to which one may generalise the study’s findings) (Yin, 1989: 40-44). The concern here was with establishing construct and external validity.

A tactic suggested by Yin (1989: 42) to enhance construct validity was initially followed. It was to have some of the transcripts reviewed by key informants, a tactic used successfully by Swanson-Kauffman (1986: 66) and Miles (1983: 128).\(^6\) Yin (1989: 43-44) and Sarantakos (1993: 27) suggested the use of analytic or exemplar (as opposed to statistical) generalisation to confirm external validity or generalisability. Exemplars were used effectively in the phenomenological model developed. The focus of the study was not on generalisable theory but on telling stories that were sometimes unique, sometimes generalisable. Value was placed on all stories - they constituted new knowledge.

Another strategy used to enhance validity and reliability is to use a manageable (small) sample 'which permits greater participation and observation on the part of the investigator' (Dreher, 1994: 286). In fact, Kvale (1994: 164) suggested that too many subjects may restrict the ability to make penetrating interpretations. This researcher agrees. The heuristic of Swanson-Kauffman’s (1986) research design provided an excellent starting point for the naive researcher: a pilot study of five individuals and a main study of twenty individuals (Swanson-Kauffman, 1986: 60-61) was used to test her methodology which comprised a 'unique blending of the phenomenological, grounded theory and ethnographic methodologies' (Swanson-Kauffman, 1986: 59).\(^7\)

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\(^6\)The following chapter details when, and why, the practice of informant transcript review ceased.

\(^7\)These numbers were not adhered to after the pilot was completed for reasons also outlined in the next chapter.
In conclusion, although this research design combined eclectic choices, the phenomenologically-based primary research objectives centred around understanding the life-world, the *lebenswelt,* 'the world of lived experience' (Cohen, 1987: 33) for PwICl. Validity was ultimately measured against the research objectives and, perhaps, even more importantly, the notion that 'in a phenomenological study [validity] depends on the extent that [the findings] truly reflect the essence of a phenomenon as experienced by the informants in the study' (Baker et al, 1992: 1358-1359).

Representativeness and Generalisability

Following Sarantakos (1993: 26-27), *representativeness* was deemed not to be of special relevance to this qualitative study, particularly as a case-study approach was employed for data gathering. This *emic* study focused on, and valued, individual experience rather than replication ability: emic data 'refers to those that are derived from the informants and address the "meaning" that informants ascribe to phenomena' (Dreher, 1994: 290).

Even when discussing *generalisability,* which is highly valued in qualitative research, quantitative sampling procedures are not relevant. 'Sampling in qualitative research is not based on probability theory, and the size of samples is usually too small to reflect the attributes of the population concerned. Instead, the sampling procedures used are related to theoretical sampling and are geared towards essential and typical units. Selection does not stress random procedures but, rather, *theoretical sampling;* that is, towards the theoretically important units' (Sarantakos, 1993: 27, emphasis in the original). Generalisability, then, is not attributed to being able to replicate the findings, but rather to generalise findings beyond the cases studied through 'exemplar generalisation' or 'analytic generalisation' (Sarantakos,
1993: 27) and defining the domain to which such generalisations may be made (that is, external validity). Both unique and generalisable findings were regarded to be of importance.

**Ethics**

In keeping with the need for qualitative research to be suitably ethical, open and honest, Sarantakos’ (1993: 23-24) guidelines for ethical standards were acknowledged: the need to maintain a suitably high standard of professional conduct; participating in work the researcher was competent to perform; and, maintaining the confidential nature of all individuals who participated in the study. These guidelines were adhered to. Further, ethical issues apposite to this research included the voluntary, informed consent of the informant; the researcher’s responsibility to informants; and the question of reciprocity (Lipson, 1994: 343-350).

First, and regarding voluntary, informed consent, the concern was that some groups are particularly vulnerable to possible harm from participating in research, especially those stigmatised or those with secrets (Lipson, 1994: 348). Maintaining the privacy of PwPCI was, naturally, of primary concern. Secondly, the researcher concurred with Lipson’s (1994: 350) suggestion of having referrals handy should informants become upset during the interview process. It was recognised that the process of asking people to recall, and therefore psychically relive, experiences that were painful and emotionally charged required the potential ability for a prompt and appropriate response on the part of the investigator.46 Third, the researcher agreed with the importance of reciprocity and obligation on behalf of the investigator:

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46 I don’t know how to better word this: as I re-read, I visualise myself thrusting referrals for psychologists into the faces of sobbing respondents. It wasn’t like that. Referrals were never used, but it was reassuring to be prepared.
What obligations do ethnographers [or any investigators] have to people who bare their souls so that researchers can write an article or a book, or get a promotion (Lipson, 1994: 350) [or a PhD]? The dilemma is not whether to reciprocate or intervene, but what to do and how to do it responsibly' (Lipson, 1994: 350). The researcher’s first responsibility is to the informant (Field and Morse, 1985: 70). To this end the researcher chose, initially, to provide all participants in this study with copies of interview transcripts, so they felt included in the process, and to be available for discussion should they feel the need to contact me.40

It was on this basis of reciprocity, and for reasons of generating a trusting relationship with respondents, that it was elected, after careful and deliberate consideration, to alert informants to the fact that the researcher was also a person with an ICI. Van Maanen (1983: 46) highlighted the need to build trust, especially when the informants have "hidden" information about themselves as these informants were likely to have. Being an "insider" brings to the research effort a perspective that is unavailable to other researchers; special, "inside" information:

Whilst it isn’t always true that the 'inside' perspective on a person’s or an organization’s actions is necessarily more charitable, it does operate on different information that does the outside view. The inside information may be more negative than the outside perspective - but whatever the case, it will

40 I also made a point of sending out copies of papers for presentation/publication so respondents did not feel "forgotten” and fully intend notifying all respondents as to where this thesis may be available for their perusal after examination.
surely be different. The locus of your information, whether from the inside or outside, is the first central difference in how you attribute meaning to your own behavior compared to how you attribute it to the behavior of others (Wilmot, 1975: 59).

Krantz (1975; cited in Field and Morse, 1985: 52) also noted the benefits of established trust and credibility as a researcher. Field and Morse (1985: 118-119), in talking about the status of the researcher, suggested that outsiders may have difficulty gaining closely held information until they have established their status with the group. The revelation of the researcher's own illness status certainly assisted in obtaining deeper, richer, more personally held information from respondents. Given the circumstances of this study, it seemed dishonest and unethical not to disclose such a material fact. Whilst not trying to be "objective", the author did try to temper proximity to the phenomenon under review; to balance the pros and cons of this unique position:

While with informants, we shun the researcher-subject distinction and recognise the fruitfulness of our intersubjective copresence. It is later when home alone with the data that we strive for objectivity (Swanson-Kaufman, 1986: 69).

The researcher was alert to the problems associated with being so close to this study. They could not be underestimated: the stress associated with empathising with the problems of others in similar circumstances, a possible loss of "objectivity" (read distance), researcher bias and a concern that familiarity with the context may be a hindrance in terms of overlooking important data (Pearsall, 1965; cited in Field and Morse, 1985: 52). Field and Morse (1985:
highlighted the danger of becoming "totally a part of the group", of "going native".

However, the author was already a "native"; there was no way to ignore it. The intimacy of the researcher with the phenomena could not be denied; indeed to do so may have created problems jeopardising the quality of outcome of the study undertaken. Dreher (1994: 286) recognised the mistake of trying to reduce or eliminate investigator bias, suggesting that a better alternative is to recognise and account for it. It was endeavoured to pinpoint one's own biases (Field and Morse, 1985: 119) especially given events that were concurrently unfolding with the research process. There was an attempt to distance oneself from informants, especially during the main study and when performing analysis, following Whyte's (1955) lead in Street Corner Society (cited in Field and Morse, 1985: 119), as a process of survival.\(^5\)

Methodological Choices: The Recognised Dangers of 'Muddling Methods'

As a naive researcher, and with the dangers of 'muddling methods' (Stern, 1994: 214) or 'method slurring' (Baker et al, 1992) closely considered (Leonard, 1989; Baker et al, 1992; Dreher, 1994; Stern, 1994), it was appreciated that combining methods was a potentially dangerous approach. However, continued review of the research questions brings one back to the same predicament: there appeared to be no one methodology/design that completely suited

\(^{5}\)This last paragraph seems at odds with earlier comments about the researcher's "special" vantage point; the "insider" perspective; the seeking and valuing of subjectivity and proximity to the phenomenon under review. The explanation of this apparent contradiction is two-pronged. First, there was a consciousness of the researcher having developed a cynical, "hardened" edge through tumultuous life events (described in later chapters) unfolding simultaneously with the research effort; of, perhaps, only seeing pain, trauma and misery in the stories. Secondly, there was a definite need for survival on the part of the researcher - some attempt at distance from the pain unfolding in the stories of respondents became mandatory during a period of personal vulnerability, especially obvious after completion of the pilot study. The valuing of subjectivity was not, therefore, submerged. There was, however, a recognition of the unusual unfolding in the researcher's life that simply had to be considered.
the stated purpose. Thus, methodological choices were made carefully and thoughtfully. The ensuing discussion is designed to elucidate some of those thought processes and to demonstrate the necessary understanding of the philosophical and epistemological underpinnings of the methodologies reviewed (ethnographic and phenomenological), as cogently argued by numerous authors (for example, Cohen, 1987; Leonard, 1989; Baker et al, 1992: 1357; Boyle, 1994; Cohen and Omery, 1994: 136; Ray, 1994: 117; Stern, 1994).  

Ethnography did hold some promise as a research methodology for this project. The original belief in the need for an ethnographic approach to the study of PwlCI was based on the need to understand 'the native's point of view' (Sanday, 1983: 27); to gain an understanding of their conceptual world so as to be able to "converse" with PwlCI. This notion was initiated with recognition of the importance of the sociological aspects of the "life-world" of PwlCI, including social and cultural processes. Additionally, 'ethnographers approach the field armed with theory developed by generations of anthropologists and, therefore, turn their attention to the culture within the framework from a particular theoretical perspective' (Stern, 1994: 215). This investigator also approached the research with some theoretical "hunches" in place that seemed to be in keeping with an ethnographic approach. Ethnographic analysis is 'the search for patterns in data and for ideas that help explain the existence of those patterns' (Boyle, 1994: 174). At such a general level, ethnographic analysis of this kind was of assistance to this study. Other characteristics of ethnography that applied here was the quality of reflexivity and the importance of a holistic, contextual emphasis (Boyle 1994: 162-166). The

\[^{54}\text{It was originally intended to base methodological choices on an ethnographic paradigm. However, the more that was read on the subject of research methodologies, the more deeply convinced the author became that it was not an ethnographic perspective that was sought for this research, but a phenomenological one that continued to recognise several ethnographic characteristics of relevance to this particular study.}^\]
reflexive character of this study, 'which implies that the researcher is a part of the world that she or he studies and is affected by it' (Boyle, 1994: 165) was not, in this case, due to the use of quality participant observation, but by the natural intimacy of the researcher to the phenomena. Further, 'a central tenet of ethnography is that people's behavior can be understood only in context' (Boyle, 1994: 162).

However, as the researcher developed a better understanding of the ethnographic approach, including all its variant 'types' (Boyle, 1994: 169), there appeared to be some fundamental reasons for not labelling this research ethnographic, even with such arbitrary classifications available. First, and foremost, ethnography is a study of culture (Boyle, 1994; Sanday, 1983): 'however it is conducted or by whom, an ethnography is always informed by a concept of culture' (Boyle, 1994: 160); and, 'ethnography relies on the concept of culture' even though different ethnographic approaches may reveal either 'the elicitation of cultural knowledge, patterns of social interaction, descriptive storytelling or the discovery of grounded theory' (Lipson, 1994: 340). Stern (1994: 215) noted that ethnographers 'may be looking at the structure that creates order or to the ritual that is part of the identity of the culture and that, in effect, holds it in place; or they may be looking into the meaning certain symbols have for this group of people.' Whilst it is theoretically possible that one could study the culture embraced by PwICl given that they are a group with something in common, it was not the aim of this study. Indeed, one may suggest that because of the very "invisibility" of the illness, a cultural analysis of this group, especially in the workplace, would be difficult given that it has been established that people often do not disclose stigmatising or "shameful"

52Boyle (1994: 169) described a classification or "types" of ethnographies: processual ethnographies; classical or holistic; particularistic; cross-sectional; ethnohistorical. Boyle (1994: 174) also described other distinguishing characteristics: binary, spatial or geographical, linguistic and theoretical.
conditions unless forced to (Nijhof, 1995: 196; Falvo et al, 1982: 5; Scambler, 1984). It has been argued that this situation only changes when a special, trusting relationship has been developed (Van Maanen, 1983: 46). Such an ethnographic study may be very interesting to determine if, and to what extent, a culture may develop, operate or survive in a workplace scenario, given the intriguing and unique variable of choice of disclosure. However, whilst this is a definable social group, it is not routinely an interacting group, particularly in the context of the workplace, but a series of individuals operating with what, it is believed, are certain characteristics in common.

Secondly, ethnographers (and other researchers) frequently advocate the need for multiple sources of data. Yin (1989: 95-103) proposed that this is one of the three principles of data collection53 when describing case-study techniques. Baker et al (1992: 1357-1358) advocated using interviews, observation and previous research in order to generate valid grounded theory (which Field and Morse (1985) categorise as an ethnographic approach). Possible sources of evidence include documents, archival records, interviews, direct observation, participant-observation and physical artefacts (Yin, 1989: 85-94).

Whilst agreeing with the importance of multiple sources of data, difficulties were identified with respect to this particular study: the ethical imperatives outlined earlier required consideration, especially the privacy of the informant in their workplace. For example, interviewing 'knowing others' (Goffman, 1963) within the organisation was suggested to gain another perspective, another view of the phenomena under review. Unfortunately, the notion

53 The two other principles of data collection that Yin (1989: 95-103) proposed include creating a case study data base and maintaining a chain of evidence. They are dealt with elsewhere.
of verification presented problems to a researcher valuing the interpreted experience of the informant in its own right: paternalistic and managerialist overtones present when working from an underpinning notion that the informant's interpretation is somehow incorrect or incomplete. It was possible, and acknowledged, that a PwICl may be malingering or demonstrating negative (or even positive) coping skills. However, this study values the existentialist perspective (as opposed to the instrumental); to understand the experience of the PwICl for precisely the reason that no-one has bothered to do so in the past and to recognise its value *per se*. In fact, it is this author's contention that a "knowing other", or any other, is unlikely to have much understanding of what is experienced by the PwICl (let alone a *better* one!).

Direct observation was considered as another possible source of data. Unfortunately, many of the problems associated with the "invisible" nature of ICI precluded its use. Observation seemed intuitively impossible. The literature had demonstrated that what is not seen is *not* understood (for example, Tate, 1991; Kantor, 1991: 81). Even an individual closely associated with the PwICl, for example, a partner, parent, child or close friend may *endeavour* to understand and never truly do so. Finally, it was felt that a workplace observation would likely bring with it the attendant and undesirable corollaries of attention and curiosity of colleagues.

As part of the data gathering process, interviewees were asked if they had any documentation surrounding problems they may have experienced in the workplace. These were *not* to be used as "validating" sources, but as exemplars only.\footnote{For example, documents relating to employment, dismissal or superannuation medical examinations.} Only one person had a letter of

\[111\]
dismissal she felt was relevant, but was unable to find it.

Third, there was a definite emphasis on the use of participant observation as a data gathering technique in ethnography, with some authors defining ethnography in terms of its use (Sanday, 1983: 20; Van Maanen, 1983: 38). Participant-observation was also precluded by the need for respondent privacy. Further, there was an appreciable need for long residence in the culture (Sanday, 1983: 19; Lipson, 1994: 346) in order to understand it. The extended nature of participant observation, with at least a year needing to be devoted to the task (Sanday, 1983: 20) for any effective cultural analysis, made it financially difficult for a full-time student to embrace, though its value is acknowledged.

Finally, the epistemological groundings of ethnography were less appropriate for an emic study. The distinction was made between the epistemology of observation and interview in ethnographies:

This epistemology is related directly to the earlier discussion of emic and etic viewpoints. Remember that emic views are insiders' accounts usually obtained from direct interviews with informants. Etic accounts are the outsider's or ethnographer's theoretical views and the emphasis in data collection and analysis is placed on observational data and scientific viewpoints (Boyle, 1994: 175).

So, whilst it was recognised that at one end of the ethnographic spectrum researchers can perform an emic study (usually only accessible through language (Boyle, 1994: 175)) and,
whilst it was this researcher's epistemological preference to do so, it was important to approach the research in terms of the importance of individual subjective interpretation, as opposed to the cultural emphasis of ethnography: instead, it was through the careful study of individuals' lives that I hoped to discover the deeper meaning of 'lived experience' (Stern, 1994: 215). It was, thus, a phenomenological methodology that would predominate.

**Phenomenology**

It was the essence of phenomenology that excited this researcher: the need to capture the subjectively experienced life of the informants as interpreted by them (Taylor, 1993: 174); to describe lived experience (Oiler, 1982: 178) and the meaning it holds for that individual (Drew, 1989: 431). Phenomenology has been described as illuminating the richness of individual experience (Baker et al., 1992: 1358), underscoring the importance, and value, of the informant's reality, and the need for the researcher to share that reality with others (Swanson-Kauffman, 1986: 59): 'being concerned with the psychological phenomena of lived experience has only one legitimate source of data: informants who have lived the reality being investigated' (Baker et al., 1992: 1357). Oiler (1982: 178-179) posited that informant "reality" is subjective and perspectival, with the "truth" being a composite of those realities.

The purpose of phenomenology, then, is 'to describe the world-as-experienced by the participants of the inquiry in order to discover the common meanings underlying empirical variations of a given phenomenon' (Baker et al., 1992: 1356). The importance of a phenomenological approach, then, centres on the legitimisation of the informant as a primary source of data; the value in learning about lived experience from the informant's subjective perspective; and the need to capture the lived experience of the informant. This, necessarily,
entailed exploration of psychological, psycho-social, social, behavioural and physiological issues, as all of these constituents of human experience guide and mediate the interpretation, understanding and response of the individual. The term 'co-constitution', originated by Heidegger (1927/1962) and explained by Koch (1995: 831), incorporates this notion of the impossibility of separating the person and their world.

Reading in the area of phenomenology revealed varying phenomenological approaches: the 'preparatory phase' of the phenomenologic movement involved Franz Brentano (1838-1917) and Carl Stumpf (1848-1936) as an innovation involving primarily psychological, scientific and descriptive influences (cited in Cohen, 1987: 32). The 'German phase' (Cohen, 1987: 32) introduced the scholars of note (Husserl and Heidegger) and the approaches of most interest here: the Husserlian (descriptive or eidetic) approach (Ray, 1994: 118); the Heideggerian (interpretive, ontological) approach (Leonard, 1989: 55; Cohen and Omery, 1994: 140; Ray, 1994: 118); and, the 'dutch school' which combined the Husserlian and Heideggerian approaches (van Manen, 1990; Cohen and Omery, 1994: 149). With this in mind, the central distinctions between the Heideggerian (interpretive, ontological) and the Husserlian (descriptive) approaches are reviewed:

The central distinction between the Husserlian and Heideggerian approaches is that Heidegger articulates the position that presuppositions are not to be eliminated or suspended, but are what constitute the possibility of intelligibility or meaning (Ray, 1994: 120).

When reviewing the aims of this thesis, the notions "interpretive" and "critical" should be
highlighted. One appreciates Weber's verstehen, 'that is, the empathetic understanding of human behaviour', and the belief that reality is 'in the minds of people . . . internally experienced . . . socially constructed through interaction and interpreted through the actors, and is based on the definition people attach to it' (Sarantakos, 1993: 33-35). The critical perspective holds that 'reality is created not by nature but by the people . . . reality is not in a state of order but of conflict, tension and contradiction' (Sarantakos, 1993: 35). In short, emphasis of this research is predominantly ideographic; that is, 'explaining each individual on his or her own terms, as opposed to nomothetic, leading us to explain things by virtue of class membership' (Minichiello et al, 1990: 63).

The aim of this research was not merely to describe the phenomena (Husserlian phenomenology) but to attempt to interpret it (Heideggerian phenomenology) and, in doing so, acknowledging the presuppositions the researcher must hold about the phenomena under review.

Heideggerian, Hermeneutical Phenomenology

Phenomenology was used as the philosophical approach to capture the intersubjective experiences (Barritt et al, 1984: 3) of PwIC; to bring them to awareness (Barritt et al, 1984: 4). Phenomenology, as a philosophical approach, was in keeping with the aims of this study: 'The phenomenological method in philosophy began to crystallise in reaction to the denigration of philosophical knowledge and the objectification of humans' (Omer, 1983: 51)

55Understanding the experiences of each individual on their own terms is the fundamental objective of phenomenological inquiry even though the phenomenological model (Swanson-Kaufman and Schonwald, 1988: 104) explicated in Chapters Five and Six will produce some elements of generalisability of themes and the common structures of experience (Oiler, 1982: 181; Omer, 1983: 60; Barritt et al, 1984: 13; Swanson-Kaufman and Schonwald, 1988: 104; Osborne, 1990: 80; Sandelowski, 1995: 372).
and, as such, provided the perfect vehicle for a study such as this. The goal of Heideggerian, hermeneutical phenomenology is 'to understand everyday practices' (Benner, 1985: 5), with the hermeneutic method proposed in Heidegger’s (1927/1962) *Being and Time* being 'a method for the study of sacred texts to a way of studying all human activities' (Dreyfus, 1991: 2) and was developed in opposition to Husserl’s transcendental phenomenology (Dreyfus, 1991: 2).

In this study, where the researcher was so close to the phenomenon under review that it seemed all but impossible to eliminate, or 'bracket', investigator experience. It seemed appropriate to adopt an approach that accepted, even encouraged, prior knowledge and experience. The researcher’s influence in phenomenological research cannot be underestimated, especially when that researcher is an ‘insider’ or ‘intimate’ to the phenomena (Wilmot, 1975: 59); a ‘native’ of the group under review (Lipson, 1994: 339). Phenomenology requires personal knowledge (Wilkes, 1991: 230), an ‘openness to the world’ (Moss and Keen, 1981: 109) and is synonymous with concern for the contents and structure of consciousness (Moss and Keen, 1981: 107). ‘The state or organisation of the researcher’s consciousness will determine what phenomena, facts and relations will enter his consciousness’ (Moss and Keen, 1981: 108). The researcher’s orientation, sensitivity and perceptiveness will shape the interpretation (Osborne, 1990: 85). Indeed, the interviewer’s own experiences influence the outcomes of the research with the interviewer’s emotional response to subjects needing to be explored because of the influences it may have on the study (Drew, 1989: 431-432); ‘In Gadamerian hermeneutics, interpretations are never considered

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56 Gadamer was strongly influenced by Heidegger in that his hermeneutics is about ontological understanding: about being-in-the-world. Gadamer, like Heidegger, believed the interpreter’s prejudices cannot be bracketed during the process of interpretation and suggested that the interpreter should be aware of one’s own
static, objective and ahistorical, but are dynamic and subject to change with the ideological and historical horizons of the interpreter' (Walters, 1996: 97; citing Gadamer, 1975). It is vital to explicate the researcher's perspective (Oiler, 1982: 181; Swanson-Kaufman and Schonwald, 1988: 103); indeed, the researcher's experiences are data (Drew, 1989: 431; Osborne, 1990: 83) and Heideggerian phenomenological interpretation requires, not detached but engaged activity (Sass, 1990: 126), ideally resulting in a profoundly reflexive research experience (Sass, 1990: 136; Steier, 1991a; 1991b).

The researcher always comes to the situation with a pre-understanding; a story that is not always rationalisable (Benner, 1985: 7). Endeavours have been made here to show material "glimpses" of the researcher's "story" as they have materialised during analysis and the researcher continued to address herself to the arduous and risky task of 'authentic writing' (Jourard, 1971: 58-59) throughout the research process. Heideggerian phenomenological interpretation was, thus, undertaken whilst concurrently sharing Jourard's (1971: 58-59) view that the greatest risk lies with letting other people know how one's experiences impinge upon one's life.


_prejudices through the process of self-reflection (Walters, 1996: 97; citing Gadamer, 1975 and Heidegger, 1927/1962). The reflexivity required by the researcher (Steier, 1991b: 163; Sandelowski, 1993: 214; Boyle, 1994: 165) will be demonstrated in Chapters Five and Six and discussed again in Chapter Seven.
philosophy that supports this anti-reductionist study. Hermeneutic phenomenology is
historicism and holistic, studying the actor in context, rather than isolating them from situation
variables (Benner, 1985: 6; Wilkes, 1991: 232). It values 'enlargement rather than reduction,
generosity rather than economy, complexity rather than simplicity, the lens rather than the
hammer' (Oiler, 1982: 181). Reductionist variants of explanation are regarded as
inappropriate (Sass, 1990: 144) as it is not intended to narrowly test a hypothesis, rather, to
allow the data to speak for themselves (Osborne, 1990: 81). It generates forms of explanation
and prediction that 'offer understanding and choice, rather than manipulation and control'
(Benner, 1985: 13); that is, a concern with not being rational or objectivist in much the same
vein as the scholars Weber, Adorno and Foucault (Benner, 1985: 13). 57

57 This seems as good a time as any to provide a rejoinder to those who regard Heidegger's work as
anti-humanist. It is important to distinguish Heidegger's early and later work, especially noting that it was his
early metaphysical explorations in Being and Time (1927/1962) that the philosophy and methodology employed
in this work are based. Heidegger's early philosophy was based around questions of metaphysics, questions
regarding the Being of entities in general. Over time, there was a substantial shift in Heidegger's thought, away
from the metaphysical towards the mystical, encouraging what he describes as an 'end of philosophy' (Caputo,
1986: 1). Heidegger differentiated thinking (mysticism) from philosophy (metaphysics) (Caputo, 1986: 1),
speaking of philosophy in an entirely metaphysical sense (Caputo, 1986: 3). Philosophy is regarded as being a
matter of reason and 'equivalent to Western rationality' or what Heidegger calls 'metaphysics'. It is a matter of
supplying reasons and argumentation, of entering the forum of rational debate' (Caputo, 1986: 3). It is
Heidegger's later work, his shift to mysticism, that calls for 'the end of philosophy':

He does not mean to say that the history of philosophical speculation is over, or that the
present age of philosophers will be the last. The role of the "thinker" is not to predict the
future course of history, not even of the history of philosophy. . . . The end is no "mere
stopping" but the "completion" (Vollendung) of philosophy. Philosophy is complete in the
sense that it has realized all of the possibilities which inheres its essence; it has unravelled
all of its potentials (Caputo, 1986: 2).

The shift in Heidegger's later work to thinking, to poetry and mysticism (Caputo, 1986: 6), to overcome
metaphysics (Caputo, 1986: 5), draws much concern. The much debated problem of 'humanism' in Heidegger's
later thought provoked Versényi (cited in Caputo, 1986: 42) to argue that Heidegger claims to speak with a
'more than human—and therefore non-humanistic tongue'. 'Because his thought is "a kind of negative theology
and mysticism", . . . his only message is the rejection of all human experience and thought. In leaving humanistic
metaphysics behind. Heidegger has sacrificed the human significance of his work. Thinking is opposed to
humanism, for Versényi, because thinking is mysticism, and mysticism is the denial of everything human'
(Caputo, 1986: 42). This anti-humanistic vein is not one sought nor embraced here, nor one that rules out the
value of his earlier work.
The role of theory is somewhat controversial in phenomenological research (Ray, 1994: 123). On the one hand, 'Husserl's aim was the avoidance of all conceptually bound and theoretically constructed beginnings' (Ray, 1994: 119). For the Husserlian phenomenologist, theory is antithetical to phenomenology (van Manen, 1990; Ray, 1994: 123). The Husserlian phenomenologist should approach the research without any preconceived notions of what will be found, as they are thought to bias the research process. Additionally, Husserlian researchers are encouraged to clarify these beliefs and positions before the data generation phase . . . and bracket these' (Koch, 1995: 830). The concept of 'bracketing' (Schutz, 1932/1967: 43; Oiler, 1982: 179; Omery, 1983: 50; Swanson-Kaufman and Schonwald, 1988: 98; Drew, 1989: 437; Wilkes, 1991: 233; Sandelowski, 1993: 215; Koch, 1995: 830; Walters, 1996: 97) or 'objectivity' is central to the Husserlian strategy (Koch, 1995: 830) and was deemed an anathema to this study. Husserl insisted that the common-sense "taken-for-granted" attitudes be transcended to render daily life an object of philosophical scrutiny (Burrell and Morgan, 1979: 233), although one may question whether the bracketing in transcendental phenomenology is actually possible (Mackie, 1985: 32). Finally, whilst the subjective perspective is valued in this research, the solipsist extreme of subjective idealism proposed by Husserl's pure or transcendental phenomenology (Burrell and Morgan, 1979: 238) was deemed inappropriate for this research project.

Heidegger's assumption of 'theoretical holism' denies the traditional assumption that there must be a theory of every orderly domain (Dreyfus, 1991: 5). Hermeneutic analysis allows the study of the person in the situation and has been used 'to understand everyday practices, meanings and knowledge embedded in skills, stress and coping' (Benner, 1985: 5): it is an ontological process (Walters, 1996: 94) and involves the systematic study of texts (Benner,
1985: 5), in this case, interview transcripts. 'This is not a hermeneutics of suspicion . . . where the goal is to discover some latent causal explanation in theoretical or power terms . . . but to accurately portray lived meaning in their own terms' (Benner, 1985: 6).

The purpose of this study is not to develop a concrete grounded theory. Heidegger substitutes ontological questions about what sort of beings we are and how we are bound up with our world, for epistemological ones about the relation of the knower and the known (Dreyfus, 1991: 3):

Heidegger's alternative vision of the nature of human existence is holistic, historicist and ontological. He would replace each of the Cartesian polarities with an understanding that . . . emphasizes the temporal and teleological aspects of human activity, and that accepts the fundamental indubitability of the world's existence (Sass, 1990: 126).

Phenomenological research has a reverence for experience and attempts to describe human experience as it is lived (Oiler, 1982: 178). Phenomena may be uncommon, extraordinary and remarkable, whilst for others they may be common, ordinary and unremarkable (Taylor, 1993: 174):

Phenomena can be taken to mean the subjective experience of individuals, whatever they are and however they are interpreted by those individuals. . . the difference in interpretation resides with the actual people involved and their unique circumstances (Taylor, 1993: 174).
The view that sociological factors cannot be separated from the individual’s life is mirrored by authors advocating the recognition and embrace of the two Heideggerian concepts of "historicality" of understanding and "the hermeneutic circle"; two vital constituents of this.

Similarly, it is difficult to ignore a thesis such as this the question mark hanging over Heidegger’s reputation as Nazi conspirator and anti-humanist (Champagne, 1995: 27): those who oppose Heidegger’s phenomenological approach because of his past association with Nazism (Bernasconi, 1993: 56). As has been explicated above, it is Heidegger’s early work that is embraced as foundational; the Being and Time philosophy, rather than the later, more mystical and much criticized, post-nazi Heidegger. It is, however, impossible to simply dismiss the ‘Heidegger affair’ (Caputo, 1986: 31; Lyotard, 1990: 4) as irrelevant, without some discussion. The affair is of his politics which are denounced, not so much for being the embrace of Nationalist Socialism, but as a silence on the extermination of the Jews (Lyotard, 1990: 4). Lyotard describes this as ‘a mute silence that lets nothing be heard. A leaden silence’ (Lyotard, 1990: 52). The political aspect of his ‘forgetting’ is of concern to Lyotard: ‘Here lies the paradox and even the scandal: how could this thought (Heidegger’s), a thought so devoted to remembering that a forgetting (of Being) takes place in all thought, in all art, in all “representation” of the world, how could it possibly have ignored the thought of “the Jews” which, in a certain sense, thinks, tries to think, nothing but that very fact?’ (Lyotard, 1990: 4). Lyotard is therupon dogmatic, and scathing, as to the value of any of Heidegger’s contributions: ‘If Heideggerian, then Nazi; if not Nazi, then not Heideggerian’ (Lyotard, 1990: 51). He continues, first acknowledging the importance of Heidegger’s thought and yet flatly stating: ‘If a great thinker, then not a Nazi; if a Nazi, then not a great thinker’ (Lyotard, 1990: 19:2), contending that one cannot possibly acknowledge the coexistence of the two faces of Heidegger (Lyotard, 1990: 53).

It is acknowledged here that Heidegger’s implication with Nazism is not merely anecdotal, but deliberate, profound and persistent (Lyotard, 1990: 52). It is also noted that followers of Heidegger are frequently enthusiastic who disregard such critiques... as "misunderstandings" of Heidegger (Caputo, 1986: 31). Others may explain that ‘Heidegger’s relationship with the Nazis was not an isolated “error”, as Heidegger’s defenders would have it, but a logical and necessary move’ (Caputo, 1986: 32) in direct response to three ‘characteristically German flaws’ (Caputo, 1986: 32): Heidegger was possessed of an arrogance ‘of the genius who knows his own worth’ (Caputo, 1986: 32); Heidegger was unmistakably nationalistic; and Heidegger was an irrationalist, whose philosophy was one of ‘melancholy nihilism’, which has given rise to the effort to find a rational meaning in things before it even begins and which has always harbored a resentment against reason’ (Hübler, 1961: 15-16; cited in Caputo, 1986: 33). Consider though, the fact that he chose to interpret his own texts as consistent with National Socialism doesn’t mean that others must interpret them in the same way (Zimmerman, 1990: 38).

The notion that one must automatically dismiss the works of a great thinker on the basis of his political leanings is rejected here. This author disagrees with the notion that ‘all of Heidegger’s work is essentially Nazi and, thus, those who treat it seriously today, who consider Heidegger to be an important critical thinker, who read him in something other than a condemnatory mode—that is, who read him at all—are either naïve or consciously perpetuating a very sophisticated and radical form of Nazism’ (Carroll, 1990: xvi, emphasis in the original). This author is neither Nazi nor naïve. One may not necessarily authorise Heidegger’s politics, but accept a coexistence (as did Carroll, 1990: xxi), albeit a perplexing and discomforting one. It is comprehensible to distinguish between a person’s politics and their Being and, it is noted, other writers have been incorrectly associated with their politics: Nietzsche, Jefferson and Heidegger have all had politics attributed to their writings that differed from the ones the original signature intended (Champagne, 1995: 31). It seems reasonable, especially given a postmodernist consciousness, to separate and recognize the complexities, the ambiguities and the contradictory nature of the human psyche. This contrary phenomenon is reported in the phenomenological model of later chapters. One may surely extend this liberty to Heidegger’s life as well. Finally, one must ponder what life may have been like for a German philosopher during the rise of the Nationalist Socialist Party in Germany pre-war. In doing so, some attempt must surely be made (as much as it is possible) to bracket current ideologies and the benefits afforded by hindsight, and to winnow out emotion, prejudices and judgements that necessarily surround the tragedy of the Holocaust.
study. Similarly, Gadamerian hermeneutics helps to appreciate that understanding is influenced by social values, interests, language, and historical contexts (Walters, 1996: 92). One of Heidegger’s assumptions was that one must always do hermeneutics from within the hermeneutic circle (Dreyfus, 1991: 4). Koch (1995: 831, with my emphasis) gives descriptions of background, pre-understanding, co-constitution and interpretation which are useful here to illuminate:

The notion of background is an inescapable part of the hermeneutic circle. Benner Wribell (1989) states that a person’s history or background is what culture gives a person from birth ... and presents a way of understanding the world;

Heidegger uses the term ‘pre-understanding’ (‘fore-conception’) to describe the meaning and organisation of a culture (including language and practices) which are already in the world before we understand;

Heidegger (1927/1962) declares that nothing can be encountered without reference to the person’s background understanding, and every encounter entails an interpretation based on the person’s background, in its ‘historicality’; and,

Co-constitutionality refers to the philosophical assumption of indissoluble unit (‘person-world’). This means being constructed by the ‘world’ in which we live and at the same time constructing this world from our own experience and
background. The division between person and world is construed as false. It simply is not possible to make this separation.

In short, understanding for Heidegger involves constant correction and modification based on the given set of forestructures which cannot eliminated; in this case, those set out in Chapters One and Two of this volume and, also, those of the researchers life: 'hence the famous "hermeneutic circle"' (Koch, 1995: 832). Hermeneutic analysis allows the study of the person in the situation and has been used 'to understand everyday practices, meanings, and knowledge embedded in skills, stress and coping' (Benner, 1985: 5). Hermeneutic phenomenological reflection concentrates on the four fundamental lifeworld themes: spatiality, corporeality, temporality and relationality (van Manen, 1990; Sandelowski, 1993: 215).

Finally, the objectivity/subjectivity conundrum must be addressed from a methodological perspective, given a thesis grounded in phenomenology. Traditional (Husserlian) phenomenology is proposed by some to be a "rigorous science" in the service of humanity (Cohen, 1987: 31), which may be viewed by others as the phenomenologists' 'objectivist illusion' (Kvale, 1983: 184). These notions of objectivity are rejected by Heideggerian phenomenologists and may be reasonably queried from a postmodern perspective. Lyotard's definition of postmodern as 'incredulity towards metanarratives' (Lyotard, 1979: xxiv; Connor, 1989: 31) suggested that the goal of objectivity is irrelevant, unsustainable and illegitimate in a postmodern age. Mackie (1985: 3) described the false idealism of (Husserlian) phenomenology and the problem of phenomenological reduction resulting in a need to recover what is lost, rather than achieving an absolutist subjectivity, as intended by Husserl. Heideggerian phenomenology seeks to uncover, interpret and understand the life-world of the
respondent, whilst recognising multiple, historicist and current, ideologes and perspectives.

Conclusion

The research methodology embraced by this study is one of Heideggerian, hermeneutical phenomenology (whilst also recognising the holistic, contextual and reflexive ethnographic characteristics of the study): it is concerned with the subjective, lived experience of the informants whilst, simultaneously, recognising the 'fore-conceptions' (Koch, 1995: 831) that come together to create the life-world of the researcher. This research is of a group of individuals with apparently much in common, but not about a group-in-process; interest is in the individuals who have an ICI, their unique experience and whether themes in common will emerge.

For those who oppose phenomenology per se, it is urgently suggested that the philosophical distinctions between Husserl's transcendental phenomenology and Heidegger's hermeneutical, existentialist phenomenology (or even other existentialist phenomenologists such as Sartre (1943/1969; 1948/1980) and Schutz (1932/1967) (Burrell and Morgan, 1979: 243)) be noted. Many of the arguments levelled against phenomenology in general cite the "objectivist" notions proffered by Husserl: his emphasis on transcendentalism, the lack of appreciation of current and extant theory; the bracketing of current beliefs; the 'procedure of époche' involving the suspension of the researcher's natural attitude (Burrell and Morgan, 1979: 233). Bracketing was strenuously avoided by Heidegger (Mackie, 1985: 78) and Heideggerian

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59Merleau-Ponty was also cited by Burrell and Morgan (1979: 243) as another existentialist phenomenologist, but no corresponding reference was found in the Bibliography.
phenomenology is *ontological* (Walters, 1996: 94, my emphasis), accepting the conflictful, and often ambiguous, nature of the social world, making it the perfect vehicle for a research project such as this.

The philosophical and methodological decision processes set out here, it is hoped, lead into a transparent research method and design which continue in the next chapter. It is hoped that the reasoning, choices and philosophical underpinnings of the methodological approach employed have been sufficiently well articulated. The author is reminded: if there is sufficient reason, the reason is sufficiently well articulated and responsibly carried out, methodological choices are entirely at the discretion of the researcher. As Stern (1994: 219) said 'I really don’t care what you do just tell me about it. I might learn something'. One hopes that Stern is right.
CHAPTER FOUR

Field Work Reflections: A Methodological Review

As I drive down the mountain, I don't know whether to laugh or cry. I settle for a rather tortured combination of both. The gut-wrenching importance of what I am doing has just struck me. I had thought at the beginning of this project that what I was doing was important. Now I am convinced: these stories need to be told.

I have just interviewed mother and daughter. June [a pseudonym], a warm, quietly spoken woman in her mid-forties, has recounted her story of what it is like to slowly, and inexorably, go blind. Her daughter, Shelley [also a pseudonym], a bright, no-nonsense young woman in her mid-twenties has described life in the face of death: she has acute lymphoblastic leukemia. Both have conditions that you cannot see. Both work full-time. Both have conditions that they have been dealing with for years. Both have demonstrated a most humbling inner strength and determination.

One the one hand, elation. From a research perspective, the interviews are gold. frank, open admissions of frustration, denial and fears for the future. Stories of the workplace that warm your heart; and those that make you shiver. With the elation, however, comes trepidation as I consider the tears I will personally shed in the weeks ahead. I feel honoured with the opportunity to tell their story, yet fearful I will not do it justice. I had never considered that I would feel so strongly. I brace myself for the rocky ride ahead (Vickers, 1996c).
A Multiple-Case Research Design

The previous chapter describes, in some detail, the methodological choices made and how they were arrived at. This chapter explicates the research design - the "nuts and bolts" of what went on in the field, both positive and negative. 'Qualitative researchers are equally expected to develop a design and to specify in some way how, where, when and under what conditions they will collect and analyse their data' (Sarantakos, 1993: 98). This is described colloquially as the 'action plan for getting from here to there' (Yin, 1989: 28).

A multiple-case design (Yin, 1989: 53) was invoked for this study. Rather than relying on a single-case design, where only one PwICl would be interviewed, or one particular ICI explored as a single "case" involving many respondents, many stories were heard involving numerous "invisible" illnesses. It was hoped that themes and categories would emerge from comparison of the stories, even though recognition is made that each case has its own unique characteristics, as did Swanson-Kauffman’s (1986: 65) research into women and miscarriage. This was a multiple-case study (Yin, 1989: 31) focusing on the individual's subjectively interpreted experiences with ICI in the workplace; their life and work with ICI.

Unit of Analysis

Defining the unit of analysis for study was imperative in order to make valid methodological choices. The unit of analysis was the individual with ICI and their interpreted experiences of life and work: 'In each situation, an individual person is the case being studied, and the individual is the primary unit of analysis. Information about each relevant individual would be collected, and several such individuals or 'cases' might be included in a multiple-case
study' (Yin, 1989: 31). This unit of analysis fits comfortably with the research questions that have been listed earlier, the Heideggerian phenomenological philosophy and, also, serves as the basis for sample selection.

*Case Study Sampling*

Yin (1989: 38) argued that using the case study method to gather data does not require statistical sampling because statistical generalisation is not the aim of this method: 'Any application of this sampling logic to case studies would be misplaced. First, case studies should not generally be used to assess the incidence of phenomena. Secondly, a case study would have to cover both the phenomenon of interest and its context, yielding a large number of potentially relevant variables. In turn, this would require an impossibly large number of cases--too large to allow any statistical consideration of the relevant variables. Thirdly, if a sampling logic had to be applied to all types of research, many important topics could not be empirically investigated' (Yin, 1989: 55). Case studies are not sampling units and should not be chosen for this reason (Yin, 1989: 38). The use of replication, not sampling logic, should be used for multiple-case studies (Yin, 1989: 53). Both ethnographic and phenomenological studies should be concerned with the data and should, therefore, use non-probability sampling (Baker et al, 1992: 1358). Informants for a phenomenological study should be chosen because they have lived the experience. Sampling therefore is purposive, aimed at illuminating the richness of individual experience (Baker et al, 1992: 1358).

*The Sample*

The data gathering technique of multiple-case studies necessitated in-depth interviews with suitable individuals. There were two primary criteria for the selection of cases as a unit of
analysis: the person had an ICI and they were currently employed. With regards the first

criterion, the dilemma surrounding the "diagnosis" of the PwICI was considerable. It was
suggested that some medical verification of the diagnosis was necessary due to a valid concern
of dishonest response: a request for a medical certificate should, perhaps, be part of the
sampling method. However, on balance, the arguments supporting a request for medical
verification were insubstantial compared to the problems of using it as a selection criterion.

After much deliberation, it was decided not to ask for medical verification for several reasons:
First, the paternalistic overtones in an assumption of potential dishonesty of the prospective
informant; secondly, the medical diagnosis could well be wrong (Watson and Kendall, 1983:
43) and, as a selection criterion, not reliable. Thirdly, the phenomenological emphasis of this
study expressly valued the subjective everyday experiences of the informant and their
interpretation of events. It was of interest to this researcher, for example, if informants have
had difficulty obtaining a medical diagnosis; if that diagnosis was insufficient or incorrect;
or, whether the diagnostic process itself brought problems for that person to their life and
work. It held no interest to verify these stories, especially utilising criteria defined by the
medical profession. It is accepted that this decision may have resulted in a small portion of
dishonest respondents comprising part of the study although, on reflection, it is doubtful that
this occurred.

With regards to the second criterion, employment, it was initially proposed that people who
had been recently unemployed would be suitable candidates. Unfortunately, this raised the
dilemma of how recently and how to determine a relevant time frame of acceptability. Also,
it was felt that unless employed persons were specifically nominated that a sample skewed
towards the unemployed would result. Current employment was then a mandatory criterion.

The "Hidden" Population

Having defined the two primary selection criteria (that of current employment and having an ICI) the next step was to make contact with appropriate respondents. Some key ethical issues (Lipson, 1994) had to be considered whilst evaluating approaches: the need for voluntary participation of informants; the paramount importance of the privacy of the individual, especially given a workplace context; and the stigmatising nature of many ICIs (Vickers, 1996b). It was assumed that the PwIC may not have disclosed their ICI at work (Goffman, 1963; Scambler, 1984; Vickers, 1996a; 1996b; in press) and, thus, great care was required.

These issues automatically ruled out certain approaches. Any workplace-centred approaches were deemed infeasible: it was felt that potential participants would be suspicious of any study advertised in an internal workplace publication. Approaches through medical practitioners were felt to be invasive of privacy. Given the peculiarities and sensitivities of this group, what follows were the serious of options canvassed in attempting to locate what was soon realised to be a "hidden" population.

Alternatives Considered

Inside AHRI: In the first instance a notice was placed in the November (1995: 8) issue of Inside AHRI (a magazine published by the Australian Human Resources Institute), a publication circulated to (mostly) Australian Human Resources professionals (see Appendix 1 - Advertisement in Inside AHRI). There were nil responses to this notice.
Necessarily, deep reflection (even panic?), including informal discussions with many associates (both with and without ICI) resulted in the following possible reasons for such an outcome. First, the notice had been edited considerably prior to finding its way into Inside AHRI in order to save space. The planned heading was changed and any description of what constituted an "invisible" illness, or of its workplace context, was deleted. Secondly, the term "chronic illness" was used, necessarily limiting possible respondents to people with a socially defined "illness" (see Appendix 2 - Original Advertisement Copy). The wide variation in lay understanding of "health" (Blaxter, 1995: 25) and "illness" (Parsonson, 1989: 217) may well have translated into wide variations of perceptions regarding what constituted "invisible" chronic illness. PwICI may not see themselves as "sick" (Stone, 1995) and this phenomenon may be exacerbated by the "invisibility" of the condition being translated, consciously or unconsciously, into one that is trivial (Whittington and Wykes, 1989: 30; Stone, 1995).

Thirdly, the circulation of Inside AHRI is quite small and directed to Australian Human Resources professionals. Perhaps this was not the most appropriate placement for such a notice. Fourthly, professional people, especially those who have a chronic illness, may not feel sufficiently motivated to respond to such a notice: they may be too busy or find that the day-to-day coping required with managing an ICI, and working, prohibits sufficient time and energy being left to participate, even if they wanted to. They may also feel, once again, that their condition is not as problematic as a visible disability (Safilios-Rothschild, 1970; Stone, 1995). Fifthly, PwICI may ultimately feel that their privacy is at risk; that even if the study is not attached to their place of work, their anonymity in illness will not be preserved if they were to participate. Finally, potential respondents may have wished to avoid being reminded of their illness and associated issues, choosing (consciously or unconsciously) a defence strategy of 'repression' (Oldham and Kleiner, 1990) or 'denial' (Parsonson, 1989: 212;
Oldham and Kleiner, 1990) to secure their illusion of 'personal invulnerability' (Raphael, 1986: 30) in order to cope.

*The Sydney Morning Herald* (Public Notices): With the problems above in mind, analysis and review of several potential notices was undertaken (see Appendix 3 - Informal Survey Outcomes). The decision was taken to submit a notice in the Public Notices Section of *The Sydney Morning Herald* (see Appendix 4 - Revised Advertisement for *The Sydney Morning Herald*) during January of 1996. However, prior to placing this notice, an informal survey of friends and colleagues relating to readership of the Public Notices Section of *The Sydney Morning Herald* revealed that few people who were busily employed were regular (or even sporadic) readers of this column. This was a problem given that this was the only placement option in this newspaper. The problems listed above pertaining to psychological defence strategies and inconsistencies in lay understandings about "invisible" chronic illness were also felt to be problematic with this approach. Additionally, respondents were likely to be heavily skewed towards those unemployed and, hence, prove unsuitable. Finally, the weighty question of researcher safety was also of concern. Rather than spending money advertising (not inconsequential amounts on a student budget) other avenues were considered.

Recognition of PwICl being a "hidden" population was increasingly vivified.

*Convenience Sample*: Convenience, access and geographic proximity can be the main criteria in the selection of the cases to be studied for the pilot (Yin, 1989: 80). Continued reflection confirmed that ICI had to be a reasonably common phenomenon: ABS statistics indicated this (ABS, 1988; 1990), as did the anecdotal incidence of ICI represented in colleagues, friends
and family of the researcher. Consideration was given to a convenience sample (Yin, 1989: 80) through the interviewing of friends, colleagues or family that were deemed to be suitable candidates. However, the problems of this approach weighed heavily: the researcher felt distinctly uncomfortable about interviewing friends about such personal matters; possibly placing them in a position of not being able to refuse an interview or a question out of courtesy, and the responses being either evasive, uncomfortable or inaccurate as a result - or worse, the interview going well but the friendship suffering as a consequence. Wilmot's (1975: 59) comments about perceptions of others being affected by intimate knowledge of the other were heeded. There was the additional danger of the cases being skewed to a representation of white, middle class Australians. This was not a suitable approach.

*Modified Chain Referral Technique:* A final alternative was considered: Watters and Biernacki’s (1989: 420) *Modified Chain Referral Technique.* This was selected after careful consideration. Rather than interviewing those known directly to the interviewer, this method entailed asking associates of the researcher (hereafter referred to as "intermediaries") if they knew of anyone who was a likely candidate for participation. Watters and Biernacki (1989) had experienced similar difficulties when trying to survey the "hidden" population of injecting drug users and were finding their target sample to be similarly elusive:

In this technique, injecting drug users known to the ethnographic team would serve as initial links in the chain and be asked to introduce persons they knew to be injecting drug users to the study. At first we were concerned that such a strategy might not give us the minimum of 100 subjects we needed to recruit at that site. However, after we explained the purpose of the study to key
opinion leaders in several networks of injecting drug users, word that anonymous HIV testing was going to take place and an $8 stipend would be paid to the participants went on the grapevine. When the research team arrived at the field site on the first day of data collection, a line of potential study respondents stretched down the street (Watters and Biernacki, 1989: 420).

It was decided not to use a stipend, thinking it an unnecessary and trivialising incentive (and a student’s budget didn’t allow it anyway), but felt that the use of another party to introduce the researcher, and the research, was a valid way to approach people and one that might prove successful. The considered advantages of working with this modified version of Watters and Biernacki’s (1989) ‘modified chain referral technique’ were many:

1. Unpressured choice for the potential respondent to participate in the study or not;

2. Privacy for the participant; the researcher never needed to know their identity if they chose not to participate;

3. Potential participants introduced to this research via a friend or colleague were far more likely to participate, given an explanation of the researcher’s academic and illness background;

4. People introduced were highly likely to qualify for the study. One was able to discuss with intermediaries the selection criteria prior to them talking
to any prospective candidates. At the conclusion of the study no prospective interviewees had been rejected as unsuitable;

5. Higher levels of safety for the interviewer;

6. Higher variation in case-study candidates, which was highly desired by the researcher in achieving the research objectives set;

7. The researcher not interviewing people known to her, therefore eliminating certain bias and discomfort problems associated with interviewing personal acquaintances; and,

8. Respondents became available very quickly and in abundance. In fact, once started, the researcher had to take great care not to become overwhelmed with participants eager to participate and be unable to keep up.

There were, however, some recognised disadvantages:

1. Participants may have still felt some pressure to participate, although this was minimised by not making contact with them until they had given permission, via the intermediary, for the researcher to do so. The potential respondent could remain anonymous until they had agreed to participate. It was made clear to intermediaries at the outset that they should not reveal the name of the prospective participant until after that person had given permission to
continue. No participants had ever been met prior to the first interview;

2. Bias was still a recognised problem in the case studies selected. For example, respondents were predominantly middle-class, young to middle aged, white, professional and female. In fact, one major problem identified in the pilot was the initial difficulty in finding male respondents due to the noted cultural bias towards females being more likely to talk about emotionally upsetting events (Lawson, 1987: 252); and,

3. Case-studies that are known-about by others may also be skewed towards those who were prepared to disclose their illness. It would be difficult, if not impossible, to locate, let alone interview, "invisibly" sick people who adopted a policy of complete non-disclosure.

Informant Selection

A list of potential intermediaries was made (consisting of family, friends, colleagues, acquaintances) and, starting at the top, intermediaries were asked if they knew of anyone who might qualify for the study (having a defined ICI and who were currently working). The intermediary was asked to make contact with the person they considered would qualify and to ask the potential respondent for agreement, in principle, to participate in the study and for permission for the researcher to make contact with the person to further explicate the study and participation requirements. This maintained the potential participants privacy in that the researcher didn't need to know their identity if they chose not to participate. It also gave some screening capability; a female researcher was less likely to be placed in a dangerous
situation via this method of introduction (although this possibility was never ruled out).

Intermediaries were encouraged to inform the potential respondent that the researcher had MS and was conducting the research as part of a PhD program. It was felt that identifying the researcher as an 'insider' or 'intimate' (Wilmot, 1975: 59), a 'native' of the group under review (Lipson, 1994: 339), would encourage some identification from respondents with the researcher. Further, the institutional backing provided the research, and the researcher, with some credibility. Finally, potential respondents were informed that the research had full approval from the University Human Ethics Review Committee. It was hoped that the combination of these factors would invoke trust.

From the initial referral, the researcher's 'judgement' was used to select cases (Brown and Williams, 1995: 697) based on discussions with intermediaries in the first instance and, then, with the potential participant. Potential interviewees, who had agreed in principal to participate, were contacted directly by telephone to explain the project and to enable the researcher to judge (Brown and Williams, 1995: 697) their suitability for inclusion in the study.

It is important to realise that the process described here was not without risk. Error in selection was possible given the peculiarities and ambiguities of social discourse. For example, intermediaries may have incorrectly identified informants (for example not realised they no longer worked or by suggesting a person whose illness was very visible). To remedy this, careful consideration was given, for each prospective informant, as to why they would be suitable, in an effort to avoid the dangers of sampling (or in this situation, selecting case-
studies) too narrowly (Miles and Huberman, 1984: 41-42). Fortunately, all suggested respondents met the criteria and were prepared to participate.

Participants were included in the study if they met the specific selection criteria and 'because it [was] likely that they [would] have detailed knowledge of the topic under study and they [would] be able to help the researcher to explore the research questions posed' (Brown and Williams, 1995: 697). It was remembered that one of the principle objectives of this study was to identify themes or trends consistent amongst different illnesses. One had to guard closely against a study that predominantly interviewed only people with one or two different kinds of illness, given the imperative of broadly examining the impact of "invisible" illness. Conversely, the special "vantage point" of the researcher in having MS had to be recognised and for this reason, and despite personal reservations, people with MS were included in the sample.

Contact with Informants

During the initial telephone contact, information about the research project and the researcher was conveyed to the potential respondents (see Appendix 11 - Telephone Information Used), as well as ascertaining whether or not they were suitable as participants. A suitable time and venue for the first interview was then arranged. Information was sent to potential participants. A covering letter (see Appendix 5 - Sample Covering Letter) thanked them for their participation and explained the details of the study, whilst also underscoring their right to decline to answer any question or to discontinue participation at any time. Attached to this were three forms: (1) an Information Sheet (see Appendix 6 - Sample Information Sheet); (2)
a Consent Form (see Appendix 7 - Sample Consent Form)⁶⁰; and, (3) a brief Demographic Survey (see Appendix 8 - Demographic Survey - Pilot Study; Appendix 9 - Demographic Survey - Main Study). The Consent Form and Survey were both to be completed by the informant and returned. All consent forms and surveys were either promptly returned by mail or brought to the first interview. Reminders or follow-up phone calls were never required.

Interviews were conducted, subsequently transcribed (see Appendix 14 - Sample Interview Transcript), summarised and some limited analysis performed on an ongoing basis. Each respondent was interviewed twice, with the second interview proving to be extremely worthwhile: important and unasked questions from the first interview (due, in some part, to the inexperience of the interviewer) could then be asked and clarification of respondent’s answers, meanings and thoughts could be sought. Transcripts of the first interviews were made available to informants as soon as possible after the interview was conducted.

Data Management and Recording

Participants were each allocated a number (for example One, Two or Three, following Swanson-Kauffman, 1986) in accordance to the order in which initial contact with them was made by the researcher. A database was designed (Yin, 1989: 98-102) and respondent details were stored in a PC database that was password protected and encrypted. Each respondent was additionally allocated a numerically sorted manual file containing all paperwork. A separate file holding duplicates of all transcripts and interview notes was used for analysis, and a third set (soft and hard copy) of all transcripts of interviews was held securely offsite.

⁶⁰The reader will note that this Consent Form confirmed, in writing, the approval received from the University Human Ethics Review Committee for this research to be conducted.
**Demographic Collection**

Demographic characteristics were ascertained using a brief, survey instrument (see Appendix 8 - Demographic Survey - Pilot Study; Appendix 9 - Demographic Survey - Main Study). As this was an exploratory study, it was difficult to know at the outset which information would be required and why: 'while recognising that it may be difficult to identify in advance the exact nature of comparisons, it is almost a given that the research [would] reveal a range of response across informants. Comparison according to variables identified within the research process is the main strategy used to account for that variation' (Dreher, 1994: 288). Demographic details were reviewed as part of the comparative analysis, particularly when attempting to identify possible explanations and possible interpretations made whilst building the phenomenological model.

**Focused Interviews**

The chief component of this research process was the interview. It was important to maintain a balance of structure and flexibility in the interviews (Swanson-Kauffman, 1986) and the best way to achieve this was to use focused, in-depth interviews. Alternatives to focused interviews were considered, and discounted. First, surveys (highly structured interviews) are employed when the researcher knows precisely what sort of information is required (Minichiello et al, 1990: 91), unusual in an exploratory study such as this. Surveys were not thought to allow sufficient flexibility to uncover the richness of the lived experience; an imperative to this study. Secondly, completely unstructured interviews (which would seem mandatory for those following the Husserlian phenomenological methodology and the mandatory 'bracketing') were deemed inappropriate for this research.
The existing theoretical framework, arrived at through academic and personal experience, writing for publication, informal discussions with other PwICl and literature review, needed to be specifically addressed. The utilisation of Heidegger's hermeneutical phenomenology necessitated inclusion of this 'background' and 'pre-understanding' (Koch, 1995: 831). There was an acknowledgment of the need for a rough theoretical framework in order to have sufficient understanding prior to the commencement of any qualitative research, otherwise 'an incoherent, bulky, irrelevant, meaningless set of observations may be produced which no-one can (or even wants to) make sense of' (Miles, 1983: 119). Additionally, the need for comparative analysis of the case studies would have been made eminently more difficult if there was no essential structure determining the direction of the interviews (see Appendix 10 - Sample Focused Interview Questions). The questions, naturally, changed through iterative review over the course of the study as the qualitative research process unfolded.

Following Swanson-Kaufman's (1986: 62) work as a heuristic, each respondent was interviewed twice. Arranging a series of interviews with a respondent allowed reflection on the transcripts of past interviews so as to gain as much interpretive insight as possible (van Manen, 1990: 99). It was originally planned that the second interviews would be held approximately four weeks after the first (as did Swanson-Kaufman, 1986: 62) to allow time for transcription, analysis, coding and review of interview questions. The purpose of the second interview was to clear up any misperceptions the researcher had from the first interview and to validate the emerging categories (Swanson-Kaufman, 1986: 62). Second

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61 Actually, four weeks was far too long in between interviews, both for the researcher and the respondents to have clear recollections of what had been talked about during the first interview. During the main study and towards the end of the pilot, second interviews were scheduled one week after the first whenever possible. This had the added bonus of forcing a swift transcription and initial analysis to be ready for the next interview. It also assisted with the necessary "immersion" in the data required for analysis.
interviews were also conducted face to face (unlike Swanson-Kaufman who conducted second interviews over the telephone) due to the then strong belief that the richest data would be revealed at the second meeting, given the opportunity to further build a relationship of trust. Second interviews remained flexible. Both interviews took approximately one hour each: this seemed sufficient as respondents became tired and drained through the process, as did the researcher.

**Question Construction**

A series of questions was generated as a guide for the focused interview (following Minichiello et al., 1990; Foddy, 1993), which initially centred around the research objectives. The questions were generated with particular care as to their wording and focus, as were potential prompts to be used. The sequence of questions (and issues covered) would change, and often did, as did question wording and key issues were reviewed in the iterative process which succeeded each interview (Yin, 1989; Minichiello et al., 1990: 287).

**The Interviews**

Interviews were conducted at a place of convenience to the respondent; usually in their home or office. All interviews were taped and transcribed and were conducted in as conversational a style as possible, noting the transactional nature of dyadic communication (Wilmot, 1975: 10) with consideration given to certain useful functions associated with dyadic communications in this setting: intimacy, social integration and the opportunity for nurturant behaviour, reassurance of worth, assistance and guidance (Wilmot, 1975: 6). The first

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However, this was not always the case. Details about interviews can be found in the section headed *The Interviews* later in this chapter.
interview was the focused interview, with focus areas predetermined by the theoretical framework (See Appendix 10 - Sample Focused Interview Questions), personal experience and, as the fieldwork progressed, from the respondents themselves, highlighting areas that needed clarification or exploration.

First interviews were usually slightly longer than one hour: introductions and social pleasantries sometimes took 20 or 30 minutes before the interview commenced. This time was invaluable in establishing some rapport and comfort level, for both researcher and respondent, prior to the interview. Many respondents appeared nervous (or perhaps self-conscious) when the tape recorder was turned on. However, this seemed to subside very quickly. No-one requested that the interviews not be taped.

Second interviews were more structured, with questions being more specifically developed from data gathered during the first interview. Questions making clarification or exploring issues uncovered during the first interview, or even probing areas not evident to the researcher until later analysis⁶², were able to be explored at leisure in the second interview. The second interview did not always demonstrate a closer relationship and higher levels of trust. Indeed, a couple of the respondents were noticeably less inclined to reach as deeply within during the second interview and, perhaps, had experienced some emotional turmoil following the first

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⁶²It was found that during the interview, one was so busy remembering to check the tape, set the alarm, explain what was going to happen, ask respondents if they had any questions, listening, thinking about the next question and staying reasonably composed, that some valuable comments were missed that should have been followed up immediately. It was only later, at home, doing the initial analysis and preparation for the second interview, that one would be hit "between the eyes" with a comment and, especially, with what was often left unsaid. The second meeting allowed exploration what often turned out to be important themes.
interview. In some cases the richest data came forth in the first interview. It seemed that what was required was not just a relationship building exercise. Circumstances on the day seemed also to have a big influence: how the researcher happened to be feeling; how the respondents were feeling; who was in the next room. However, with some respondents there was clearly a need to get beyond the "mask", to build a sufficient level of trust. When this was achieved, the second interview did reveal more closely held, more intimate, information.

The Pilot Study

This section reviews, in some detail, the process of the pilot study and notes changes made in research design as a result of the "learning-in-process" experience. Changes documented here were implemented during the later "main study" phase of the project.

The pilot case studies were used to assist this researcher in both substantive and methodological ways. This researcher was keenly aware of inexperience (as was Swanson-Kaufman, 1986). From a substantive perspective, the pilot was to assist in providing insight into the study's theoretical framework (Yin, 1989: 81) and was used in conjunction with an

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64 One respondent, in particular, was very upset after the first interview, although this wasn't known until arrival for the second. She certainly "shared" her feelings with me then. The process, understandably, had dredged up vast amounts of emotion for her and her anger was, naturally, directed at the person who was responsible for this - me. After leaving her, it was my turn to be upset: first, because she had accused me of not considering my ethical responsibilities; and yet, I had taken such care in this regard (as relayed in Chapter Three). That hurt. Secondly, she spoke to me as if I had no knowledge of what she was going through. She seemed to have conveniently forgotten that I, also, had an ICI, as did my husband.

65 On one particular occasion I remember going to an interview feeling unwell, exhausted and, correspondingly, emotional. All the way in the car I wondered how to succeed in "keeping it together this time", given the depth and richness of what had been revealed at the previous interview with this particular respondent. I was afraid of the respondent's emotions escaping the "cage", and of my own. Well, I did keep emotions in check, but the interview data gathered was correspondingly flat, colourless. I was conscious afterwards of the 'transactional nature' of the interview (Wilmot, 1975: 10) and that each person influences, and is influenced by, the other (Wilmot, 1975: 12). I promised myself I would reschedule when feeling like that again.
ongoing review of the relevant literature so that 'the final research design was informed both by prevailing theories and by the fresh set of empirical observations' (Yin, 1989: 81). Using Swanson-Kaufman's (1986) experiences as a heuristic, and for want of something better, a pilot of five case-studies seemed sufficient to assist me in finding my way.

From a methodological perspective the pilot was used to help develop the correct focus and wording of interview questions through an iterative review of interviews: the process of 'cyclical adjustment' (Yin, 1989: 82) or 'the qualitative research process' (Minichiello et al, 1990: 287). The pilot interviews were transcribed, coded and reviewed as quickly as possible after the interview to guide subsequent interviews, both with that individual and with others. The pilot test was not regarded as a 'pretest', where a 'test run' is being performed, but was being used to test both substantive and methodological aspects (Yin, 1989: 80) and to gather valuable data.

**Pilot Study Objectives**

The case study design is rarely completed at the outset of the study (Yin, 1989: 59). The pilot case-study interviews were conducted, with the intention of revealing potential inadequacies in the initial design, specifically question construction, sampling criteria and researcher inexperience. It was intended to be 'a small-scale replica and a rehearsal of the main study. While pre-tests help to solve isolated mechanical problems of an instrument, pilot studies are concerned with administrative and organisational problems related to the whole study and the respondents' (Sarantakos, 1993: 277). 'After some early data collection and analysis, an investigator has every right to conclude that the initial design was faulty and to modify the design. This is an appropriate and desirable use of pilot studies' (Yin, 1989: 59).  

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Fortunately, apart from some minor modifications, the pilot revealed that the research design was workable and effective. It also underscored the researcher’s inexperience in some instances.

**Pilot** study objectives were as follows (and were distinct from research objectives):

1. To find out what (or if) a general trend of issues, **themes** and concerns emerges regardless of the "invisible" illness or, whether the issues were dependent upon the specific invisible condition or **category** of condition;

2. To explore the psychically and socially constructed reality of life and work for PwDCL (the "what" or interpretive, descriptive analysis) and whether this coincides with hunches derived; and, to uncover additional issues of concern and behavioural responses not yet considered by the researcher. (This pilot study objective supports the first and second Objectives of the Research Objectives: see Chapter One);

3. To explore initial themes, build initial linkages and develop initial explanations about the subjective interpretations reported by PwDCL and their life and work through thematic analysis of multiple-case studies. (This pilot study objective supports the third Objective of the Research Objectives: see Chapter One);

4. To confirm and extend interview focus and question appropriateness;
especially comprehension by respondents, responses elicited in accordance with research objectives, effectiveness of prompts and probes, and appropriateness of issues covered; and,

5. To give an inexperienced researcher experience at correctly and professionally conducting the interviews, and developing an interview atmosphere of trust and disclosure essential to such a sensitive topic.

These objectives were achieved. General trends (as well as unique experiences) were uncovered for all PwICI, as sought in the first Objective. These are detailed in the phenomenological model in Chapters Five and Six, as are outcomes from Objectives 2 and 3 above. The following sections outline some of the difficulties and serendipities that emerged from the pilot study. Where difficulties were encountered, the sections also describe what action was taken before, or during, the main study to counteract this. The reader will find that the following sections respond to the Objectives 4 and 5 above.

**Difficulties Encountered**

**Case Study Participants:** First, it was possible that prospective participants contacted by intermediaries would not fit the criteria; for example, not be working or their condition not be suitably "invisible". Whilst this did not occur, greater care was taken during the main study when briefing intermediaries, and during the initial telephone call to participants, to determine participant suitability.

Secondly, intermediaries contacted may have been unaware of friends or colleagues who had
an ICI because of the "invisible" nature of such conditions and a policy of non-disclosure on the part of the PwICI. However, whilst some people may have been "missed", no difficulty was experienced in finding sufficient respondents to finalise the study once the modified version of the 'modified chain referral technique' (Watters and Biernacki, 1989) was employed.

Thirdly, it was decided whilst completing the pilot study that respondents with MS would be avoided during the main study, due to the perceived need for the researcher to distance herself from the problems faced by the participants in the study - to reduce personal stress. This decision was reconsidered on the basis of the special "vantage point" the researcher had, especially when interviewing people with MS. To try and counteract the problems experienced, a University counsellor was sought, and regularly visited, during this period.

_interviews:_ Problems were initially encountered with taping of interviews, the majority of which were caused by inadequate sound resolution of recordings (in other words, a cheap tape-recorder!). Softly spoken individuals proved very difficult to record, even when the recorder was placed directly in front of them. The initial decision to have tapes

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66 The author thanks participants at the Department of Management and Administration Research Colloquia for this insight. They pointed out to me the value and uniqueness of my special viewpoint, especially in interviewing people with MS, pressing me to continue. It was worthwhile to do so, although the need for careful consideration in following this path is re-considered in the final chapter.

67 Interestingly, the potential problems surrounding interviews gave me a "reason" to seek counselling: the "real" reason for the necessity of counselling will become clear in the next chapter.

68 On one particularly disastrous occasion, the tape was turned off inadvertently by the participant (who was very softly spoken and had been requested to hold the tape-recorder like a microphone). The entire interview was lost. Reconstruction of the majority of substantive aspects of the data was possible the following morning, given that it was a second interview and the question schedule was well structured. However, the affective component and the actual narrative was lost forever. A harsh lesson had been learned: a better quality tape recorder was sought prior to re-start of interviews during the main study.
professionally transcribed exacerbated the problem: the transcriber was unfamiliar with the content of the interview and by the time tapes and transcripts were returned for correction, the use of the researcher's memory as an aid was largely lost. An improved tape-recorder, and a decision to personally transcribe all interviews, made subsequent interview transcriptions relatively problem-free.

A minor, but noteworthy, problem encountered during interviewing was the intrusion of sexuality. This author notes that few others have the courage to note such problems, looking to Fine's (1993) frank, if not cynical, comments for support. Whilst there were no 'obnoxious or brazen attempts at sexual acquaintanceship' (Fine, 1993: 283), and certainly no spicy trysts, there was a recognised and somewhat distracting intrusion during one particular interview that was simply not present at the others. The intrusion could perhaps also be attributed to the female researcher's existence in a predominantly sexist world or, it could be that the male respondent was very motivated to portray an untroubled, tough, if not blatantly "macho", image or, perhaps, he wasn't particularly troubled by his condition. Whilst recognising the tendency for women to be more likely to talk about emotional reactions (Lawson, 1987: 252), the researcher also experienced difficulties early in building the requisite atmosphere of trust with this respondent, attributing this to the cultural predominance of male stoicism in the face of adversity. Finally, it is acknowledged that the preceding commentary could comprise a very simplistic and possibly biased or inaccurate projection (Wilmot, 1975: 63) but, it was felt, one still worthy of comment.

*Transcription of Interviews:* As noted above, personal transcription of interviews was found most efficient (in contrast to the advice of Peterson et al, 1994). Transcripts prepared by
another still had to be corrected and summary notes needed to be made prior to sending tapes away to guard against accidental loss of data. Professional transcriptions were found to be largely inaccurate, with the process time consuming (especially including turn-around time and error correction) and costly. The latter half of the pilot study interviews and subsequent main study interviews were transcribed personally by the researcher as soon as possible after the interview took place.  

Perceived benefits of making transcripts available to participants to get feedback (Miles, 1983; Swanson-Kauffman, 1986; Peterson et al, 1994) were outweighed by perceived problems of Freud's notion of 'secondary revisionism' (Gay, 1995: 28); that is, respondents would come to the subsequent meeting having reflected upon their previous comments. This seemed to contradict the Heideggerian notion of capturing the life-world of the respondents, as perceived by them, at a particular point in time. During the pilot, interview transcripts were made available to respondents, but only at the commencement of the second meeting (so there would be no time for review prior to the second interview). However, even this practice ceased as most participants didn't seem particularly interested in getting the transcripts; no feedback was received. Second interview transcripts were subsequently not routinely made.

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I found this out the hard way also. A couple of early interviews were very difficult to hear and at least a week had passed before transcription was attempted. Some of what was said was lost, especially given an observed tendency for respondents to speak more quietly when levels of emotion rose. Transcription was very difficult and very time consuming without the aid of recent memory. After this, it was deemed to be imperative that interviews be transcribed within 24 hours of the interview.

One participant suggested to me that it might be useful for participants to be encouraged to jot down any thoughts, recollections or incidents they believed relevant in between interviews for review at second interview. Reflection and subsequent discussion with colleagues left me with the same problem of participants reflecting upon their stories which would influence future storytelling. The suggestion was not adhered to.
available, although were made available upon request.\textsuperscript{71}

\textit{Interview Scheduling}: Interview scheduling became problematic in some instances, with up to three or four weeks elapsing between the first and second interviews during the pilot. This presented the problem of having to go in to the second interview almost as "cold" as the first, with the burdens of rebuilding trust and rapport almost as heavy, and recollections of what was said in the first interview being lost. No more than a week was allowed (where this was practicable) to elapse between first and second interviews during the latter pilot study interviews and the main study. Sufficient time between interviews was required to structure the second interview, with questions derived from initial analysis, summary notes and first interview transcripts. Necessarily, no more than two, or possibly three, interviews were scheduled over the course of a week. Follow up phone calls (as suggested by Swanson-Kauffman, 1986; Minichiello et al, 1990: 251) were never used instead of second interviews to confirm facts, events or meanings.

\textit{Researcher Problems}: Empathy with participants, considered essential to the building of trust, became a personal stumbling block. The necessary reflexivity, where 'the researcher is a part of the world that she or he studies and is affected by it' (Boyle, 1994: 165), became somewhat problematic.\textsuperscript{72} Even though the ICIs studied varied, themes of personal concern

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\textsuperscript{71} One respondent during the main study requested a copy of the transcripts. When the first transcript was supplied at the commencement of the second interview, she didn't bother to read it, instead handing it back to me. She seemed pleased that I had responded to the request and I sensed that the request was one relating to trust. She seemed satisfied and didn't want copies of further interview transcripts.

\textsuperscript{72} Nothing could be more accurate. An exacerbation of my own ICI, MS, was of some concern during this process. Any emotional distance available earlier in the research process had largely evaporated, and fear and feelings of personal vulnerability (Lawson, 1987: 252) had surfaced, due both to the illness exacerbation and to the constant confrontation of what "might be" in every transcript, every hour of analysis. Every interview became a living reminder of what could happen to me: interviewing Daphne (a respondent with MS) revived
were continually reflected in the stories. All but the most hard-hearted amongst us (and even those professionally trained and experienced) would find it hard to remain passive and unaffected when hardship in the lives of others unfolds: the researcher listened to stories of unthinking callousness, the tragedy of lost loved ones and calm (and sometimes not so calm) discussions of the prospect of one’s own death and disablement.

The successful methodological approach used to locate the "hidden" population also had some negatives: the people closest to the researcher, who had frequently acted as intermediaries, were necessarily (and notably) absent for cathartic discussion or any form of de-briefing due to the need to protect the confidentiality of participants. Counselling helped with this.

*Analysis:* The sheer volume of qualitative data (Miles and Huberman, 1984: 56; Minichiello et al, 1990: 285) (about 20-30 pages of data for every one hour interview) was daunting to an inexperienced researcher. Difficulty was also initially experienced generating coding keywords. Abortive early attempts were made from the literature reviewed. Unfortunately, these were arbitrary lists that were endlessly updated, were not sufficiently "meaningful" and, thus, were difficult to remember and use. It was only when re-reading Miles and Huberman (1984: 61) that it was decided to give some reason to the coding, some order, if only to enhance memory and usability. So, the ideas developed in Chapter Two were used as the basis for a coding framework. Master code keywords were representative of the major "entities" of influence identified in the earlier chapters. This made recollection of keywords and heightened the researcher’s fears at a much greater level than was anticipated. Routine, and (up until then) unconscious, use of repression (Oldham and Kleiner, 1990) as a defence mechanism was clearly no match for the "reality" of looking across the table at my possible “future”. This woman was only a few years older than the researcher and the disease was creating significant problems for her. Very discomforting.
and their likely placement noticeably easier. Categories developed were refined on an ongoing basis, but seemed to be work reasonably well.

A further analysis problem was actually starting. Procrastination, inexperience and knowing where to begin were major problems. The researcher read the transcripts several times initially to get a "global" idea of the issues and refresh herself as to the facts of the various cases. Revisitation of the appropriate literature to refresh analysis approaches (for example, Miles and Huberman, 1984; Yin, 1989; Minichiello et al, 1990; van Manen, 1990; Sarantakos, 1993; Morse, 1994b) and an early draft of this chapter also preceded and assisted with coding and analysis. Coding commenced, with themes and exemplar vignettes noted.73

The question of using my own intuition to interpret findings created insistent, and largely unanswerable, questions: Were the chosen codes reliable and valid representations of the experiences being recounted? Was this being done correctly? One hoped so. Certainly reflections on the lives of people being interviewed were almost constant, an experience shared with another:

The reflective nature of qualitative research must leave room for the fact that ideas are 'intuited'; and by their very nature intuitions come where and when they will, which is not always where or when they are sought. . . . My reflections on miscarriage became my constant companion: I lived, walked, talked and slept my study (Swanson-Kauffman, 1986: 65).

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73 A full discussion of analysis considerations can be found in the later section of this chapter: Analysis Considerations.
Demographic Data: Demographic data collected during the pilot (See Appendix 8 - Demographic Survey - Pilot Study) was, mostly, sufficient but lacked information about what the person did in their job and how they travelled to and from work. This would have been useful to refer to during analysis and was unavailable. The demographic survey was updated prior to returning to the field for the main study (See Appendix 9 - Demographic Survey - Main Study).

Serendipitous Outcomes

It wasn’t all bad. One of the most notable, and heartening, manifestations of the study was the apparent desire of the participants to talk - to tell their story. All respondents were ready and waiting at the appointed hour; all had remembered to fill out their demographic survey and consent forms and return them to me either at, or prior to, the first interview; all reported that the experience was a largely positive one; no-one forgot an appointment; and, any rescheduling was done with plenty of advance notice. The researcher was even given a box of chocolates by one respondent. It was most impressive.

The research design articulated here did work well. Some problems, described above, were notable but could not have been avoided given the researcher’s inexperience. It was a valuable learning experience and, on balance, a very positive and enriching one.

Final Changes

One final point that became clear whilst analysing the pilot was that it was likely that saturation was going to be reached well before interviewing 25 people, twice, as was originally intended. One was reminded to use a manageable (small) sample 'which permits
greater participation and observation on the part of the investigator' (Dreher, 1994: 286). The researcher felt she was going to "drown" in transcripts long before that arbitrary figure was reached. It was recalled that Swanson-Kauffman's (1986) study had only involved one face-to-face interview with each person. It was decided to continue until it was felt that sufficient data had been gathered to meet the objectives set and build the phenomenological model planned. Twenty interviews were completed, with ten different respondents.

Finally, the adoption of Swanson-Kauffman's (1986) usage of numbers assigned to each individual interviewed (for example, One, Two and Three) was reviewed. Whilst this was highly successful from the researcher's perspective, it was pointed out by colleagues that such an approach was highly rationalist and objectivist; completely at odds with the tenor and philosophical underpinnings of phenomenological research. Hence, at the completion of the pilot analysis, all five respondents were given aliases instead and notified of the change of procedure in writing as a courtesy (and to remind them that they had not been forgotten by the researcher) and so they could watch out for themselves in future publications.

Analysis Considerations

'The aim of data analysis', argued Minichiello et al (1990: 285), 'is to find meaning in the information collected' (own emphasis added). Bogdan and Taylor (1975; cited by Minichiello et al, 1990: 285) have identified three stages of analysis: 'The first stage involves coding the data, discovering themes and developing propositions. The second stage is refining one's themes and propositions. The third stage centres around reporting the findings.' The substantive findings of this study are reported in Chapters Five and Six. Here, it was
endeavoured to report the methodological analysis of the data; the analysis process and reasoning used to discover themes, and to develop propositions described in the phenomenological model.

The intention was always to intersperse analysis with the field work:

Analysis during data collection lets the fieldworker cycle back and forth between thinking about the existing data and generating strategies for collecting new—often better quality—data; it can be a healthy corrective for built-in blind spots; and, it makes analysis an ongoing, lively enterprise that is linked to the energizing effects of fieldwork. . . . Periodic field visits are interspersed with time for data reduction and display, for drawing conclusions, and for testing those conclusions—either through other analyses in the existing data base or through a new round of data collection (Miles and Huberman, 1984: 49).

However, concurrent analysis did not proceed initially quite as planned: the researcher quickly became swamped with tapes to transcribe, summarise and review, and succeeded only in some initial analysis involving completing transcriptions, planning questions for the second interviews and making summaries of issues and processes that emerged from each interview. Contact Summary Sheets (Miles and Huberman, 1984: 50) were generated following first interviews with respondents covering:

1. What people, events or situations were involved?
2. What were the main themes or issues in the contact?
3. What new questions should be addressed in future interviews?

4. Questions to ask at next interview (see Appendix 12 - Sample Contact Summary Sheet).

Additionally, random thoughts, conclusions and questions were initially captured on a tape-recorder kept at hand and, later, recorded in notebooks used respectively as an Analytical Log and Personal Log respectively (Miles and Huberman, 1984). Whilst it is recognised that this all comprised part of the analysis process, no real synthesis of concepts or cross-comparison of cases was formally attempted during the interviewing phase of the pilot; a fault rectified during the main study. Sufficient time was required for thinking; for exploring ideas and themes, and incorporating them into existing explanations. Thus, "pauses" were incorporated into the main study interview schedule to allow for this.

**Coding**

Coding was performed with words (as opposed with numbers) despite the problems that words inherently hold as codes; that they are ambiguous or may lack any meaning when taken out of context (Miles and Huberman, 1984: 54). Numbers were perceived to be relatively meaningless to this researcher and it was thought they would unnecessarily add to the complexity of conversion (Miles and Huberman, 1984: 55) during the coding process. *Open coding* was used: 'To initiate, coding is rather "open" and general, and allows further refinement and reinterpretations. Only significant data are considered for coding. Codes are

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74This particular suggestion sounded very workable at the outset. The tape-recorder was kept at hand to record thoughts whilst driving or working. However, when it came to transcribing the "gems" that had been captured on tape, the task soon proved an onerous, cumbersome burden: additional transcribing work was not needed. After the pilot study, a return to the "old faithful" pen and paper: once the idea was down, it was quick and easy to access.
then verified and saturated’ (Sarantakos, 1993: 272).

Coding was performed as accurately and responsibly as was possible (Sarantakos, 1993: 272). Genuine categories were developed, rather than paraphrasing sentences; the underlining of key data to aid in sorting was done whilst coding; categories and subcategories were related; and unrelated and unused categories were eliminated over the course of the analysis (Strauss, 1991: 122-123; cited in Sarantakos, 1993: 272). Codes were developed to consider the setting or context; the definition of the situation; perspectives of participants; ways of thinking and meanings given; processes involved; activities undertaken; specific events; and strategies used by participants (Biklen, 1982; cited in Miles and Huberman, 1984: 57). The coding scheme was dynamic and inductively developed (Miles and Huberman, 1984: 57) in that it was set prior to analysis commencing but was constantly under review, with categories included and eliminated. However, one remained wary that:

Codes should relate to one another in coherent, study-important ways; they should be part of a governing structure. Incrementally adding, removing or reconfiguring codes produces a ragbag that usually induces, in turn, a shapeless, purely opportunistic analysis. It also makes the codes harder to memorize and use; the retrieval and organization of the material becomes burdensome and difficult (Miles and Huberman, 1984: 60).

Late coding was recognised to weaken analysis (Miles and Huberman, 1984: 60; Minichiello et al, 1990: 295) and, thus, the theoretical framework of Chapter Two remained the basis for codes. Units of data (sentences or paragraphs) (Minichiello et al, 1990: 297) were coded by
writing codes in the right hand margin and marginal, reflective remarks in the left hand margin (the reverse of the format suggested by Miles and Huberman (1984: 65) and adopted simply because this researcher found it easier) and, it was recognised that any block of data would often be a candidate for more than one code (Miles and Huberman, 1984: 63) or remark. Frequently, a particular transcript paragraph drew multiple codes as it served to exemplify numerous themes at once.

From coding, then, the analysis of emergent categories commenced. Following Leonard (1989: 54) analysis commenced with (1) a thematic analysis; (2) an analysis of exemplars; and, (3) a search for paradigm cases. Being an exploratory study, concern was primarily with *emic analysis* (Sanday, 1983: 32) of the life-world of the PwICI, which involved developing a set of elementary concepts in order to describe and understand the more complex ones encountered. The primary focus of the research was constantly borne in mind: the uncovering of the story; the need to make sense of what life is like for the PwICI, as opposed to proving existing theory.

*Thematic Analysis*

All interviews were fully transcribed, manually reviewed and summarised before content analysis began (Boyle, 1994: 179) using the researcher generated categories and keywords (Minichiello et al, 1990). This interpretive content analysis sought subjectively experienced themes or 'structures of experience' (van Manen, 1990: 79) which involved uncovering thematic aspects and isolating thematic statements; and composing linguistic transformations and interpretation through conversation using lifeworld existentials as guides to reflection (van Manen, 1990: 90-101).
Thematic analysis was the primary means of synthesis of the data. This was begun with reflections on the researcher's own experiences, then the examination of transcripts, highlighting descriptive words, etymological sources and idiomatic phrases (as suggested by van Manen, 1990: 54-63). "There are four existentials that may prove especially helpful as guides for reflection in the research process: lived space (spatiality), lived body (corporeality), lived time (temporality) and lived human relation (relationality or communality)" (van Manen, 1990: 101, emphasis in the original). Analysis was approached following three interrelated interpretive processes: (1) thematic analysis, where interviews and field notes are 'read several times in order to arrive at a global analysis' (Leonard, 1989: 54), elsewhere described as 'narrative analysis' (Peterson et al, 1994: 206; Brown and Williams, 1995: 697); (2) analysis of exemplars, where specific episodes or incidents are analysed and coded: 'From this analysis come exemplars, stories or vignettes that capture the meaning of a situation in such a way that the meaning can then be recognised in another situation which might have very different objective characteristics' (Leonard, 1989: 54); and, (3) the search for paradigm cases (read exemplar cases), 'strong instances of particular patterns of meaning' (Leonard, 1989: 54). Leonard's articulation of interpretive analysis seemed particularly close to van Manen's (1990) and was specifically presented for use with Heideggerian phenomenology. Lifeworld existentials, then, were guides to reflection:

All phenomenological human science research efforts are really explorations into the structure of the human lifeworld, the lived world as experienced in everyday situations and relations. Our lived experiences and the structures of meanings (themes) in terms of which these lived experiences can be described and interpreted constitute the immense complexity of the lifeworld. And, of
course, we can even speak of the multiple and different lifeworlds that belong
to different human existences and realities (van Manen, 1990: 101).

Three analytically distinct features of language which feature simultaneously in any story:
textual, ideational and interpersonal. 'The textual refers to how parts of the texts are
internally connected via a variety of semantic and syntactic devices. The ideational refers to
the content of what is said. The interpersonal refers to the relation between speakers' (Brown
and Williams, 1995: 697). The 'emphasis was on analysis of the ideational content of the
.narratives, although as previously indicated, it was recognised that the content of interviews
is a mutual construction' (Brown and Williams, 1995: 697, emphasis added). Thematic
analysis undergone in this study required a multiple-case analysis (as opposed to single case-
study analysis) (Yin, 1989: 136). Finally, the distinction was made between essential and
incidental themes:

In determining the universal or essential quality of a theme our concern is to
discover aspects or qualities that make a phenomenon what it is and without
which the phenomenon could not be what it is. . . . In the process of
apprehending essential themes or essential relationships one asks the question:
Is this phenomenon still the same if we imaginatively change or delete this
theme from the phenomena? Does the phenomenon without this theme lose

For example, after re-reading and coding the interviews with Daphne, an ideational list of
categories for the interviews was developed (Brown and Williams, 1995: 697). Lists of
ideational themes were compared and 'themes which appeared to be common were identified' (Brown and Williams, 1995: 697). Immediately, certain themes became apparent; a useful starting point. This was repeated for each interview of the pilot study in an iterative fashion (Minichiello et al, 1990: 286) providing the ability to formulate early propositions to be followed up during the main study (see Appendix 13 - Sample Ideational Category List). This iterative, and ideational, analysis assisted with future interviews in shifting the focus of the next case, or to highlight or explain certain themes that had emerged during the analysis process.

In addition to this, the number of repeated observations of a theme (or code) was considered for use as an additional analysis tool, to give some perspective as to the value or importance that the particular respondent may attach to that category. However, 'what makes the use of repeated observations a lesser mode of analysis is that the analysis is not likely to reflect all of a case study's concerns' (Yin, 1989: 122). Using repeated observations would have been attempted as merely a supportive mechanism; another way to view the data, rather than a means in itself. However, the folly was recognised of using statistics for problems involving complex situational and emotional content (Sanday, 1983: 29). It was decided against doing 'frequency counts' (Minichiello et al, 1990: 289), or repeated observations of particular words (Yin, 1989: 122), for similar reasons: 'Sometimes, the researcher does a frequency count—seeing how many times a word (which has been designated as significant) appears in the text' (Minichiello et al, 1990: 289). Such an approach would surely have detracted from a sensitive, phenomenological study such as this.

All the mechanistic suggestions in the world may not necessarily have helped the
inexperienced researcher transform strings of sentences (raw data) into meaningful insights which contribute to knowledge. The specifics of analytic induction were proffered to help make this leap, not just to justify the theory (or in this case the model), but as a means of creating them (Minichiello et al, 1990: 286). The following steps were highlighted by Glaser and Strauss (1967) which one endeavoured to follow: (1) develop a general statement about a topic (as was the objective with the theoretical framework of Chapter Two); (2) collect data to gain a better understanding of the topic (in the form of a pilot study); (3) modify, revise and expand the statement as data are collected (which was done with early drafts of the phenomenological model in Chapters Five and Six); (4) search for cases which do not fit the explanation proffered, revising the formulation accordingly; and (5) develop a satisfactory explanation (Glaser and Strauss, 1967; Minichiello et al, 1990: 286). Research objectives were kept at hand whilst this took place. Thus, the early data collection and analysis involved the discovery of concepts and development of propositions, while the latter interview analysis focused on testing the links established between themes, assessing the validity of propositions (Minichiello et al, 1990: 288) and exploration of new themes.

Finally, some additional important points. First, it was deemed vital that the researcher understand 'the informant's use of idiom'; one needed to be careful to study 'the whole text, not only in the context of what was said, but also in terms of what was not said, and within

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In developing a phenomenological model, as opposed to a grounded theory, unique experience was incorporated into the model as a variant, rather than deviant, characteristic that did not need to be "explained away" or reviewed. Unique outcomes were valued as the experience of this unique individual in these unique circumstances; or, perhaps, recognised as being a unique (or incorrect or incomplete) interpretation by a researcher, similarly, in a unique position. The importance of locating a negative case; one that will not confirm the proposition is important (Yin, 1989: 114; Minichiello et al, 1990: 288) and is termed 'agon analysis' - the analysis of oppositions or contradictions between themes (Peterson et al, 1994: 207). This was performed but did not necessarily result in a revision of the model. This is in contrast to grounded theory development where agon analysis should be continued 'until you feel that you can no longer find a negative case which will force you to revise your proposition' (Yin, 1989: 115).
the boundaries of the paradigm the researcher chooses to apply’ (Minichiello et al, 1990: 292). It was also vital that the informants understood the questions in order to provide the information being sought. Secondly, the perspective and the necessity of correctly interpreting that perspective of the participants needed to be considered; their 'filters' of interpretation (Minichiello et al, 1990: 292) needed to be understood; it was recognised that changes in perceptions one way or the other could 'actually change the behaviour of the person we see' (Wilmot, 1975: 11). One needed to distinguish between participant concepts and theoretical concepts: 'Participant concepts are created by informants and couched in their everyday language. Theoretical concepts are created by the researcher and not immediately recognised by the informants as part of their terminology' (Minichiello et al, 1990: 291). 76

Explanation Building

Initially, and in keeping with initial thoughts of pursuing a predominantly ethnographic research methodology, it was thought that the generation of grounded theory using the methods advocated by Strauss and Corbin (1990) (as opposed to Glaser and Strauss, 1967) would be most appropriate. However, the development of a complete and integrated theory (Stern, 1994: 216-217) from an exploratory study such as this seemed premature and

76 The importance of this was discovered during the early interviews when questioning respondents about their coping strategies. When asked, for example, what 'coping strategies' were used (Kasl, 1981: 65; Dewe, 1989: 1009; Miller, 1992b: 19; Koeske et al, 1993: 319; Callan and Terry, 1994: 39), a term used frequently in the literature, respondents were frequently uncertain as to how to respond. The question was later reframed in terms of how the respondents manage with having an illness and going to work; what things they did (or didn’t do) to make life easier. These reframed questions were more successful in eliciting the information sought.

77 The author became increasingly aware of the differences between the methods purported to be grounded theory. Stern (1994: 213) referred, for example, to the methodological differences between Glaser and Strauss's work, who originally, jointly, developed the methodology described in their book The Discovery of Grounded Theory (1967). The separate approaches are now referred to as grounded theory (for the Glaserian school) and conceptual description for the Strassian school (Stern, 1994: 213). This, of course, does not cover the myriad of unclassified approaches taken by numerous researchers that may correctly, or incorrectly, be identified as grounded theory; a point also underscored by Stern (1994: 212).
ambitious. Subsequent review of literature (Leonard, 1989: 53-55; van Manen, 1990; Peterson et al, 1994) proposed the benefits of interpretive thematic analysis which seemed in keeping with the aims of this Heideggerian phenomenological multiple-case study such as this: 'In a multiple-case study, one goal is to build a general explanation that fits each of the individual cases, even though the cases will vary in their details' (Yin, 1989: 114).

Explanation building (Yin, 1989: 113; Sarantakos, 1993: 263) commenced from coding, thematic analysis and initial (albeit speculative) propositions about the data emerging. These propositions, explanations and possible linkages were documented in 'theoretical memos' about the data. The need to think about the data, its connections and general meaning and sense was endorsed, and the use of conceptual memos was suggested, not just to report the data, but to cluster different pieces of data or to show that a particular piece of data was an instance of a general concept (Miles and Huberman, 1984: 69). These notes can be written when: data is intensely puzzling or surprising; data may indicate an alternative hypothesis to previous ideas; to propose a specific new pattern code; to integrate a set of marginal or reflective remarks; to clarify concepts that the researcher does not clearly have in mind but is struggling to understand; or, when a general metaphor is used to organise discrete observations (Miles and Huberman, 1984: 71). These were made in the early stages on tape and, later, in a notebook kept handy at all times during analysis.

The process of building explanations from transcribed, coded data is called sifting: a 'process that shakes off the insignificant "noise" from the aggregate stories, leaving only the common but important features' (Morse, 1994b: 31) and may be achieved through use of a computer program, "cutting and pasting" in word processing documents or by hand. Typologising
(Minichiello et al., 1990: 304) was also used to help understand phenomena better by grouping ideas to form 'ideal types' (Freund, 1966/1972: 60; Minichiello et al., 1990: 304; Beilharz, 1991: 226; Sarantakos, 1993: 303; Leivesley et al., 1994: 42; Cohen, 1996: 113), a notion first evolved by Max Weber to give complex social "realities" a clarity in establishing causality for the purposes of research and understanding (Freund, 1966/1972: 60), to help make sense of complex ideas (Minichiello et al., 1990: 304) and social processes, a 'type-made-up-of-ideas, those ideas which are salient through their value-relevance to the heuristic enterprise at hand' (Leivesley et al., 1994: 42). This synthesising (Morse, 1994b: 30), 'pattern

78 The notion of Weber's 'ideal type' (Weber, 1921: cited in Cohen, 1996: 113; Freund, 1966/1972: 59) requires further comment. Indeed, it was this researcher's experience that not only was the notion of the ideal type referred to, at times, without any reference to Weber (for example, Minichiello et al., 1990: 304) or with his name mentioned seemingly in passing (for example, Sarantakos, 1993: 303), but that there was much inconsistency and incongruity in the suggested usage and explication of the notion, especially when considering qualitative research practices. Weber's ideal typologising was useful to this research process, even given what have been described as shortcomings in his theory (Freund, 1966/1972: 70) or, perhaps, it is that 'the sweep of Weber's methodological thought is broad and not systematically complete' (Leivesley et al., 1994: 42). Building the phenomenological model required some synthesis of the stories and, whilst eschewing generalisation as Weber has advocated (Freund, 1966/1972: 61), there was an awareness that 'the individualizing method does not exclude the generalizing method' (Freund, 1966/1972: 62) whilst, also, not subsuming the originality and uniqueness in the stories. The development was the result of the researcher's endeavour to construct a 'one-sided accentuation of one or more points of view' which necessarily comprised 'the synthesis of a great many diffuse, discrete, more or less present and occasionally absent concrete individual phenomena, which [were] arranged according to those one-sidedly emphasized viewpoints into a unified analytical construct' (Shils and Finch, 1949: 1; cited in Freund, 1966/1972: 60).

What was also regarded of importance here was Weber's insistence that interpretive sociology begin with the individual (Bendix and Roth, 1980: 114-116; cited in Leivesley et al., 1994: 42). It is used, as Weber intended, to formulate a 'unique piece of reality' (Freund, 1966/1972: 61) for the purposes of research. The phenomenological model presented in chapters Five and Six is one-sided; it is subjective, it is phenomenological: 'we must understand Weber's definition of the ideal type, in which he speaks of accentuation or one-sidedly emphasized viewpoints according to which the traits and characteristics of individual phenomena are arranged in a unified analytical construct' (Freund, 1966/1972: 62). It attempts to make some sense of what 'would otherwise seem incoherent and chaotic' (Freund, 1966/1972: 63) whilst acknowledging that it remains fragmented (Freund, 1966/1972: 64).

79 There are some aspects of Weber's typologising that this author finds less useful for this particular research project. First, the ideal type 'seeks perfection of a logical, not a moral, order and it excludes all value judgements' (Freund, 1966/1972: 64). The practice of bracketing or suspending of value judgements has been avoided in this Heideggerian phenomenological study for reasons detailed in Chapter Three.

Secondly, whilst Weber's rationalisation is not a notion of the rationality of history 'which professedly directs human evolution on a course of universal progress culminating in a sort of least of reason, in the sense of a flowering of true justice, genuine virtue, equality, peace. It is, rather, the product of scientific specialization and technical differentiation peculiar to Western culture... a striving for perfection... an ingenious refinement
matching\(^6\) (Yin, 1989: 109; 1991; Sarantakos, 1993: 263), 'typological analysis' (Sarantakos, 1993: 210) or development of typologies was used effectively, incorporating 'the merging of several stories, experiences or cases to describe a typical, composite pattern of behaviour or response\(^8^1\). It is the ability of the researcher to merge several stories or cases to describe the typical patterns or behaviours or responses of the group. Synthesising is the 'sifting' part of the analysis--of weeding the significant from the insignificant--and it begins when the investigator is "getting a feel" for the setting' (Morse, 1994b: 30). It was the synthesising and sifting processes that helped build the categories, explanations and, ultimately, the phenomenological model presented in subsequent chapters.

Several things assisted with theorising (read explanation building): avoid premature closure; ask questions of the data to create links to established theory; examine similar concepts in other settings; develop the explanations (or theory) incrementally and check out hunches in the interviews; and, allow informants to verify or refute (Morse, 1994b: 33-34). One was always conscious that the original intention of this study was one of hermeneutic analysis.

\(^6\) of the conduct of life and the attainment of increasing mastery over the external world' (Freud, 1966/1972: 18) and, thus, it remains a methodology 'that was at once empirical and evaluative, one which emphasised the value-bound problem choices of the investigator and the value-neutral methods of research' (Leivesley et al., 1994: 49). Heideggerian phenomenology can never be a value-neutral method and the reductionism peculiar to Western culture and valued in Weber's approach has also been avoided in this project, as argued in Chapter One.

\(^8^1\) The only problem with using 'pattern matching' (Yin, 1989: 109; Sarantakos, 1993: 263) in this analysis was that it is generally used in conjunction with patterns of behaviour that have been observed by the researcher. Thus, any pattern matching employed here was based on the stories shared by respondents, rather than direct observation by the researcher.

\(^8^2\) The incompleteness of Weber's theory has given rise to much confusion and distortion of his intentions of the 'ideal type' (Leivesley et al., 1994: 43). Without being drawn deeply into debate, this use of the word 'typical' here seems to give one example where the origins of Weber's 'ideal type' may be distorted. Freud (1966/1972: 64) argued that 'the ideal type is not to be identified with reality in the sense of expressing reality's "true" essence. On the contrary, precisely because it is unreal and takes us a step away from reality, it enables us to obtain a better intellectual and scientific grasp of reality, although necessarily a fragmented one. . . . The ideal type is not intended to be in any way exemplary and must not be confused with an ethical model or even with a practical rule of conduct.' Clearly, it was not Weber's original intention to use the ideal type to create exemplar models as Morse (1994b: 30) seems to be suggesting.
One remained conscious that:

The concern of Heidegger's hermeneutic is to uncover the hidden phenomena and, particularly, their meanings. As with eidetic phenomenology, hermeneutics presupposes that what is to be interpreted has meaning. Yet the aim of hermeneutic phenomenology is different and more ambitious than eidetic phenomenology. Hermeneutic's goal is discover of meaning that is not immediately manifest to our intuiting, analysing and describing. Interpreters have to go beyond what is given directly. Yet, in attempting this, they have to use the ordinary, everyday given as a clue for meanings that are not given, at least not explicitly (Cohen and Omery, 1994: 146)

The focus of this hermeneutic tradition then was used here 'to empathically grasp the minds of others, the subjective meaning of their behaviours; that is, using verstehen or empathic understanding' (Minichiello et al, 1990: 291, emphasis in the original).

Finally, analysis of exemplars (Leonard, 1989: 54) was another useful interpretive process: specific stories, vignettes and soliloquies are found throughout the model to exemplify the explanation. Chapters Five and Six demonstrate the use of exemplar soliloquies to vivify various themes in the model.  

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82 Paradigm cases (in-depth exemplars) were used extensively by Lawson (1987: 254) to demonstrate a particular phenomenon. In endeavouring to develop a phenomenological model, the singling out of paradigm cases was avoided. It was preferred, instead, to build explanations and cite examples during analysis. However, writing efforts outside this work have made use of this technique, for example, Vickers (1996b) used a paradigm case to introduce the notion of workplace stigma for PwI/CI.
Participant Response to the Research Process

All respondents were routinely asked at the conclusion of the second interview how they felt about the research process and what their experience had been. Most indicated that the process had been, on balance, a favourable one, with altruistic reasons frequently proffered as reasons for giving of their time (and valuable energy) in participating and sharing such closely held information with a complete stranger, as was the feeling of not being alone in the struggle:

Shelley: I guess it could help somebody else down the track. It’s, well, I guess in a lot of ways, like mum and I were speaking as well, that you sort of, I think in a lot of ways it makes you aware that "Yes. You’re not on your own". That there are a lot of people out there. You probably don’t even know yourself. I could have passed you in the street and wouldn’t have even known. So, in that respect you think, "Hey yeah, there are other people in this same situation that have to mask everything and carry on with life as if you’re normal".

MV: Whatever that is.

Shelley: Whatever that is! [laughter] (Shelley, #2: 14).

It is acknowledged that respondents gave a great deal personally and emotionally to this research process.

Limitations of Study

Below are listed some potential limitations of this study. Explanations have not been repeated when the issue has been discussed earlier in this, or the previous, chapters.

1. Use of primarily one source of data versus multiple sources of data (Yin, 1989);
2. Investigator bias and intimacy with subject under study (Field and Morse, 1985: 119; Swanson-Kauffman, 1986: 69; Dreher, 1994: 286);

3. Researcher inexperience (Swanson-Kauffman, 1986);

4. Dangers of combining methods (Swanson-Kauffman, 1986; Baker et al, 1992; Dreher, 1994; Stern, 1994);

5. Use of primarily verbal interview data (including problems of informant memory, temporal effects, including the informant ability to articulate their experiences and feelings (Fodd, 1993)); as well as the problem of meaning creation by the interpreter. Barthes (1967; cited in Appignanesi and Garratt, 1995: 74) sensational proclamation of the 'death of the author' referred to the idea that readers of text create their own meanings, regardless of the author's intention. The same problem applies with researcher interpretation.

Chapters Five and Six meld the themes, concepts and explanations discussed into a phenomenological model of Life and Work for People with "Invisible" Chronic Illness, using the philosophy and methodological processes described in this chapter and analysed previously.
CHAPTER FIVE

Life and Work with "Invisible" Chronic Illness (ICI): Authentic Stories of a Passage Through Trauma

Well, it is four months and one day since Michael's seizure. All this time and yet this is the first time I have had the courage to put finger to keyboard on this particular subject. Whilst I am embroiled in the lives and trauma experienced by PwICI in organisational life, my own husband has a very public, very lengthy, very serious brain seizure - at the office for all to see. That single event has changed every aspect of our individual and collective lives forever.

For Michael, the passage has been swift and cruel. For us both, the trauma remains

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82 The author addresses herself, once again, to the arduous and risky task of being an 'authentic writer' (Jourard, 1971: 58-59) believing it would be irresponsible not to equip the reader with some modicum of understanding as to what was transpiring in the life of the researcher performing the analysis, description and interpretation of participant's stories. The importance of explicating the researcher's perspective (Oiler, 1982: 181; Swanson-Kauffman and Schonwald, 1988: 103) is recalled; that the researcher's experiences are data (Drew, 1989: 431; Osborne, 1990: 83) as they influence outcomes (Drew, 1989: 431). This was notably the case during this research and, in keeping with the philosophy of Heideggerian phenomenology (see Chapter Three), there has been no attempt during the development of the phenomenological model to "bracket" personal experiences or the insights available from the literature. Indeed, you will see either or both referred to as often as is necessary to make sense of the stories under review and, especially, when events impinging on my own life seemed relevant.

84 It is important that the reader also note that each journal entry placement has been a deliberate and careful choice to parallel the chronological series of events that took place whilst concurrently creating this work. The Prologue was written before methodological decisions were made, being a record of the decision point for following the "invisibility" theme. It was certainly written prior to the unfolding of tumultuous events recorded here, hence its placement as a Prologue. Commentary about the first meeting with June and Shelley was made early during the pilot study and, thus, was deliberately placed at the head of the research design chapter. Michael's seizure took place after the pilot study interviews had been completed, but prior to the main study commencing. The researcher was, literally, embroiled in the trauma of others through early transcript analysis when this personal, illness-related crisis unfolded. Personal commentary heading the next two chapters and finishing with the Epilogue have been, similarly, carefully chosen and placed to reflect the researcher's "voice" during times of work-in-progress.
unending: endless medical consultations, medical tests, fears for the immediate future and beyond. Our past lives a fond memory as we struggle to embrace what the future holds, and with what? Our communication patterns, our relationship of old, our plans for the future, our financial security, the security of hearth and home; decimated in a single afternoon, never to be relied upon as before.

Michael has not returned to work and if no miracle is bestowed upon us shortly, is unlikely ever to do so. He remains cognitively impaired - memory problems; speech difficulties; reading, writing and comprehension difficulties that have left him confused and uncertain about his place in his world. In addition to this, over the past week Michael has become somewhat clumsy and is staggering as he walks: signs of further neurological disease. His anti-convulsive medication has been increased due to recent petite-mal episodes, indicative of another impending seizure, as has the Prednisone, which is supposed to control disease progress. We are uncertain what is wrong with him; the medication appears to being having little effect; the future is bleak. The most likely diagnosis (unconfirmed) is neuro-sarcoidosis. Sarcoidosis is a systemic disease and a potentially life-threatening one. Michael’s story will be told another time.

For now, I return to the fray: sadder, tougher and surer than ever that the stories of my informants must be told. If what we, and so many like us, are enduring is not a crisis to be recognised, a story worth telling, a situation worthy of some societal and organisational compassion, I must wonder, what is? (Vickers, 1996d).
The Research Participants: A Brief Biography

Prior to describing the first sector of the phenomenological model, each of the research participants has been introduced to allow a better understanding of the stories and the interpretations that follow. These biographies have been constructed using the demographic details collected prior to interviews and are most certainly not intended to "pigeonhole" anyone. Details were correct at the time of interview and, naturally, pseudonyms have been used to protect the anonymity of participants.

Daphne

Daphne is a 39 year old married woman, of Greek descent, born in Egypt. Daphne was diagnosed with multiple sclerosis (MS) in May 1995, although she recalled that her first MS symptoms were some 8 years earlier. Daphne has not told her mother, father, mother-in-law or two of her sisters about having MS. Daphne has a technical college certificate and earns between $A50K and $A75K as a middle manager in the computing industry. She works long hours, with 60-70 hour weeks being reported at the time of her first MS episode. When the researcher met with Daphne at her office and at the conclusion of each of the interviews (around 7.30 - 8.00 pm) she preferred not to leave the office, still having some work to finish off before going home.

---

Multiple sclerosis (MS) is an unpredictable neurological disorder (Scheinberg, 1987: 2); a chronic, and sometimes disabling, disease (Scheinberg, 1987: 1) "in which the insulation surrounding nerve fibers of the central nervous system (the brain and spinal chord) is damaged" (Whitaker, 1987: 13). The presence of this insulation (called myelin) reduces leakage of "current" (electrical impulses) along nerve fibres. When the myelin sheath is damaged, transmission of messages along these nerve fibres may be delayed or cease completely (Whitaker, 1987: 14). "As the myelin is damaged, certain other cells proliferate and form dense tissue at the site of damage. This proliferation causes a firmness of the tissue (sclerosis) . . . The loss of myelin, the sclerosis, and the fact that the lesions (often referred to as plaques) occur in many sites throughout the CNS (Central Nervous System) account for the name "multiple" or "disseminated" sclerosis" (Whitaker, 1987: 14).
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Shelley

Shelley is a childcare assistant. Aged 25 years old, she is a single, English woman earning less than $A25K per annum. Shelley has acute lymphoblastic leukemia. She was diagnosed with this in July 1986 when aged only fifteen. Shelley has a visual arts degree already and is currently working full-time whilst studying psychology part-time. She hopes to go on and do a Master’s degree. It has also been relayed to the researcher since the interviews (via the intermediary) that Shelley is engaged to be married.

June

June is a 47 year old English woman who works as a social worker at a hospital in the Western Sydney district. She has a Technical College Certificate, earning between $A25K and $A50K. June was diagnosed with glaucoma in 1985, a condition which adversely affects the pressure in the eye, ultimately causing blindness. In addition to this, June has dealt several other traumatic blows in her life: not only does her daughter Shelley (above) have leukemia, but her husband was quite recently and senselessly murdered. June has endured numerous surgical procedures in efforts to remedy her eye problems although without long-term success.

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*Leukemia* is defined as 'any of a group of malignant diseases in which the bone marrow and other blood-forming organs produce increased numbers of certain types of white blood cells (leucocytes). Overproduction of these white cells, which are immature or abnormal forms, suppresses the production of normal white cells, red cells and platelets. This leads to increased susceptibility to infection...anemia and bleeding. ... Other symptoms include enlargement of the spleen, liver and lymph nodes. Leukemias are classified into acute or chronic varieties depending on the rate of progression of the disease. They are also classified according to the type of white cell that is proliferating abnormally' (Martin, 1990: 387). In Shelley's case, her leukemia is characterised as being acute, with an overproduction of lymphoblasts (abnormal cells in the blood).

*Glaucoma* is 'a condition in which loss of vision occurs because of an abnormally high pressure in the eye... In all types of glaucoma, the eventual problem is to reduce the intraocular pressure. Drops are put into the eye at regular intervals to improve the outflow of aqueous humour from the eye, and drops and tablets (diuretics) are used to reduce the production of aqueous humour. If this treatment is inadequate, surgery may be performed to make an accessory channel through which the aqueous humour may drain from the eye in sufficient quantities to allow the pressure to return to normal' (Martin, 1990: 287).
Rodney

Rodney is a 34 year old married, English man. He has a professional post-graduate accounting qualification and earns between $A100K and $A125K in the private banking sector. Rodney was diagnosed with spondylolisthesis\textsuperscript{88} eight months prior to the interview. Rodney reported having chronic back problems for at least eight months prior to this diagnosis due, in some part, to poor lifting technique and injuries sustained whilst working around the house. Rodney commented during our first conversation, and again during the first interview, that he didn't think we would have much to talk about.

Linda

Linda is a married, Australian woman, aged 28 years. She completed high school and now earns between $A25K and $A50K working in the private banking sector as a computer applications engineer. Linda is a regular gym goer who doesn't drink or smoke. Linda was diagnosed with breast cancer\textsuperscript{89} in May 1994, necessitating the entire removal of her breast (a full mastectomy). She was subsequently treated with chemotherapy. Subsequent metastasis\textsuperscript{89} in her sternum (breast bone) approximately six months after the mastectomy necessitated a course of radiotherapy. At the time of our interview, Linda had not gone twelve cancer-free

\textsuperscript{88}Spondylolisthesis is 'a forward shift of one vertebrae upon another, due to a defect of the joints that normally bind them together. This may be congenital or develop after injury. The majority of cases in which pain is present are treated with rest and a surgical belt or corset; in a small minority, showing severe disability of pressure on nerve roots, surgical fusion may be required' (Martin, 1990: 654).

\textsuperscript{89}Breast cancer is the commonest form of cancer in women and involves a malignant tumour: 'The classic sign is a lump in the breast, which is often noticed after minor local injury... The tumour may also spread to the bones, lungs and liver' (Martin, 1990: 87).

\textsuperscript{89}Metastasis is 'the distant spread of malignant tumour from its site of origin. This occurs by three main routes: (1) through the bloodstream; (2) through the lymphatic system; and, (3) across body cavities, for example, through the peritoneum. Highly malignant tumours have a greater potential for metastasis' (Martin, 1990: 426).
months since finding a lump in her breast.

Maryanne

Maryanne is a 35 year old single, Australian woman, living with her mother. She is currently completing a postgraduate qualification at the University of Technology, Sydney and earns between $A25K and $A50K. She is employed as a Liaison Officer for a charitable institution, where she has been working for the past eight years. Her position is one involving multiple administrative and public relations functions, including working with volunteers for the organisation. Maryanne has endometriosis\(^1\) and interstitial cystitis\(^2\). Maryanne was the only participant who volunteered when hearing of my work, rather than being "recruited" through an intermediary.

Rosalie

Rosalie is an articulate, 48 year old, married Australian woman with three children, all living at home. She has a Master’s degree and is in partnership with another woman in a consulting/training business, doing much of her work from home. Rosalie has chronic fatigue

\(^1\)Endometriosis can be an extremely painful ICI affecting women (Donoghue and Siegel, 1992: 13). It is characterised by the presence of tissue similar to the lining of the uterus (endometrium) at other sites in the pelvis. . . . The tissue may also be found in the ovary, fallopian tubes, pelvic ligaments, on the pelvic peritoneum, and even in the cervix and the vagina. This tissue undergoes the periodic changes similar to those of the endometrium and causes pelvic pain and severe dysmenorrhoea. The pain continues throughout and after menstruation. . . . The formation of pelvic adhesions is a common sequel to endometriosis’ (Martin, 1990: 226). 

\(^2\)Like the lining of the uterus, endometrial growths usually respond to the hormones of the menstrual cycle. They build up tissue each month, break down and cause bleeding. However, unlike the lining of the uterus, endometrial tissue outside the uterus has no way of leaving the body. The result is internal bleeding, degeneration of the blood and tissue shed from the growths, inflammation of the surrounding areas, and formation of scar tissue’ (Endometriosis Association, 1992: 1). Endometriosis may also be regarded as a "woman’s problem" and, as such, is not widely nor comfortably discussed (Vickers, 1996b; in press).

\(^*\)Interstitial cystitis is a chronic, non-bacterial inflammation of the bladder of unknown cause (Martin, 1990: 357). It is an extremely painful and uncommon bladder condition, often producing very disabling symptoms including severe frequency, dysuria (pain, burning or stinging during urination) and lower abdominal and urethral pain. It may affect women or men.
syndrome (CFS)\textsuperscript{93} (or myalgic encephalomyelitis (ME))\textsuperscript{94}, as has her daughter, and has been plagued by constant malaise, and fatigue, since the beginning of 1993. She earns between $25K and $50K.

\textit{Shirley}

Shirley is another of the participants with more than one ICI. Shirley has endometriosis, lipodystrophy\textsuperscript{95}, a hearing impairment and a learning disability. She lives with her mother who also is profoundly deaf and a kidney dialysis patient, requiring dialysis nursing on a

\textsuperscript{93}Chronic fatigue syndrome (CFS), or myalgic encephalomyelitis (ME), is a condition characterised by muscular fatigue and pain, lack of concentration, memory loss and exhaustion (Martin, 1990: 447). There has been more than a passing suggestion in the literature that CFS is psychosomatic (Conant, 1990: 18; Blake, 1993a: 26), related to depression or to psychiatric disorders (Manu, 1992: 71; Price et al, 1992: 514). It is posited here that such an assumption is made because no "scientific" test currently exists to definitively validate the presence or absence of this disorder. The question also remains unresolved as to whether the disease is associated with depressive disorders in the first instance or whether the depression associated with CFS follows the illness experience, including scepticism received. Where the a priori assumption is made that CFS is psycho-somatic, the assumption may follow that CFS only affects neurotics, hypochondriacs and malingerers. Women, substance abusers and the depressed all become likely candidates: 'Despite the prevalence of ME today, its causes and even its authenticity remain in question by health professionals and the general public. What cannot be questioned is the profound impact it has on the lives of those who suffer from it' (Blake, 1993a: 28). It is not my place, nor intention, to question the authenticity of this condition.

\textsuperscript{94}David Bell exaggerates little referring to CFS as 'The Disease of a Thousand Names' (1991; cited in Blake, 1993a: 26). CFS was initially defined in the \textit{Annals of Internal Medicine} in March 1988 (Holmes et al, 1988; cited in Conant, 1990: 2). Prior to the 1988 definition, sufferers of CFS were frequently, and erroneously, diagnosed with Chronic Epstein-Barr Virus (CEBV) (Conant, 1990: 2) perhaps due to the fact that CFS sufferers had elevated titres (antibodies) to the Epstein-Barr virus (Blake, 1993a: 25). Conant (1990: 4) listed other possibilities: 'chronic mononuclear illness, chronic epstein-barr virus syndrome (CEBV), chronic fatigue and immune dysfunction syndrome (CFIDS), chronic viral syndrome, chronic epstein-barr-like syndrome, and post-viral fatigue syndrome' (Conant, 1990: 4). Two other common labels for the illness are: myalgic encephalomyelitis (ME) and "yuppie flu". The label appears to be culturally determined, for example, in the United States the illness is called CFS, whereas in the United Kingdom and Canada ME is more common (Blake, 1993a: 25). In Australia, we can't seem to make up our minds: the 1994 \textit{White Pages} lists the support society as "M.E./CHRONIC FATIGUE SYNDROME SOCIETY OF NSW " (p. 1812), whilst the \textit{Australian Doctor} wrote specifically about CFS (Bisset, 1995: 1).

\textsuperscript{95}Lipodystrophy is another very rare chronic condition. It is a more "visible" chronic condition, as opposed to the numerous ICIs described here, in that some evidence of the condition can be seen just by looking at that individual. However, it was included here because Shirley lives with it in conjunction with three other ICIs and because it is not a condition that would be obvious to the uneducated observer. Lipodystrophy involves any disturbance of fat metabolism or fat distribution in the body (Martin, 1990: 391); an 'abnormality in the metabolism or deposition of fats' (Anderson et al, 1994: 915). In Shirley's case, she has a thinner upper body, with greater deposits of fat on her buttocks and legs. However, given that this tendency of fat distribution is not unusual for women, this observer wouldn't have noticed the problem unless it had been pointed out.
regular basis from Shirley. Shirley has been employed full-time in the public service for the
past ten years and also works a weekend job as well. Shirley is Australian, earning between
$A25K and $A50K. She is 41 years of age. Shirley faces the possibility of an unwelcome
hysterectomy (in response to the endometriosis) and of her impaired hearing deteriorating to
a profound deafness, as has been the case with her mother.

Beverley

Beverley is also aged 41 and is an Australian, single mother living with her two daughters.
She has a postgraduate university qualification and earns between $A50K and $A75K in the
public sector. She has been with her current employer for the past three years and during that
time was diagnosed with multiple sclerosis. Her diagnosis followed a particularly stressful
period in her life: she left her husband and moved from the country to Sydney to find a new
home, and life, for herself and her daughters.

Fred

Fred is a 54 year old Italian man. He completed high school and works as a sales
representative earning between $A25K and $A50K. He has been with his current employer
for six years. Fred was (eventually) diagnosed with a malignant tumour in his lung in
October of 1991, after a somewhat protracted diagnostic process. Fred also has a slipped disc
in his spine causing him a great deal of pain. Fred is divorced and lives alone.

This author finds the commonly held notion of malingerer in association with ICI offensive, especially when
meeting someone like Shirley, with her four chronic conditions, two jobs and a very sick mother to care for.
Other authors seem similarly offended: Yelin (1986: 623-624) described 'The myth of malingerer'; Falvo and
colleagues (1982: 3-4) described a lack of social validation for ICI and the associated perception of malingerer
(1982: 5); and Conant (1990) devoted an entire chapter to 'Fighters and Maligners' in an effort to improve
understanding.
<table>
<thead>
<tr>
<th>Name</th>
<th>ICI(s)</th>
<th>Job</th>
<th>Ethnicity</th>
<th>Age</th>
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<tbody>
<tr>
<td>Daphne</td>
<td>Multiple Sclerosis</td>
<td>Senior Project Manager, Computing Applications</td>
<td>Greek</td>
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<tr>
<td>Shelley</td>
<td>Acute Lymphoblastic Leukemia</td>
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<td>June</td>
<td>Glaucoma</td>
<td>Social Worker</td>
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<td>Rodney</td>
<td>Spondylolisthesis</td>
<td>Senior Financial Accountant</td>
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<tr>
<td>Linda</td>
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<td>Computer Applications Programmer/Analyst</td>
<td>Australian</td>
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<tr>
<td>Maryanne</td>
<td>Endometriosis; Interstitial Cystitis</td>
<td>Liaison Officer for a Charitable Institution</td>
<td>Australian</td>
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<tr>
<td>Rosalie</td>
<td>Chronic Fatigue Syndrome</td>
<td>Self-Employed; Education and Consulting Services</td>
<td>Australian</td>
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<tr>
<td>Shirley</td>
<td>Endometriosis; Lipodystrophy; Hearing Impairment; Learning Disability</td>
<td>Administration Officer with Public Sector</td>
<td>Australian</td>
<td>41</td>
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<tr>
<td>Beverley</td>
<td>Multiple Sclerosis</td>
<td>Senior Manager with Public Sector</td>
<td>Australian</td>
<td>41</td>
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<tr>
<td>Fred</td>
<td>Lung Cancer; Slipped Disc</td>
<td>Sales Representative</td>
<td>Italian</td>
<td>54</td>
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**Table 1: Summary of Participant’s Details**

*Note:* Job titles have been varied so as to further protect the confidentiality of informants. It was endeavoured to use titles that have captured the essence of the work involved, striving for accuracy in impression.
What follows is the story of life and work with ICI, as reported by these ten participants.\textsuperscript{97}

**A Journey - From Crisis to Chronicity**

One generally thinks of a journey in terms of getting from point A to point B: a simple linear progression with an end point. This journey is different: it is characterised by its iterative nature; by its turbulence; by its uncertainty; and by the fact that it may never end for that person. Chronic illness is, in many cases, a long journey: its consequences and limitations reinforced with every exacerbation and remission.\textsuperscript{98} It is what Glaser and Strauss (1971: 15) have described as an 'inevitable passage': one that may be 'nonreversible' (Glaser and Strauss, 1971: 14) and, like other significant passages of status, has the properties of centrality in the life of the bearer (Glaser and Strauss, 1971: 4-5). It is frequently an 'undesirable passage' (Glaser and Strauss, 1971: 113) which may demoralise, stigmatise and affect other passages (for example career paths) in that person's life (Glaser and Strauss, 1971: 114-115). The review begins with what the author has ascertained to be "the beginning".\textsuperscript{99}

\textsuperscript{97}Many of the themes that follow encompass both the "work-world" of PwICl and other aspects of their lives. One of the important early observations made was that when interviewing PwICl and asking them about their work-lives, it was clear that they do not draw an arbitrary line encircling, and separating, their work from the rest of their lives. This was also noted by Burgess-Limerick in her PhD study of women who own-manage small businesses. She described the 'work-home mesh' (1993: 360) and 'boundaryless lives' (1995: 97). It seems that PwICl simply reported their lives as they were lived: a rich melange encompassing work and non-work activities and relationships.

\textsuperscript{98}It seems imperative to warn the reader that not only do PwICl endure a 'passage of trauma' (Vickers, 1997a), but that the reader may embark on a similar passage when undertaking to read the following model. The author acknowledges her supervisor, Professor Alexander Konzmin, for pointing out that an apparent insensitivity to the voices of respondents may have been as a result of defence mechanisms unconsciously employed; of "blocking out" lives of pain; of not wanting to absorb fully the experiences recounted here. This discussion is continued in this chapter.

\textsuperscript{99}Curtin and Lubkin (1990: 4) argued that the time and origin of the disease process is debatable. It is suggested here that, just as disease origins and timing are debatable (whether it be when the first cancer cell divides, as opposed to when it is diagnosed ten years later), the commencement point of the "journey" must also be debatable. Initial thoughts found "the beginning" to be at the point of diagnosis. Deeper reflection led to
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<th><strong>A Journey - From Crisis to Chronicity</strong> (Chapter 5)</th>
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<td>Initial Symptoms</td>
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<td>The Diagnostic Process</td>
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<td>The Shock of Discovery</td>
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<td>Expectations of Colleagues</td>
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<th><strong>Themes of Survival (Chapter 6)</strong></th>
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<th><strong>Themes of Optimism (Chapter 6)</strong></th>
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<td>Self Changes</td>
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Table 2: The Phenomenological Model

A firm rejection of such a positivist, medicalised notion. From the stories heard and the one the researcher lives, the journey frequently begins well before diagnosis. As a phenomenological researcher trying to understand meaning in lived experience one must not trivialise the essential clarity with which those first symptoms were repeatedly described to me. When asking respondents to "start from the beginning" this is where they started.
Initial Symptoms

All participants were able to recount the beginning of their particular journey, regardless of whether their journey began days, months or years earlier. When asked simply 'What happened?' all began with the point where an initial problem or symptom was experienced. These recollections were easily and clearly recalled, with responses usually complete with timings, approximate dates and periods of time involved indicating the significance of that moment for the respondent. It is this moment, as described by respondents, that was considered to mark the beginning of the changed life (Sheehy, 1974: 3); the beginning of the often undesirable status passage (Glaser and Strauss, 1971: 113), maybe resulting in a downward shift in social mobility (Goffman, 1969: 31) or 'individual downward mobility' (Horton and Hunt, 1972: 278); the beginning of a life with stigma (Goffman, 1961; 1963; 1974a; Becker, 1963; Scott, 1974; Leonard et al, 1989; Saylor, 1990; Goldin, 1994; Jacoby, 1994; Susman, 1994; Milburn, 1996); and, as with other loss of social status or threatened loss, can be very unsettling (Horton and Hunt, 1972: 498). It is this author's contention that this passage begins with initial symptoms, rather than at the time of diagnosis, signalling many of the life changes that present with inexplicable symptomatology. As Sheehy (1974: 3) explained, the speed of the change can be felt in an instant: 'Up to that moment in my life I thought everything could be mended'. Rodney (#1: 3) described his encounter with a heavy bag of cement, which ultimately left him with acute, incapacitating pain for many days and subsequent chronic back problems; Fred (#1: 3) described pains in his right shoulder and a shooting pain down his right arm that wouldn't go away; the moment Linda found the lump in her breast signalled a swift, irrevocable change in her life:

Linda: In May 1994, I was having a shower and I felt a lump under my nipple. I showed
it to my husband and asked him what did he think about it and he said "I'd go to the doctor" and I thought, "Oh no, I'll leave it a week and see if it gets any smaller or goes away." And of course it didn't... So I went to the doctor's, but I thought, I really wasn't thinking breast cancer. I just thought [it was] a cyst or something (Linda, #1: 1).\textsuperscript{100}

The Diagnostic Process

Following the "beginning", heralded by initial symptoms, a diagnosis may frequently be sought by PwI to allay fears (Johnson, 1991: 13) or to solve the problem. The diagnosis thus marks the 'discovering of the status passage' (Glaser and Strauss, 1971: 83, my emphasis), rather than the commencement of it. The diagnostic process has powerful outcomes for the PwI. The power of a social label (White, 1982: 126) cannot be underestimated: the medical profession have first claim to labelling the illness (Veatch, 1981; Turner, 1987: 73) - a label which may be one of deviance (Becker, 1963; Nijhof, 1995: 200); which may amplify deviance (Lindesmith and Strauss, 1968: 400; Turner, 1987: 73); which may go towards constituting the social identities of people and in doing so becomes part of the maintenance of relations of dominance and social control (Parsons, 1951: 206; Liggett, 1988: 265; Turner, 1987: 61; Helman, 1990); which may define the person rather than one small part of them (Christenson, 1992); which may become a means of ostracising from the group those that are different (Gething, 1984); and, which may be culturally determined (Mechanic, 1981; Becker and Rosenstock, 1984; Turner, 1987: 54; Helman, 1990: 270; Wang, 1992; Hooijberg et al, 1994: 385; Curtin and Lubkin, 1990: 12) and identified (Helman, 1990: 270). It gives permission to the sick person to adopt the Parsonian 'sick role' (Parsons, 1951; Lambert and Lambert, 1979: 2; Mechanic, 1981; Falvo et al, 1982: 5; Becker and Rosenstock, 1984; Harrison, 1984; Yelin, 1986: 623-624; Lubkin, 1990: 53; Morse and Johnson, 1991: 2;

\textsuperscript{100}The notation of (alias, interview #: page #) has been followed for citations from transcripts.
Ford, 1992: 338) or, more appropriately, the 'impaired role' (Lubkin, 1990: 47; Curtin and Lubkin, 1990: 13) and the diagnosis also allows the sick person to name and validate their illness, and not feel they are neurotic or crazy (Register, 1987: 3).

However, coming to the diagnosis is rarely as simple as seeing the doctor, explaining the symptoms and leaving with a firm diagnosis, despite traditional Western objectivist (Kvale, 1994: 153; Brown and Williams, 1995: 696), positivist expectations (Taylor, 1993: 171; Brown and Williams, 1995: 696; Walters, 1996: 93), as shaped by the traditional 'medical model' (Mechanic, 1978; Bransen, 1992: 98; Thorogood, 1992: 47; Meyerson, 1994: 637; Blaxter, 1995: 26). Coming to a diagnosis is argued here to be a processual experience which may be experienced in terms of hours, days, week, months or even years. For Linda, the diagnosis of breast cancer was relatively swift, although certainly not painless:

**Linda:** So what happened was he sent me off for a mammogram. So I had the mammogram and it came back highly suspicious. So then they sent me off for a needle operation, a biopsy. So I had that and then that came back very, very highly suspicious.

**MV:** What kind of a time frame are we talking, since you first found the lump, and all these things?

**Linda:** About a week. It all happened really quick. And even when, then they sent me off for a biopsy, just under a local anaesthetic and I knew at that stage, 'This is cancer'. But you want to block it out of your mind, even though, you know, you still think 'Well, maybe it isn't.' But then it came back, yes, it was malignant and it had actually spread outside of the duct wall, so it was pretty serious. . . so they couldn't actually just take a lumpectomy, they couldn't just take the lump out. They actually had to remove the whole breast (Linda, #1: 1).

For others the diagnosis took longer. Daphne reported seven years elapsing after her first major MS attack: during the ensuing years she experienced loss of peripheral vision, aching and loss of total vision in one eye, extreme fatigue, ataxia (difficulty walking, climbing stairs,
feeling drunk) and reduced immune response. Fred also reported a protracted diagnosis process: the search for his cancer took nine months, over which time a malignant tumour was growing in size and presenting an ever increasing threat to his life. His story exemplifies the sometimes "long and winding path" to diagnosis. He begins with his first report to his GP after experiencing pain in his right shoulder region:

Fred: So eventually I went to the doctor's about it and he said "Oh, you've just got a pinched nerve." Because it was all the symptoms of a pinched nerve. So he started treating me for a pinched nerve. . . . And so this went on, and it was dragging on and on for weeks on end, and I kept on trying all these other tablets, because things weren't working, and then gave me a bit of heat treatment, and it wasn't getting any better, and all this sort of nonsense.

MV: How painful was this?

Fred: It wasn't very painful, but it was just constant pain. But the worst part about it, not so much the pain in there [indicates the back of his right shoulder again], but it was down the arm, because you couldn't sort of leave your arm hanging loose. You were forever sort of walking around holding your arm like that. [Fred indicates holding his right arm folded up against his chest with his left arm supporting it. Right arm bent and hand at upper chest level.] It was probably like, you know, you have a lazy arm or something, and you know. And it was just there all the time, 24 hours a day, you know, waking me up of a night in bed, and all that sort of thing. So I just kept trusting my doctor, because I'd been to him for a long, long time and I just kept going back to him, and he kept, you know, using me basically as a guinea pig with these, trying all these different pills out and giving me heat treatment and all the, you know, cortisone injections and that all. That went all right for a couple of days, the pain was going away. Then it come back. So after about six or seven months of this, which I suppose I was a lot to blame too because I should've, I didn't carry on with it. I just trusted him. I should have gone somewhere else. He said "Oh," he said "I think I'd better send you to St Vincent's hospital and see the doctor out there. And he had a look at it, and all he said, he said the same thing.

MV: He said you had a pinched nerve?

Fred: Yes. Nothing else and he didn't sort of go on with it, to think it could have been anything else. So he couldn't find nothing wrong. So I went back to the doctor's and said, "Well, he can't find nothing. Blah blah blah." And so I just got a bit cheesed off and someone said "Oh, look, go to a physiotherapist." Because if it is only a pinched nerve they'll fix you up in no time. So I went to a physiotherapist and they said "Oh, yes. No problems. We'll
fix you up in a fortnight." So, two weeks went by. No change. Three weeks: nothing. Four weeks: nothing. And they said "Oh look, we can't do any more here. You'll have to go, there's something wrong with you, you know." So from there on I went to-

MV: And this had been how long? Eight, nine months?

Fred: This would be going into about nine months by this stage. And then the doctor finally sat up and took notice that there was something wrong. So he sent me into the Edgecliff Medical Centre to have these CAT Scans done, or scans, or whatever you call them, you know, ... And the doctor said to me at the time, "Oh," he said, "this doesn't sound very good to me. It sounds like the symptoms of a tumour in the lung." I thought "Oh Jesus," you know? So, anyway he was right (Fred, #1: 3).

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The Shock of Discovery

The actual diagnosis is likely to confront psychological, social, physical and even economic aspects of the PwICI's life (Curtin and Lubkin, 1990: 6): it is, in terms of the journey, a crisis point. For most there is a strong reaction to the news of their illness which, depending upon the nature of the condition, the individual involved and what events may already have transpired, may be negative - including reactions such as grief; fear; anxiety; initial hopelessness; impaired social relations; and, negative changes in body image and self-perception (Spicer, 1978; Lambert and Lambert, 1979: 5-15; Masiow and Mittleman, 1981: 49-50; Schneider, 1984; Register, 1987; Montgomery and Morris, 1989; Friedman and VandenBos, 1992: 1178; Miller, 1992e: 419). The level of threat perceived by the individual

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101 The reader may believe such long quotations to be unnecessary to make the point. However, in this case Fred was describing a most protracted journey and his lengthy and earnest description served to underscore this very point. The researcher was aware of the importance of reporting faithfully the meaning uncovered in qualitative research and of using the extract to support the author's arguments (Street, 1996a: 9-10) and of the obligation that qualitative researchers have to 'report what a person actually said and mean' (Sandelowski, 1994: 480). Thus, after much deliberation, this passage has not been heavily edited for fear of reducing it's impact.

102 The 'crisis' point is traditionally and medically defined as a turning point, where the patient either gets worse and dies or gets better and lives (Maltz, 1960: 196; Martin, 1990: 162). Whilst disease crisis points also exist in ICI's, they are not of concern here. Indeed, chronic illness rarely follows this simplistic, linear and socially prescribed progression of illness (Donoghue and Siegel, 1992: 56). For the individual diagnosed with a chronic and often degenerative or overtly life-threatening illness, a 'life crisis' (Montgomery and Morris, 1989) or 'psychological crisis' (Reber, 1985: 166) may result in a state of disequilibrium, resulting in feelings of tension, anxiety and helplessness (Aguilera, 1994:1).
is also a factor here (Lazarus and Folkman, 1984: 167). The response may also include invocation of positive coping mechanisms (Callan and Terry, 1994: 27; Friedman and VandenBos, 1992: 1177-1178) or positive problem-focused coping strategies (Koeske et al, 1993; Callan and Terry, 1994: 22). Finally, there may be feelings of ambivalence (Lambert and Lambert, 1979: 9).

Where there is a negative response, one of the major concerns seems to be what the future may hold and when it may arrive: 'The rate of passage is of deep concern to agents and passagees' (Glaser and Strauss, 1971: 41). The notion of the "world crashing down" may be as a direct result of facing one's own mortality, of lost control over their bodies and lives (Johnson, 1991: 27-28) or a keenly felt loss of 'personal invulnerability' (Raphael, 1986: 79).

Fred recalled his response when told in October that he would be lucky to see Christmas: 'The world really fell. You know I just sat in the chair and I froze' (Fred, #1: 7). June also panicked:

June:  Yes, I actually came back to work the next day quite shattered. So I decided "I'm going to go blind" there and then. I went quite hysterical about the whole thing. And I can vaguely remember being sort of -- I worked on a different ward then. There was a different group of people and I vaguely remember being off my face saying "I'm not going to go out with Than [then boyfriend, later husband, now deceased - murdered] any more. I can't bear him -- I can't live with him if I'm going to be a burden on him." And one of the girls said "Come on, I think we need to go for a walk". And I remember her saying to someone, "Is there any brandy around the place?" (June, #1: 11).

However, positive responses were also noted. Shirley reported triumph upon her diagnosis:

Shirley:  So, Shirley goes on and she went and saw another gynaecologist who happens
to be with the Women's Hospital and he told me it was all in my head. So that's OK, that's fine [sarcastic]. That went on for another couple of years. Anyhow, I was finally put on to the guy that was the superintendent of Crown Street Women's Hospital at that stage and he said "Oh, you've got endometriosis." So it took four years.

MV: And how did you feel when somebody believed you and told you you had this problem?

Shirley: I turned around and I thought "All you sickheads that have had all this big education with going to Uni and all this sort of thing, you couldn't work it out." And I thought, all I thought was "One on me." [Shirley licks her finger and draws a "point" on the imaginary scoreboard in the air.] I just thought, "I knew all along" (Shirley, #1: 3-4).

For Daphne the positive response was one of relief and understanding: 'It's good to know exactly what it is so you can deal with it' (Daphne, #1: 1). For Beverley, though, ambivalence: on one hand she was shocked with the diagnosis of MS and yet found it somehow comforting in explaining, even justifying, her perpetual tiredness (Beverley, #1: 17).

As a variation, we must consider what may be the unique experience (Barritt et al, 1984: 8) of Rodney, where no strong feelings were indicated in response to his diagnosis. There may be a number of possible explanations for this: his commonsense beliefs about his condition may be demonstrated in a lack of concern in his behaviour (Klonoff and Landrine, 1994: 416); he may be adopting a normalising stance (Branson and Miller, 1992; Robinson, 1993: 12) where the significance of the problem is minimised; he may be attempting to maintain personal control over the situation (Johnson, 1991: 21); he may be less informed than medical professionals about his condition (Blaxter, 1995: 26) and unaware of its possible future outcomes; he may have been 'masking' his true feelings (Goffman, 1969: 17; Parker, 1989: 67) for any number of reasons; he may have been employing Freudian defence mechanisms, such as denial or repression, to cope with his situation (Bowlby, 1980: 140; Kline, 1984: 20; Carr, 1989: 30; Parsonson, 1989; Oldham and Kleiner, 1990; King and Singh, 1989: 63) or
Freud's notion of avoidance of 'unpleasure' (cited in Storr, 1989: 47); it could be symptomatic of a male struggle against sentimentality (Schafer, 1986/1996: 95); it could be related to the fact that Rodney doesn't experience 'felt stigma' with regard to his condition (Scambler, 1984: 215; Jacoby, 1994: 270; Nijhof, 1995: 201; Vickers, 1996b) perhaps because of the perceived 'routine' nature (Mechanic, 1981) of back problems in the community (due to frequency of occurrence and familiarity of symptoms); or, it could be that he has nothing genuinely to be concerned about. As Barritt and colleagues (1984: 6) have asserted, these kinds of open questions are not a sign that something is wrong with the analysis, but should serve as a flag for further research.

_A Passage of Status_

Chronic illness is indicative of long-term illness (Curtin and Lubkin, 1990: 2); unpredictable and liable to drag on for years defying efforts by the medical profession to control it (Register, 1987: 3). Freidson (1970: 240) described 'illness as process'; Schmidt (1989: 24) described illness as a 'way of life'; Miller (1992b: 28) referred to chronic illness as a 'loss of self'. ICI combines these problems with symptoms that are not externally manifested (Donoghue and Siegel, 1992: 4): 'Chronic illnesses take many forms. They can occur suddenly or through an insidious process. They can have episodic flare-ups or exacerbations or remain in remission with an absence of symptoms for long periods of time' (Curtin and Lubkin, 1990: 2). ICI also combines problems of illness not seen and not readily understood (Tate, 1991; Kantor, 1991: 81-82). Temporal articulation is described as the attempt to pace the passage according to schedules and transitional statuses (Glaser and Strauss, 1971: 53). For PwICI, temporal articulation can lead to negative outcomes of being left behind, for example, they are left behind in training schedules or are unable to keep up at work. Shirley
expressed such a concern, describing her inability to keep up with a training course at her work due to her learning disability (Shirley, #2).

Hence for people with ICI the journey is not an easy one; it may be turbulent, painful, unpredictable. The downward nature of the passage may be associated with the actual disease progress and/or associated stigma. For example, a diagnosis of MS may evoke inappropriate images of childhood or old age frequently associated with wheelchairs and incontinence (Robinson, 1988: 44). The downward physical passage was acknowledged by Daphne’s frank admission that her multiple sclerosis is ‘really going a bit downhill at the moment’ (Daphne, #1: 2), illustrating her feelings of powerlessness in the face of the disease process (Hastings, 1992; Miller, 1992a).

The lowered status of the individual may be influenced by the stigmatising nature of the condition. For example, the shame associated with Parkinson’s disease (Nijhof, 1995: 193) and epilepsy (Scambler, 1984; Jacoby, 1994) is likely to exist where a Protestant ideology emphasises guilt and shame (Perinbanayagam, 1985: 94; Finerman and Bennett, 1995). Personal responses to MS are reported to include fear, uncertainty, anger, changes in self-image (Register, 1987: 17; Robinson, 1988: 36 and 44-45), confusion and frustration (Scheinberg, 1987: 1). Beverley confirmed that the diagnosis of MS presented fears for her able-bodied future and of shaking her confidence deeply when dealing with colleagues (Beverley, #2: 14-15). Evidence of ‘felt stigma’ was also demonstrated by Linda who reported not only the fear associated with having to face her own mortality at a very young age, but of losing her breast (Linda, #1: 11) and the attendant impact to her self-esteem, especially her sexuality, in a very “body conscious” society.
Some respondents did not describe any loss of self-esteem or loss of status, and this may genuinely be their experience. However, the literature reports that consciously, or unconsciously, there is a masking of feelings (Goffman, 1969: 17; Parker, 1989: 67), the socialising of performance (Goffman, 1969: 30), a reducing of the significance of acts (Perinbanayagam, 1985: 2) or the inability to admit or recognise enacted stigma, as was reported in Pinder's (1995: 606) study of people with arthritis. This may contribute to the understanding of why, on the surface, Fred (#1: 13) seemed pleased that his colleagues were prepared to drive him to-and-from the office when his cancer precluded him from doing so. It is argued here that this situation may have threatened his sense of autonomy and self-esteem, and yet this was not reported.

The status passage the bearer must endure is also likely to be influenced by the nature of the condition, its symptoms and subsequent "status". Rosalie (#1: 19) and Beverley (#1: 21) both described the problem of this lack of "status" associated with fatigue. Fatigue is a common and frequently debilitating problem for those with invisible (and visible) chronic illness (Register, 1987; Wheeler and Dace-Lombard, 1989; Donoghue and Siegel, 1992; Miller, 1992c). For example, fatigue has been reported in relation to chronic fatigue syndrome (Conant, 1990; Price et al, 1992; Blake, 1993a; Blake, 1993b); multiple sclerosis (Scheinberg and Smith, 1987; Lechtenberg, 1988; Robinson, 1988; Wheeler and Dace-Lombard, 1989: 59; Hastings, 1992; Rosner and Ross, 1992); sarcoidosis (Anderson, 1982); arthritis (Miller, 1992c; Pinder, 1995); and systemic lupus erythematosus (Krementz, 1989; Szasz, 1991; Donoghue and Siegel, 1992). Beverley (#1: 21) shared the experience of persistent fatigue that plagued her due to MS whilst stressing the problem that 'tiredness isn't really an illness'.

From Rosalie also:
Rosalie: I think there's a double discrimination depending on the illness. I'm sure if I had leukemia it would be seen in a different way, because cancer has a status that something like chronic fatigue syndrome hasn't. Chronic fatigue syndrome is still seen as not a proper illness and it doesn't have any status and it's likely to be seen as "It's in your mind" or "It's an emotional problem." And particularly if you're a female with it, it has to be something going on within you (Rosalie, #1: 19).

Themes of Trauma

The journey continued as PwICI demonstrated the chronic nature of grief experienced and the invisible nature of much of this trauma. These problems are borne much of the time with little compassion, knowledge or understanding from those around them.

Grief and Loss

Chronic illness can be a source of ongoing grief and loss for the bearer (Bowlby, 1980: 100) resembling the grief associated with death and dying (Register, 1987: 21) except that illness persists (Register, 1987: 24). Chronic illness may result in loss of physical function; energy; sense of control; independence; resilience; patience; innocence; security; competence; visibility; privacy; body-image; self-image; faith; expectations for the future; social contact; shared responsibilities; financial power; self-esteem; affection; autonomy; optimism; ability to protect; sexual communication; freedom; equality (Wheeler and Dace-Lombard, 1989: 62). There may also be the need to embrace numerous role changes (Wheeler and Dace-Lombard, 1989: 63). Threat of loss may arouse anxiety, whilst actual loss results in sorrow: both may arouse anger (Bowlby, 1980: 40). The various 'tasks' of grieving (Schneider, 1984: 63), in addition to Kubler-Ross’s famous 'phases of grieving' (Kubler-Ross, 1969; Schneider, 1984: 66; Barbeau, 1987a; 1987b; Register, 1987: 21; Sellick and Bolton, 1989: 177-178) may
accompany multiple 'status passages' (Glaser and Strauss, 1971: 142) associated with the 'psychological crisis' (Reber, 1985: 166; Aguilera, 1994) or 'life crisis' (Montgomery and Morris, 1989) of diagnosis and continued existence with an ICI. The issues associated with 'chronic mourning' (Bowlby, 1980: 138) may be poorly understood by the sick person (Schneider, 1984: 25), let alone others, and is another aspect of the "invisibility" of the illness process that PwICI have to endure.

There was a clear theme of loss from the stories heard and it is acknowledged that grieving and coping responses can vary tremendously based on demographic characteristics such as gender (Bowlby, 1980: 103; Helman, 1990: 143-144; Klonoff and Landrine, 1994: 414); culture (Bowlby, 1980: 126; Curtin and Lubkin, 1990: 12; Helman, 1990: 117); levels of social support (Argyle, 1989: 277; Hastings, 1992: 236; Ray, 1992); and the personal or internal characteristics (Schneider, 1984: 35; Robinson, 1988: 49; Callan and Dickson, 1992: 49-50; Miller, 1992c: 196; 1992d: 397; 1992e: 414; Koeske et al, 1993: 319) of the PwICI.

One of the major areas of loss associated with a chronic condition is the area of physical loss: 'One's body often becomes unreliable: it can no longer be taken on trust' (Pinder, 1995: 610); bodily life is plagued with uncertainties (Johnson, 1991: 14) and physical limitations may require constant juggling to maintain any semblance of normality in the PwICI's life. Even physical appearance may be altered for PwICI as a result of disease activity or medical regime (Vickers, 1996b). Loss of physical abilities, including "invisible" ones, may be keenly felt by sick individuals. Every loss, large or small, may provoke a reassessment of (actual or potential) future problems and may be exacerbated by the very fact that others are blithely unaware or simply cannot understand the loss felt or what the loss implies. All respondents
indicated some form physical loss that others either may not be aware of or properly understand: Linda lost a breast; Judy lost vision and anticipates much greater visual impairment; Rosalie never feels healthy any more; Fred lost the use of his right arm for a lengthy period; Rodney lost a painless, trustworthy back; Rosalie, Beverley and Daphne reported substantial losses in energy levels; Maryanne has largely lost control over her bladder function; and both Maryanne and Shirley have lost the ability to have children.

*Psychological losses* are also manifest in the stories: Loss of self-esteem or reduced self-image (Lambert and Lambert, 1979: 2; LaRocca et al, 1987: 207; Robinson, 1988; Miller, 1992d; Callan and Terry, 1994) can result and yet remain "invisible" to others. Linda reported embarrassment that others knew about her lost breast, although one suspects such a loss is more profound than "embarrassment", as evidenced by her regressive (Oldham and Kleiner, 1990: ii), poignant words: "I just felt like a little girl again, like, you know, I just felt like "Oh, I want my mum."" (Linda, #1: 11). Beverley commented upon her psychological loss at the deepest levels:

**MV:** How does it, how did [the diagnosis] influence your self-image? How did it affect your insecurities?

**Beverley:** Oh, look, it affected me, it affected me at work. I was really not doing very good work. I just was being put in positions with people who were, you know, sort of directors or whoever, and I'd sort of cringe at the thought of having to go and face them and talk to them about things, and, and, it was just, it was really bad. It just threw me so badly for a while.

**MV:** Just your confidence generally?

**Beverley:** Yes [MV: Right] and it wasn't because I have MS. It was just because of what it did to me personally knowing that I had it. It wasn't thinking "Oh, I've got MS therefore I can't talk to this person." Its just that it shook me at a much deeper level than that, and it took me a long time to work out that I was actually OK and I could do my job. Because you see when I first got it I had about two months off and I just was really
disoriented, and while I was getting it, and not knowing, and then after that, and, you know, it was just, it was a really bad time. And it did take a long time to sort of get back on my feet again and get my confidence and, as you say, self-esteem back. Mmm (Beverley, #2: 14-15).

Relational loss and threat to relationships was frequently reported. The literature supports the view that chronic illness can have substantial impact on interpersonal relationships (Curtin and Lubkin, 1990: 7; Miller, 1992d: 409; Rosner and Ross, 1992: 154). Beverley described her initial reticence in dating men after the diagnosis of MS; Shelley wondered how her boyfriend would react when he saw her when she was "really sick" with leukemia; Rosalie recounted the strain that her chronic fatigue has placed on her marital and family relationships; Rodney suggested, half-jokingly, that his wife would leave him if he injured his back foolishly again; but perhaps the most poignant relationship losses were those experienced by the two respondents with endometriosis: both reported resulting absences of partner (sexual) relationships and a loss of the ability to have children. Maryanne (who also has interstitial cystitis) shared her distress which arose from the thoughtless comments of another:

MV: What about other aspects of your life?
Maryanne: Oh, sex, relationships, children. I mean there's all of that. There's this thing of not wholeness. The whole attitude of being a woman and having a family stuff, that you're not complete... I once, my mother and a friend of mine and one of my sister's, we were talking one day, and I do have a natural affinity for children. They love me. They just come to me. And it was always "Maryanne will make a great mother," and all this sort of stuff... and one day we were sitting there and someone said "You don't have children. You don't know." I said, "That is the cruellest thing you can ever say to a woman that will never have children." It's the only time I get upset when I talk about-- you know, and I said, "That is the cruellest thing you could ever ever say. That is the most thoughtless thing you could ever say" (Maryanne, #1: 28).

Loss of life-choices were also reported widely. Dyck (1995: 307) referred to a loss of the
taken-for-granted nature of the lifeworld or 'biographical disruption'; specifically, those aspects of our lives that are planned for in the future. These could include such specific things as career or education or, more broadly, the availability of future choices as to how one may live one's life. For many, the imposition of the physical limitations of a chronic condition, its treatment regimen, the iatrogenic effects of treatment or future physical losses may mean a radical alteration to a life; an enormous cost to the PwCI. For Maryanne (#1: 28), this meant a lost career in science or medicine. Rosalie demonstrates a heartfelt sense of loss through truncated careerist aspirations:

**MV:** What's the worst thing that's happened to you, with regards your work, because of having chronic fatigue?

**Rosalie:** It's the loss. It's inevitably the loss. I was a high flier [Rosalie becoming very emotional] and it's, it's incredible loss. I mean I will never do the sort of things that once were open to me. I would never have the range of opportunities that were once there. I have lost opportunities at working at a very top level that I would, I will never see. So, I suppose there's a whole lot of words [strangled laughing/crying combination] but the top one would be enormous loss (Rosalie, #1: 21).103

Life-choices, especially for the careerist, may include education. For Shelley, the Master's degree she plans to do may not eventuate depending on the course of her leukemia. For Maryanne and Rosalie, the completion of postgraduate studies has been most difficult. This loss of choice was also sensed by Rosalie (#1: 19), who sees herself as being unable to

103 The author is struck whilst reviewing this section at how the "words-on-the-page" fail to adequately capture this moment. My recollections reconstruct a picture of this passage that the reader would, unfortunately, not be able to share. It is a case of not being able, using just "words-on-a-page," to capture sufficiently the emotion, the electricity and the pain that was rendered here. Rosalie recounted her story with tears streaming down her face, confronting the pain and loss she had endured from lost career aspirations perhaps, consciously, for the first time. The researcher is indebted to her supervisor, Professor Alexander Kouzmin, for pointing out that this passage and its lack of ability in capturing the essence of Rosalie's experience, exemplifies the essential phenomenological methodological dilemma: How is one to truly capture and report another's experience, pain or emotion? It also, perhaps, highlights a fundamental inadequacy of current social methodological processes.
physically 'turn-up' to work for another organisation with the requisite nine to five (or longer) hours plus travel, and the time and energy spent in personal preparation for that. For Shelley, loss of choice in her life-plan was experienced in her job search when another took away her choice of illness disclosure by telling the potential employers of her illness; a disclosure which, she believes, subsequently cost her the job. Whatever the ICI, loss of life-choices occur: whether it is not digging holes in the garden (Rodney, #1), remaining in a job because you don’t have the stamina to change (Linda, #1) or remaining in a home where you know where everything is so that when your vision finally fails you will be able to find your way (June, #2). Loss is ubiquitous for PwICI.

Loss of financial security\textsuperscript{104} was also perceived to be an issue, although certainly not widely discussed by respondents. 'Environmental constraints' (Lazarus and Folkman, 1984: 166), especially material resources such as money, are usually finite. The threat of illness and disability to livelihood is one of import. As single mothers, both Beverley and June felt the pressure to work and support their offspring. For June, this imperative outweighed potential risks to her sight:

\textbf{June:} Probably the worst ordeal was at the very beginning, nine years ago, because at that stage I naturally had to go to work otherwise I would have had to take the children out of school. I could survive on a pension to pay the house off fortunately, but I couldn’t pay for the children so I pushed myself to go to work and I guess, thinking about it, I probably did put my eyes in jeopardy in a way, because I sort of fiddled around with medications. I’d get up at five in the morning so that I’d have [the eye drops] in. I’d be able to see to drive to work and I’d be able to run a group when I got to work because I had to function when I got to work and by having them in every four hours it worked that I could still see to drive home, and yes, sometimes, I didn’t just about make it, seeing to drive home (June, #1: 7).

\textsuperscript{104}Coping with financial loss is discussed more extensively in the following chapter.
Beverley also reported future concerns regarding getting to work: How would she get to work if her MS worsened to the point where she was unable to drive and catch the bus to work? More worrisome than this perhaps was her admission that if she were disabled such that she couldn’t get to work she also wouldn’t be able to live where she lives (a two-storey townhouse); worse still for her, she confided a fear that her children might have to go and live with their father (Beverley, #2: 28).

"Negative" Feelings

In telling the stories of others and endeavouring to follow a hermeneutical method involving obtaining a common and valid understanding of meaning (Kvale, 1983: 185), there has been a deliberate decision here to remain with the simple terminology - "negative" feelings. Using the term "affect" arguably sounds overly scientific (Harré et al, 1985: 5) and, in keeping with Heidegger’s usage of ‘ordinary language’ (Dreyfus, 1991: 7), the term has been avoided here although it captures the world of "feeling" being discussed: 'A general term used more-or-less interchangeably with various others such as emotion, emotionality, feeling, mood’ (Reber, 1985: 15, emphasis in the original). At the broadest level, there is an attempt to report "bad feelings"; feelings of pain, whether they be sadness, shame, anger, sorrow or guilt. (Conversely, "good feelings" are reported in Themes of Optimism in Chapter Six).

"Negative" feelings varied widely and had an enormous impact on individuals at work and home. They were observed during interviews and later analysis, not merely from the linguistic framework, but from what was not said; from reading between the lines (Barritt et al, 1984: 6-7). It may be argued that many of these feelings would be unknown to colleagues, especially given that they cannot see that anything is wrong. They are likely to be
experienced on a chronic basis. The literature comments on the existence of uncertainty (Robinson, 1988: 36; Wheeler and Dace-Lombard, 1989: 13); anxiety (Lawson, 1987: 255; Ray, 1992), anger (Barbeau, 1987c; 1987d; Register, 1987: 17; Lane and Hobfoll, 1992) and fear (Bowlby, 1980: 40; Barbeau, 1987d; Lawson, 1987: 256; Register, 1987: 17; Maslow and Mittleman, 1981: 49-50) associated with chronic or terminal disease; of being disabled (Szasz, 1991: 168); and of 'aloneness' in the personal experience (Sheehy, 1974: 359). One becomes conscious of the likelihood of a 'growing aloneness' (Fromm, 1942/1960: 23) for PwICI in their experiences105, especially in our individualist culture: 'When one has become an individual, one stands alone and faces the world in all its perilous and overpowering consequences' (Fromm, 1942/1960: 23).

105This notion of a "growing aloneness" reminds the author of the debate between herself and her supervisor, Professor Alexander Kouzmin. The discussion centred around a perceived problem, hotly debated, that the stories reported here were "insufficient", "weak", somehow "lacking" in a "rawness" that had been anticipated, especially when compared to the "voice" of the researcher and her partner. Long and careful reflection reveals a number of possible solutions in such a discrepant response (between investigator and supervisor) to the voices of the respondents. First, there was previously reported (in Chapter Four) a perceived need for the researcher to maintain some distance from the respondent's stories in order to survive. It is accepted that this need for distance may have influenced an unconscious repression or suppression of the stories; an inability to dig more deeply to uncover the anger, the fear, the anxiety that lay with respondents or, perhaps, the reporting of a "sanitised" version to avoid pain. Secondly, and conversely, it may be argued that these stories are rich - what more could be asked of people, strangers, than tears shared, stories revealing an absence of sexual relations, tears of losing one's children or of never having children, of having to urinate in the street in desperation or, simply, of not being understood by colleagues or family. The researcher is, of course, fortunate enough to be able to place a person behind these stories making them "real"; to recall the shaking hands, the nervous laugh, the uncomfortable shift in the seat - constituents of the "voices" that remain out of reach to those who only view "words-on-the-page". The burden and the difficulty in sharing the essence of these experiences, exemplified by this very debate, is re-considered in Chapter Seven and centres around the need, perhaps, to have experienced the trauma to recognise it in others.

However, neither of these explanations satisfied the researcher completely. Consternation remained as to why the impact of respondent stories was so much weaker when an "outsider" (supervisor) reviewed them. A third possibility is proffered. It is suggested that the reader may experience their own 'passage of trauma' (Vickers, 1997a); that the recognition of hardship suffered by others is so strong that saturation is reached and various Freudian defence mechanisms (as reported in earlier chapters) are invoked by the reader to survive the journey of readership. Finally, a fourth possible explanation is offered. Reflection revealed the researcher's human "connection" to the respondents in the stories, to her partner and to her own experiences. For the supervisor there was no such connection with the respondents - they remained "words-on-a-page". There was, however, a connection with both of the other "voices" reported here; the researcher's "voice" and (to a lesser extent) her partner's. Both of these voices could be associated with people known to the reader.
"Negative" feelings were reflected clearly in the stories of Fred, Shelley, Shirley, Rosalie, Daphne, Beverley and June. For example, Shelley articulated her fear for the future, her anxiety and uncertainty, and her aloneness in her concerns with her future with acute lymphoblastic leukemia:

**MV:** And how do you feel at work if you've got an ache or a pain and waiting for results, and they're still "on your hammer" at work?

**Shelley:** I think it's just anxiety [much emotion in her voice now; fear]... I do, I just, even though it could be something negative, I sort of, I do, I wait for mum to ring, just to give me the AOK, or no, so I know. Because I guess if everything's OK I stop worrying. It's the worrying that stops and the pain; everything seems to disappear. If there is a pain there, everything feels bigger and larger than life until I feel that it's been cleared. Yes (Shelley, #2: 11).

Later in the same interview, Shelley confirms the ongoing nature of these concerns and her aloneness in the experience; the lack of support from colleagues - 'There's ongoing worry for me that other people aren't aware of' (Shelley, #1: 15). Fear seemed ubiquitous, although was not always openly acknowledged. Linda's use of imagery vivifies her fear:

**MV:** What is it like for you to have Cancer?

**Linda:** Scary. Really scary. Like, you know, how I describe it is I feel like a time bomb [controlling rising emotion here]. I just feel like one day I'm going to wake up and explode. I'm just taking time to wait for, like the ticking of the clock [Points to the timer being used]. That's how I feel. I just feel like a time bomb; that I'm OK at the moment but maybe, you know, next week, one day I'm going to wake up and, you know, I could be dead or something (Linda, #2: 4).

Humour, jokes and asides during interviews, including laughter, undoubtedly conveyed meaning (White, 1982: 145; Kline, 1984: 27; Gabriel, 1991: 858) and, whether it was used to trivialise the import of what was being said (or felt) (Kline, 1984: 31), to 'normalise' it
(Branson and Miller, 1992: 19; Robinson, 1993: 8), to resolve contradiction and release tension (Denhardt, 1981: 55) or as a reaction to the striking of a "nerve" during a tense, personal moment (Denhardt, 1981: 55), humour was used frequently to lessen tension during the interviews, by both respondent and interviewer. The use of euphemism also betrayed fear: Fred euphemistically described the plight of his colleague, who almost died from breast cancer, as being 'between the devil and deep blue sea' (Fred, #1: 18). Mostly, however, it was the words that were omitted that resonated with the strongest fear. Storytellers frequently left out descriptive words earmarking death or disability. What was "unspeakable" for them became evident upon review of the transcripts: for Beverley, it was that she had MS; that she was afflicted by it' (Beverley, #2: 21); for Shelley, it was the uncertainty of life itself that was "unspeakable"; when asked about what might happen in the future (Shelley, #2) the possibility of death was never mentioned, yet its dark presence was felt hanging palpably between us.

Themes of anger, described by Bowlby (1980: 128) as a ubiquitous feature when mourning loss, reverberated through the stories. Fred reported irritation with the pity that he felt was his constant companion in and out of work from those around him (Fred, #1: 30); Rosalie

\[106] As the transcripts are reviewed and the stories recalled, the researcher's own feelings of fear and inadequacy, particularly when confronted with the spectre of death, were demonstrable as tension was released through nervous laughter during the first interview with Shelley as the seriousness of her condition was exposed:

**MV:** So at the end of this period, this two years you're on at the moment, are they aiming to take you off medication altogether?
**Shelley:** Yes. Well, there's only so much medication I can have now. I have really been whacked with chemotherapy and because it's so highly toxic, they don't know what it does to the organs and that sort of thing. So, I guess I'm assuming that at the end of the two years they will probably take me off the treatment and, say, give me a little bit of time, not - I wouldn't say it would be too long for fear of me relapsing off treatment. They'd be giving me the bone marrow, an unmatched bone marrow, so that in respect, is really my last chance. If that doesn't work, there isn't anything they can do [Tape ends] [Nervous laughter from MV] (Shelley, #1: 11).
resented anything that placed unnecessary demands upon her very finite levels of energy (Rosalie, #1: 15); Linda felt angry that others didn’t understand (Linda, #2: 14):

**MV:** How do you feel when they don’t understand?

**Linda:** Angry!

**MV:** Angry.

**Linda:** Yes. But for a lot of my questions I’ve said I’ve been angry. Frustrated and angry and annoyed and --. You know, sometimes I wish they would come up to me and ask me questions about it (Linda, #2: 15).

Interestingly, much of this "negative" feeling seemed to stem from the response of others towards the PwI CI; the lack of understanding about the "invisible" condition and its effects, rather than from the condition itself. Linda demonstrated 'helpless anger' or 'humiliated fury' (Fanshel, 1977; cited in Scheff, 1994: 288) and likely feelings of 'violation' and betrayal (Temby et al, 1996; Morrison and Robinson, 1997) at her manager’s rather insensitive suggestion that she find another job when she returned from seven months leave:

**Linda:** I was really angry that he wasn’t considerate. . . . It was just, he just didn’t really care basically.

**MV:** And how did you feel about that?

**Linda:** Angry. Frustrated. I just wanted to cry, but I knew I couldn’t because, you know, I was in front of my senior manager and like if I just dissolved into tears it wouldn’t look too good. So, yes, just really emotional (Linda, #2: 2).

Linda also reported, specifically, frustration with her illness, her life and the lack of understanding felt from others (Linda, #2: 15). Fred described his frustration at the continuing, and well-meaning, phone calls during his illness and protracted convalescence. Again, the sense of not being understood, of not being "heard", unfolds. Fred recounts his
frustration at having to continually relive his experiences with his cancer treatment at a time
when he wanted, perhaps needed, to think about other things: 107

MV: What about people ringing up all the time to find out?
Fred: It drove me nuts.
MV: Did it? Did it? Yes.
Fred: And it was my own family too to a certain extent. A lot of friends as well,
because you just found yourself, that's all you're doing, all day long, just sitting there, just
saying the same thing. "I went to the doctor. I had the treatment." "How do you feel?" "Got
home all right?" (Fred, #1: 31).

Another theme that reappeared with monotonous regularity and has been reported in the
literature is that of felt stigma or shame (Freidson, 1970: 205; Scambler, 1984; Jacoby, 1994;
Scheff, 1994: 277; Susman, 1994; Finerman and Bennett, 1995; Nijhof, 1995): 'The urge to
belong, and the intense emotions of shame and pride associated with it, may be the most
powerful forces in the human world' (Scheff, 1994: 277). Felt stigma was observed in
various forms: shame, embarrassment, humiliation, rejection experienced, feelings of
inadequacy or even guilt. Rosalie reported feeling rejected because of her chronic fatigue
syndrome (Rosalie, #1: 23). Daphne reported feeling conspicuous walking around the office
with a slight limp from the MS (Daphne, #1: 6), a limp that made it difficult for her to keep
up with others whilst walking (#1: 9). In fact, she reported making a habit of ringing team
members when needing to communicate with them to avoid walking down a long hallway in

107 Fred's story resonates so strongly with me here: over the crisis period of Michael's illness I became
less and less able to recount the depressing story of his condition, his decline and our situation. Friends just
didn't seem to understand that in order for me to survive I could not continually talk about, think about and
relive Michael's illness or my own. Use of the defence mechanisms of avoidance or repression (Parsons, 1951:
203; Kline, 1984: 21; King and Singh, 1989: 63; Parsonson, 1989; Storr, 1989: 12; Oldham and Kleiner, 1990:
i), in my case, saved my sanity. I was struck by the judgement of others that I am avoiding them, denying
reality. I am angry with their inability to empathise and my inability to be "heard" when I do explain. I remain
unsure, however, about how I wanted them to behave; what I did expect of them.

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her office. Rodney reported feeling 'a little bit embarrassed' about the possibility of not being able to help a (female) colleague lift something heavy; that 'I guess it's an admission that you can't do something that prima facie you would expect someone of my age to be able to do' (Rodney, #2: 2-3). Finally, Linda (#1: 11) expressed feelings of embarrassment, even humiliation\(^1\), that people in the office would know she had lost a breast.

Shame felt may be closely aligned with capitalist, careerist organisational expectations of adherence to the protestant work ethic (Whyte, 1956/1963: 18; Perinbanayagam, 1985: 94; Argyle, 1989: 111). Shame was felt by Beverley prior to her diagnosis of MS, perhaps in response to others blaming her for her for not looking after herself, inferring that her constant fatigue was somehow her fault.

**Beverley:** No, I mean, I guess, probably, you think that too. You think well, you know, you're tired, "I should get out there. I should get better. I should lose weight. I should do whatever." You know. And I should be able to do it and now, I mean once you know there's a reason for it and accept that you can't then it's, it's fine [laughter] (Beverley, #1: 17).

**Pride** was frequently demonstrated by PwC1, perhaps having negative ramifications: 'Individuals and groups seek to increase their pride/shame balance, their moment-by-moment social status' (Scheff, 1994: 286). Individualism (Whyte, 1956/1963: 9; Slugoski and Ginsberg, 1989: 49; Armstrong, 1995: 48) in our culture emphasises strength in the face of adversity, especially for men who may regard it as "unmanly" to shed tears, express feelings

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\(^1\)Humiliation is distinguished from shame by some authors, but not all. Those who do, distinguish it on the recognition of knowledge of feelings of shame and embarrassment by the "other". Many PwC1 do not experience humiliation due to the invisible nature of the illness; others rarely know what is going on. However, Linda's experience in other's knowing of her lost breast made her experience of shame (involving her lost breast) an especially social one - a humiliating and embarrassing experience involving a consciousness and reflective viewing of the self from the point of view of the other (Scheff, 1994: 287).
or admit to grief stricken anger (Bowlby, 1980: 104) and who struggle against sentimentality (Schafer, 1986/1996: 95), with masculinity argued by some to be associated less with sexuality than with power, physical presence and a combination of force and skill (Harré, 1991: 55). It is not only men who live in an individualistic culture: many of the women respondents also emphasised managing on their own; not wanting to ask for help; for example, June, Daphne, Shelley, Shirley and Beverley. Pride may also be indicative of concealed hurt (Gabriel, 1991: 872): Shelley recounted earlier that her colleagues don’t remember her illness; that they don’t seem to care. Concurrently, Shelley reported a proud independence; that she wouldn’t ask for help until she was desperate (Shelley, #1: 3).

*Cruelty and Insensitivity*

*Colleagues:* Whilst many people stated that they had tremendous support from their colleagues, that the organisation had been "great", closer inspection revealed little in the way of clear support.109 There was evidence of insensitive, and callous, disregard for people's pain. One of the most evident and most pernicious sources of cruelty and insensitivity evidenced in the stories were those centred around the preponderance of managerialism in organisations (Easton, 1995: 39; Rees, 1995a: 15; 1995b: 198; Solondz, 1995: 212; Wheelwright, 1995: 36) and the managerialist dogma of efficiency, under the guise of economic or instrumental rationalism (Kouzmin, 1980: 148-149; Rees, 1995a: 15; 1995b: 197; Solondz, 1995: 215; Wheelwright, 1995: 30). These expectations permeate organisational life and have no small impact on the lives of PwICI.

Shelley portrayed the managerialist tradition of colleagues making decisions on her behalf:

109 This apparent inconsistency in the stories is dealt with in Chapter Six: 'Themes of Ambiguity'.
she was not being included in certain outdoor activities, that she would have been fit for, at the childcare centre where she worked; it was assumed that she would not be able to participate. June reported overt pressure (which she eventually succumbed to) to drive a bus when her vision was clearly not good enough to do this (June, #1: 13-14). Daphne and Shelley both reported inflexibility of management and problems experienced when wanting to have a day off due to illness (Daphne, #1; Shelley, #2: 8), but the most pernicious incident recounted was from Linda, who described a meeting with her senior manager only days after her return from seven months leave, over which time she endeavoured to recover from her secondary cancer:

**Linda:** So my senior manager came and saw me [four days after returning to work after seven months off] and said "I need a decision by this Friday where you want to move to. Your job no longer exists."

... I said, I asked him, "Do you realise what I've got is a life-threatening disease?" And he just looked at me and he said "Yes, but I didn't really factor that in when I was thinking of what to do with you." I was just totally blown away. ... I'd heard actually two days before this he had to cut about four people out of his budget (Linda, #1: 9).

Evidence of enacted stigma or discrimination (Safilios-Rothschild, 1970; White, 1982: 114; Scambler, 1984; Northdurft and Astor, 1986; Cacioppe, 1988; Aikin, 1989; Rayner, 1992; Jones and Stone, 1994; Stone, 1994; Susman, 1994; Klimoski, 1994; Jacoby, 1994; Small, 1995) were reported by PwID, such as work discrimination and, even where it had not been experienced, respondents often indicated either directly or indirectly their fears in this area. For Shelley, the stigma was keenly felt through the loss of a workmate's friendship (Shelley, #1: 6). For Linda, it was being told by her boss to find herself another job - fast (Linda, #1: 9). For Maryanne, it was a blatantly unfair dismissal from her workplace:

**Maryanne:** In the end I became so late for work and was so unwell they, the bank, at
the time, asked me to go and see their doctor. And he didn’t know what to say. I think he was thinking I was neurotic and they asked me to leave work. . . .

**MV:** Who asked you, your manager or the doctor?

**Maryanne:** The manager, after medical consult. Nowadays, nowadays I’m not naive and nowadays I would take them to court on unfair dismissal.

**MV:** And what, did they give any reason or, what, what did they say?

**Maryanne:** The letter was just so simple it was ridiculous. I saw it coming. . . . It was like two lines. I just didn’t cry at that stage or anything. (Maryanne, #1: 8).

**Lack of understanding** from others presents problems for PwIC. The fact that little or no visible manifestation of the condition exists makes understanding for other people difficult: however, there was little evidence of any serious attempt at consideration on the part of others. Being part of the organisation seemed to absolve organisation members of any humanistic responsibility, in much the same way as the phenomena of ‘bystander apathy’ and adherence to norms of obedience and rule following (Jackson, 1989: 78-80) prohibits the normally anticipated, humanitarian response. For June, this meant being pressured into driving a bus to enable hospital outings, endangering the lives of herself and numerous passengers: ‘I actually was pressured into driving it . . . We only drove to . . . Kurrajong. It’s a windy lane and when we got there the girl I worked with said “I’ll drive you back.” So it must have been quite awful’ (June, #1: 13-14). For Linda, colleagues apparently have little idea of, or concern for, the ongoing worry she experiences, or the pain and the grief she has so far experienced:

**Linda:** I haven’t even gone 12 months clear yet and I mean they don’t give the all clear until five years. . . . I think they all think “Oh, she’s fine now. She’s had her treatment. She’s okay. She’s back at work. She’s moving. She’s upright” (Linda, #1: 10).

For Shelley, colleagues’ lack of understanding makes having to ring in sick at work something
to dread:

Shelley: So, I know definitely if I have a day off, if I ring in and I'm not well, I know definitely that she's carrying on [about Shelley behind her back]. And whoever has to tell her the news that I'm not in will wear it. Yes. It happens with everyone (Shelley, #2: 8).

The notion of assumptions of malingering (Asher, 1972/1995; Falvo et al, 1982: 3; Yelin, 1986; Register, 1987: 8; Conant, 1990; Szasz, 1991: 33) by colleagues was explored earlier, especially for invisible conditions even when a bona fide diagnosis exists. Linda reported the total incomprehension of a colleague as to her need for lengthy time away from the job to recover from cancer. The assumption seemed to be that her recuperation was some kind of holiday that was enjoyed:

MV: You mentioned . . . that other people judge you . . . Can you explain that? Linda: I just feel that like -- I felt when I had the seven months off, people were thinking and I know they were thinking, I just know in my own mind that they were thinking "Why does she need seven months off? She's having a holiday." I mean even a couple of people said . . . "Oh, where have you been for seven months?" and you say "Oh, I've been really sick you know" and you go into it and they say "What did you have?" and I say "Cancer." Then they say, "Oh. Do you need seven months off for that?" and "You must have had a good holiday then." And you think "Bloody hell, it's not a holiday. I'm trying to get over it!" (Linda, #1: 7-8).

Beverley also indicated feeling judged about her constant complaints of fatigue associated with MS; that 'tiredness isn't really an illness' and 'sometimes they think "God, not again."
[laughter]' (Beverley, #1: 21). Rosalie extends the concept of lack of recognition of illness or illness symptoms to a lack of 'illness status' (Rosalie, #1: 19). For June, visual problems associated with glaucoma are not recognised: a colleague's ignorance and disbelief is
especially irritating on top of the actual physical frustrations of not being able to see properly:

June: I don’t think this guy, who I’ve know for some years really, he probably doesn’t know about my glaucoma, because he knows I’ve got glaucoma but I don’t think he knows what glaucoma is or how it’s affecting me. He keeps on saying, “Well, put your glasses on.” And I’m saying “But it doesn’t make any difference.” So every time I see him he says “Glasses that don’t make any difference” and shakes his head. Yes, so, and I feel a bit irritated. I don’t know if irritated is the word but, yes, I felt a bit annoyed that he -- I didn’t want any sympathy or empathy or anything from him. I just wanted him to recognise the fact that the glasses don’t make any difference and, yes, I do have an eye problem and that I could lose my eye sight. . . . Yes, you know, I didn’t want that sympathy. I just wanted him to recognise that fact and I did actually say to him “Dave, I can’t see” . . . So probably what will happen, if I end up having to go into hospital he will then realise and then - he’s a really lovely guy - and he will then probably be beside himself. But there is no way I can actually make him realise because I’m doing normal things. I mean I’m driving.

MV: He sees you driving and working?
June: Yes. So he doesn’t -- and he sees me with glasses on sometimes, sometimes without (June, #1: 12).


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110 At one point during interviews the predominance of the medical profession in the stories was felt to be imbalanced with that of experiences in organisational life. However, deliberate avoidance of questions pertaining to the medical community and respondent’s experiences with them still found respondents recounting stories along similar lines. It seemed impossible to divorce these experiences from the ‘life-world’ of the participants (Kvale, 1983: 174) and still understand the phenomena under exploration.
reported paternalism, condescension and even bullying and incompetence\textsuperscript{111}, for example, reported earlier was Fred’s nine month journey to his diagnosis of cancer (Fred, #1: 3), a dangerously protracted journey which could have cost him his life. Daphne reported being given penicillin-based antibiotics to which she was allergic by her medical practitioner, even though this information was listed in her medical history (Daphne, #2: 3). Linda’s (first!) GP seems to have been similarly negligent and patronising when Linda reported bone pain just months after having her breast removed because of a malignant tumour:

\textbf{Linda:} I had really bad pains to the point where I’d go to lie down in bed and I’d just cry. I couldn’t -- like the pain was so bad, like mainly it was getting, descending down and getting into bed and stuff. On normal days with those sort of movements, sort of moving, “Oooh!” sudden, you know.
\textbf{MV:} Is that how you found out that you had it? [the secondary tumour]
\textbf{Linda:} Yes. Yes. That’s how I thought “This isn’t right.” And that’s when I went to the doctor and he said then, “Oh, you’ve been doing too much at the gym.” I was under my old doctor then and he said “Oh, it’s just muscular” and he gave me these anti-inflammatory tablets to take. And he said “Oh, give me a ring in a few days if you don’t feel any better.” So I rang him back in a few days and said “I don’t feel any better” and he said “Oh. OK. We’d better send you off for a bone scan.” So that was probably, that was probably what made my decision, too, to leave my GP back then, was because he didn’t seem very concerned. And he asked me actually then, he said “Oh Linda, tell me the honest truth, are you really concerned that the cancer is going to come back?” And I said “Yes. I am, especially the way I’m feeling now.” And he just said, “Oh. OK.” Because he said “You can’t be paranoid.” I don’t know if he used ‘paranoid’ but it basically meant... “You can’t worry the rest of your life about cancer.” And I said “But, I’ve got good reason to. I’ve only had it six months ago”\textsuperscript{112} (Linda, #1: 19).

\textsuperscript{111}This section is not intended to denigrate all members of the medical community. Indeed, reports from PwCIC about their doctors also included examples of sensitivity, caring and efforts beyond the call of duty. However, traumatic episodes repeatedly appeared in the stories and could not be ignored.

\textsuperscript{112}Unfortunately, Linda was right. The bone pain was indicative of the presence of a spread of malignancy to her sternum.
Shirley reported a clear abuse of the power relationship with her gynaecologist. It is important to remember when reviewing this story that Shirley is a woman of limited education and with a learning disability; facts which makes this example all the more chilling:

Shirley: He said to me: "Either you have a full hysterectomy or you get another doctor." He was a specialist. He was a gynaecologist specialist.
MV: How old were you then?
Shirley: I was under him for about, I was under him for about five years, so I must have been about 30. Maybe 35? . . . . And he said to me I needed a full hysterectomy. No, I must have been 30 and he said I needed a full hysterectomy. There was no other way out of it (Shirley, #1: 3)\(^{113}\).

Interesting to note in both of these stories involving young, arguably vulnerable, women, was their choice of terminology: that they were "under" the care of their male medical practitioner. The patriarchy pervading the medical profession and consequently evident in the community especially towards women, is well documented (Turner, 1987; Helman, 1990: 138; Bransen, 1992; Denny, 1994: 62; Oakley, 1995: 332; Nettleton, 1995: 139-143). This condescension frequently manifests itself in assumptions of hysteria, depression or hyperchondria. Shirley shared one such example:

Shirley: At 19, I saw a gynaecologist and this really smart very intelligent gynaecologist [sarcastic] just said, "Oh, your body is just going through a cycle. When you get to 26 it'll all be fixed up." So Shirley goes on and she went and saw another gynaecologist who happens to be with the Women's Hospital and he told me it was all in my head (Shirley, #1: 2).

However, it was Fred who articulated the ultimate insensitivity from the medical practitioner

\(^{113}\)Of course there was another way out of it: to ignore his advice and not have a hysterectomy. This is what Shirley did.
who delivered his definitive, "mindblowing" (and wrong) prognosis. Fred recounts this story some five years after the transaction described:

Fred: I had the X-Rays. I had to take them back to him and the minute he seen it he said "I've got some very bad news for you, Fred." I said "Yes, how bad?" He said "It's malignant." And he said [deep breath from Fred] "With the size of your tumour" and this is exactly what he said to me, he said "I think you better go and get your house in order." In other words, get the will made out and all these sort of things. And I said "Oh, you're kidding me aren't you?" and he said "Look, you won't see Christmas." Just like that. Yes. It was real, a bit of a sadistic sort of a bloke, you know, and I don't, I don't really think he meant to say it that way but I just said to "Give it to me straight," you know? I said "Just don't muck around. Just give it to me straight," you know. And he said, "Well, the way things look at the moment, the size of that and seeing it is a malignant tumour and it is growing" he said "You know, you'd be lucky to be here around Christmas. Easter, the latest" he said. Yes, he said "The latest." Oh jeez and then the world really fell. You know I just sat in the chair and I froze (Fred, #1: 6).

Family and Friends: Again, whilst tremendous social support was reported by respondents from friends and family\textsuperscript{114}, certainly this was not universal as was supported in the literature: 'Victims of life crises sometimes have difficulty gaining the support they desire and need' (Silver et al, 1990: 397) which may be a function of the feelings of vulnerability and helplessness evoked in potential helpers and beliefs about appropriate reactions to display towards people experiencing life crises (Silver et al, 1990: 398). Not all social ties may be supportive (Hobfoll and Stephens, 1990: 454) and social support may have a mixed effect (Hobfoll and Stephens, 1990: 461). The literature is distressing in its indication that those 'in greatest need of social support may be least likely to get it' (Silver et al, 1990: 398) and that 'the supportiveness of social ties waxes and wanes as stressful events are confronted and take their toll on the resources of those involved' (Hobfoll and Stephens, 1990: 455). Being a

\textsuperscript{114}This is another inconsistency dealt with in the next chapter.
product of social relations, social support is likely to have costs and benefits associated with it (Hobfoll and Stephens, 1990: 455) and may be dependent upon the perceptions of others of the individual's need for support (Sarason et al, 1990: 18). The problem may lie with how to present the problems to others: 'If they display their distress and report difficulties in coping, they may drive others away. But if they fail to exhibit their distress, they may not signal a need for support' (Silver et al, 1990: 398). Additionally, with invisible conditions, problems may not be readily observable by others. The horrifying conclusion is reached here that PwICl cannot necessarily depend on those closest to them for support, due largely to the "invisible" nature of their condition: 'Our ability to imagine the illness experience and to empathise with those who are ill is severely limited' (Morse and Johnson, 1991: 1). Finally, denial of the illness and its consequences by those closest to us may be infuriating (Szasz, 1991: 168) and even the most supportive relationships may be characterised by negative exchanges including unwanted obligations and feelings of dependence on the part of the sick person (Hobfoll and Stephens, 1990: 462).  

There was evidence in the stories of ignorance, denial, trivialisation, insensitivity, disbelief and even assumptions of malingering. Beverley, with invisible problems associated due to MS reported her former-husband's response to her persistent fatigue (prior to diagnosis) that she was unfit and was not taking good care of herself (Beverley, #1: 16). Linda reported her husband, whilst being very supportive, didn't really understand why she would sometimes 'break down' and cry a lot for no apparent reason (Linda, #1: 4). Fred explicated living with  

\[115\] It is acknowledged that 'social support is not a bottomless well' (Hobfoll and Stephens, 1990: 465) and that, frequently, people who are potential givers of support may not know how to react when dealing with people during a life crisis (Silver et al, 1990: 398). Certainly, this has become abundantly clear to me: I know what I don't like people to do but remain uncertain how they should respond given the volatile, unpredictable nature of crisis situations and my own volatile, emotional and inconsistent behaviours. How are they to know if I do not?
endless unsought advice (Fred, #1: 31) and nauseating pity from friends at his regular social haunt:

Fred: Oh, it's not so much what they say, just the way they sort of looked at you [MV: laughing] and you know what I mean. You could see it in their eyes and "Oh Jeez. Here comes Fred. I wonder if he's going to be alive next week sort of thing." You know.

MV: [laughing a lot] Yes.

Fred: Like "How are you going love? How are you? Are you all right? Anything I can do?" [said in a quiet voice, indicating exaggerated concern] and all this sort of stuff, you know.

MV: . . . How did you feel about that?

Fred: I found it got a bit boring after a while actually.

MV: Yes.

Fred: Yes. I didn't want it.

MV: Did you ever get irritated by it?

Fred: It used to. Yes. It used to and especially down the club too, I suppose. Down the club, not so much at work, I suppose. Mainly down at the club, you know. They think "Oh, there's that guy. He's got cancer. He's dying." [Fred whispering] You know, you can see them telling their friends or, you know. And you have people looking at you, you know, which they'd never looked at you before. So you knew darn well that, what they were talking about (Fred, #1: 30).

For Daphne, the problem with family and friends is different. Daphne feels unable to tell members of her family (only one sister knows), indicating feelings of inadequacy, even failure (as did Beverley), in having MS. She commented that she felt unable to adequately explain the MS to her mother and father (given her parents native tongue of Greek); that the MS was not a problem and so refused to tell them to save them from worrying\textsuperscript{116} and to avert what

\textsuperscript{116} Interestingly, this need to "protect" others dominates in the West. One may see this in the managerialist ethic (Easton, 1995: 39; Rees, 1995a: 15; 1995b: 198; Solondz, 1995: 212; Wheelwright, 1995: 36) and also in the medical community. For example, Elan and Dean (1985: 27) reported the withholding of diagnostic information by neurologists - a course of action that was supposed to be in the patient's best interests. There is no reason to think that this reasoning does not extend to other areas in the community. Indeed, this blanket withholding of truth about illness is referred to, rather sardonically, as a 'noble collusion among doctors, patients and family members to shield the one who is sick from the harshest truths' (Konner, 1993: 4). There is no reason to believe that sick people cannot and do not apply the same logic.
she considered would be a highly emotional, distressed response. This is not unusual: 'Distressed individuals hide their needs and negative feelings from members of their social network so as not to burden, upset, or scare them off, as well as to ensure that others do not form an impression of them as weak or needy' (Silver et al, 1990: 400). Additionally, cultural factors may influence the response to illness (Turner, 1987: 54), incorporating a different 'language of distress' (Helman, 1990: 117), different 'psychosocial interpretations' (Meyerson, 1994: 644), different perceptions of illness (Fitzpatrick and Scambler, 1984: 72) and different role expectations (Turner, 1987: 54). Daphne's ethnic background may be responsible for her and her family's (predicted) response to her having MS. The emotionalism she anticipated was sustained through example: she reported that, during a period of loss of vision in one eye, her mother burst into tears every time she saw Daphne (Daphne, #1: 3). Unfortunately, her apparent feelings of guilt about having MS and her perceived need to protect others in her family may serve to increase the traumatic experience of having MS through inadvertently reducing her access to social support and having to "bear the burden" in silence. It seems that 'just because relationships exist, it does not necessarily mean that they are supportive' (Sarason et al, 1990: 14–15).117

Problems at Work

The issue of self-disclosure of illness or any other potentially stigmatising trait (Jourard, 1971: 6; Lazare, 1992: 232; Rosner and Ross, 1992: 48; Crispin, 1993: 299; Philip, 1993: 14; Vickers, 1996a; 1996b; in press) is a major and complex decision for PwMS, especially in the

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117 From the researcher's perspective, other people's forced cheerfulness during crisis situations was exasperating: the literature confirmed suspicions that people assume they must be cheerful and encouraging to benefit the sick person (Silver et al, 1990: 400), however, their attempts to be cheerful and to provide reassurance are, frequently, unconvincing (Silver et al, 1990: 400) serving only to irritate or trivialise the serious nature of the situation and may, falsely, convey a lack of understanding and care.
workplace (Vickers, 1996a; in press). Theoretically, PWI have the choice of "information control" (Goffman, 1963: 113; 1969: 123) or playing 'the information game' (Goffman, 1969: 7) not available to those with visible disabilities, which can be so important in 'validating the self' (Lindesmith and Strauss, 1968: 286); of 'impression management' (Goffman, 1969: 208; Young, 1989: 153; Turner, 1991: 124); 'self-presentation' (Turner, 1991: 124); 'protective practices' (Goffman, 1969: 12); 'idealising social performances' (Goffman, 1969: 30); 'self-knowledge' and 'knowing how' to present the self (Gergen, 1989: 75); hiding, displaying and controlling the social self (Wilmot, 1975: 44; Parker, 1989: 67; Parsonson, 1989: 219); and of 'social being' (Harré, 1993). Nine of the respondents must, in the first instance, have disclosed their illness to someone, sometime, or the researcher would not have been introduced to them. (Only Maryanne volunteered to participate.) However, what became clear in the stories was that in all cases of employment disclosure, the disclosure had apparently been forced on participants, whether they were conscious of this or not. So, whilst, in the first instance, the researcher believed herself to have been talking to a group of "free-and-easy-disclosers" (my colloquialism), deeper reflection revealed that many worked for their current employer during the diagnostic process, as was the case for Fred, Rodney, June, Daphne, Linda and Beverley, or had been previously known personally to their employer (Shelley). For Linda, her distress was public when she received a phone-call at work about her secondary cancer (Linda, #1). Fred clearly demonstrated that when the diagnosis came he had little choice but to share it with colleagues:

Fred: Yes, because they used to see me walking around like this [indicates his arm being up against his chest, supported by the other arm] and doing this and all sorts of things, and walking around, and they knew. They used to always say to me "What was wrong?" And then once I started going through all this treatment, going to physio and all these things, everyone was aware of all that. And when I went and had the CAT scan done and all that
type of thing, and then when I actually got the d-, when they actually said to me, naturally the word spread around, everyone, well you know, you tell one person and they tell everybody, you know (Fred, #1: 17-18).

Jourard (1971: 65) suggested that one of the most powerful determinants of self-disclosure is the relationship between the two people. Crispin (1993: 300) confirmed this need for trust, intimacy and reciprocity in authentic relationships for deeply intimate information to be revealed. The author would add a temporal dimension: when a person receives the news of a potentially life-threatening, chronic or disabling illness, they are not likely to sit quietly and think through the possible ramifications of their choice of disclosure (Vickers, 1996a). They are what one may term "disclosure ignorant" due, in large part, to their naivety in dealing with a stigmatising illness. Interesting also, was the response to the question of disclosure with a future employer: most had remarked that their condition didn’t affect their ability to do their job (Rodney; Daphne, Beverley, Shelley, June, Shirley). Most also stated that they didn’t mind people knowing (although this statement is under scrutiny in the next chapter). However, all disclosers seemed uncertain as to how they would handle the most difficult decision of disclosure when confronted with their next prospective employer. Beverley, perhaps more than anyone, let the "truth come out" after a lengthy, rational and (almost) plausible explanation:

**MV:** Do you ever think you’ve been discriminated against because of the MS?

**Beverley:** No.

**MV:** Do you think it ever might happen in the future?

**Beverley:** [Pause] I suppose it could, but I mean, I guess I know that I do my job really well, and . . . I mean there are limitations on the fact that I’ve got responsibilities to kids and they’re young or youngish and so I can’t put in long hours, and anything much higher than what I am now would require a bigger commitment and less assurance that I’d be able to get to them both the times that I had to and things like that. So I think it’s limited a lot by that.
But I also think that if, you know, if I went for any SES jobs, you know, the higher executive jobs and things or if I wanted to sort of take my path up through that then I'd have to be fairly honest and say "Look, I have got MS and this" because it does place limitations on you and whether you like it or not, you know. I think you have to be honest about that. So people do have an opportunity to think "Well, OK. If she's got MS, I don't want her." And as I said, theoretically, in the public service they shouldn't be able to do that, but I think that they'd have to. I mean if I was honest with them and told them that there were limitations then they'd have to take that into account. And I mean I think that's realistic. I don't know that that's being necessarily discriminating. I think it's probably realism, apart from discrimination.

MV: And, and if you told them, you were honest with them and, and then you really thought that it had influenced their choice, a choice against you, how would you feel about that?

Beverley: Oh [Pause; indicating discomfort]. It would depend on whether I thought that I could do the job myself and then I'd be pretty pissed off. But I mean if it was a job I really wanted and I thought I could do it I mightn't tell them anyway [Peels of laughter from both!].

MV: The truth comes out! I love it [laughter].

Beverley: Not before I'd signed on the dotted line anyway (Beverley, #2: 15-16).

Most respondents did indicate some problems at work and whilst these didn't prevent them from doing "a good job", they made certain aspects of the job more difficult. Rodney reported problems with sitting for long periods in the office and lifting anything substantial, such as heavy printouts (Rodney, #1); Fred reported substantial problems for a sales representative driving the car and doing paperwork (Fred, #1: 26). For Daphne, going to client sites presented problems, not just in terms of driving the company car there, but in socialising with clients there (Daphne, #1). Shirley reported pain from endometriosis whilst having to walk around the office (Shirley, #1: 5); Beverley reported feeling 'fuzzy', not coping and not doing her job as well during an MS exacerbation (Beverley, #1: 2-3; 11-12). For Shelley and Daphne asking for time off when it was needed also presented some difficulties for them (Shelley, #1; Daphne, #1). The problem of getting to work was evident.
in some of the stories, if not now, a perceived potential problem for the future as well as the potential threat to livelihood. For June, further visual deterioration would preclude her driving to work. For Beverley and Daphne further deterioration of their MS would present problems getting to work, either in driving and catching a bus (Beverley, #2) or, in Daphne’s case, she had already reached a point where travelling on the trains during peak hour is too difficult (Daphne, #2).


MV: You made a comment in our last meeting and I quote “generally speaking, I don’t think most people like to admit that they’ve got a problem, or they can’t cope with things, particularly in this sort of environment in here.” What is the environment like in here?
Rodney: I guess what I meant by that was -- not necessarily yuppies, but people who would consider themselves as upwardly mobile, who want to get on. . . . Generally speaking the people in this department are degree qualified and have a postgraduate qualification - professional, masters or whatever, and want to get on. So, don’t want to exhibit signs of weakness.
MV: So tell me why you think exactly, why wouldn’t people want to admit that they’ve got a problem? Why wouldn’t they want to show weakness?
Rodney: Oh, because that would, they would be concerned that it would restrict their
progress up the corporate ladder. That doesn’t say, I think I said to you before it doesn’t, I prefer actions to speak louder than words. . . . Either I’m good enough to do the job or I’m not. If I can’t do the job, one way or the other, then you can’t. I don’t think you can wish yourself into it. Yes. If there was a lot of physical activity involved at the next stage up the corporate ladder then, yes, if I can’t do it, I can’t do it. Fullstop (Rodney, #2: 6-7).

Finally, there is an expectation in respondents that the illness is 'their' illness; that it should be their choice to disclose, or not, to others. Shelley (#1: 17) recounted the story of her "friend", who unwittingly told a prospective employer about Shelley’s leukemia. Shelley was angry about this and was subsequently confused as to whether to continue with the job application at all. What the prospective employers might think, what they might ask during the interview, how far the information had gone, what she should now tell them, and when, concerned her. She concluded:

Shelley: She did it on one hand for me in recommending me but on the other hand I’m thinking “Oh gosh, that’s just lost me the job.” I don’t know which way it will swing. It could swing either way, but I feel in them knowing I wouldn’t get the job even though they’re in a hospital situation (Shelley #1: 18).

The Disease Process

The physical aspects of chronic illness seemed also to be quite traumatising, especially for the individual still maintaining (full-time) employment. Symptoms reported from respondents that were likely to make their working (and home) life difficult included chronic or acute episodes of pain (Rodney, Shirley, and Maryanne); persistent fatigue, even exhaustion (Beverley; Rosalie; Daphne; Maryanne); cognitive problems (Maryanne; Beverley); emotional lability (Maryanne; Rosalie); and nausea, vomiting and very heavy menstrual bleeding (Shirley; Maryanne). Most of these manifestations are substantially invisible.
In addition to problems caused the ICI, iatrogenic effects were also heavily reported. Rosalie (#1) found that her veins collapsed from constant vitamin infusions; Fred (#1: 9-10) lost the use of his right arm for months, with his voice also slightly affected from the radiotherapy; Shirley (#1: 9) described several medical interventions including several abdominal curettes and a major piece of surgery where she described the disconnection of all nerves in her abdomen; Beverley reported "bruising" from her Betaferon drug trial therapy and pain when injecting the drug (Beverley, #1: 5); Shelley hated getting fat from steroid (prednisone) use and losing all her hair from chemotherapy (Shelley, #2); and Linda reported that, in addition to losing her breast to cure/treat her breast cancer, she became very hyperactive after chemotherapy (Linda, #1). It was recognised that in some cases the loss of functionality or attendant symptomatology associated with drug use or medical procedures was worth the benefits: for Fred, Shelley and Linda, the meaning of medical intervention for them was an extension of life - a worthwhile trade-off. However, this was not always the case. Maryanne described treatments to her bladder that have exacerbated the pain and difficulty controlling her bladder, and left her feeling violated and devastated (Maryanne, #2: 16-17).

Another issue, not widely discussed by respondents, must be the cost of illness (Curtin and Lubkin, 1990: 13). Sickness and disability almost inevitably mean extra expense (Blaxter, 1976: 90). Beverley reported that her drug, Betaferon would cost in the order of $18,000 per year if she had to pay for it herself (Beverley, #1: 10)\footnote{Prior to being included in the Pharmaceutical Benefits Scheme (PBS) in Australia, from November 1996 (James, 1997: 25), Betaferon was available to ambulatory people with relapsing-remitting MS at a cost of $1500 per month (Mortimer, 1996: 14). Being on the trial Beverley would have paid nothing, although the inclusion on the PBS means she can now have access to the drug at around $20 per month.} Fred reported that the payable portion of his cancer treatment was marginal compared to the total cost incurred, noting the...
benefit to him (Fred, #1: 25) in terms of life expectancy. However, it was deemed surprising that there was not more discussion about this. Medical treatment, doctor’s visits, drugs, hospital stays: all cost money (even with private health insurance) and at a time when income may be drastically reduced. These must surely be important considerations. Without merely dismissing this anomaly it is concluded that there may be one of two possible reasons: first, that in the scheme of the shock of discovery of the diagnosis and all the attendant social and psychological ramifications thus wrought, money is not considered to be a primary issue. Secondly, perhaps PwIC believe that they should not be complaining about how much it costs to get well (or not get well), feeling, instead, that they should be eternally grateful for the medical attention received. The researcher leans on her own experiences here, concluding that the illness costs do matter, although may be rarely discussed outside the home which may explain their absence in the stories here.119

In the next chapter the phenomenological model is extended to include themes of ambiguity and inconsistency, themes of survival and, finally, themes of optimism.

119 The issue of financial coping is discussed in the following chapter.
CHAPTER SIX

Life and Work with "Invisible" Chronic Illness: Themes of Ambiguity, Survival - and Optimism

The crisis deepens for Michael and I. Reminding myself of the importance of the researcher's experiences in this Heideggerian, phenomenological study, especially as an "insider" to the phenomenon, I feel compelled to record more of my thoughts whilst immersing myself in the task of analysis. This is a rather painful and depressing assignment, but I procrastinate no longer.

As I continue working on my thesis, my own ICI (multiple sclerosis) presents problems. Due to the crisis unfolding with Michael I have, through necessity, pushed thoughts of my own condition to the outer reaches of my mind: it is simply too appalling and too fearsome to comprehend that my own health could be falling apart, as is his. Finally, last week, I admit defeat. Both my feet are without feeling; my right hand is feeling strange, thick as if it doesn't belong to me; and my speech is becoming increasingly tortuous and jumbled. If I continue to ignore this any longer I will shortly not be able to drive the car or sign my own name; reasonably important functions in most people's lives, mine being no exception. There is no guarantee of resolution but I guess I really should see if anything can be done.

A brief consultation with the Neurologist confirms treatment is recommended: a "pulse" of Prednisone to be administered intravenously as an outpatient at the hospital. Enquiries about the likelihood of side-effects are met with a definite response: 'You shouldn't experience any
problems.' I ask: 'Can I still work?' The reply: 'Oh yes.' The only noted problem was the possible long-term effect (decalcification) of my bones.

Well, the rather euphemistically named "pulse" of prednisone has seen me nauseous, turn yellow, then grey; feel pain, palpitations and hot flushes, my face swell up like a balloon; be unable to do anything that meant remaining awake or getting out of bed; uncharacteristic aggression; and what I would describe as general and complete, debilitation. And no wonder: Michael currently takes 50 milligrams of the drug on a daily basis (what is generally considered a very high dose); I have been subjected to one gram a day, for three days; 20 times his dose and straight into the vein. I regarded the symptoms experienced as being somewhat problematic during sensitive, phenomenological interviews. The interviews were postponed and the respondents inconvenienced were, I thought, rather understanding when hearing of my predicament.

As I write this, however, the first work I have done since entering the hospital five days ago, I can feel my toes, intermittently, for the first time in six months. I feel an irrepressible and ridiculous sense of optimism (Vickers, 1996e).

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I have the courage to write again. A lot has happened since the last note. I did recover most of the feeling in both my feet and right hand after the Prednisone treatment. It took about a month or so. Unfortunately, my respite was short lived. For about the past four weeks my entire right side is completely without feeling from my chest down and I have been having
difficulty emptying my bladder. This is not good: two successive attacks in just months.
The "pulse" of Prednisone is not available again so soon after the last one (indicating a high
level of toxicity). The neurologist says, "No more than twice a year."

I am terrified that I am sliding into the progressive form of MS where the inexorable down-
hill shift will become swifter, more far-reaching and without reprieve. I am fearful, so fearful
in fact, that I have reached the point of being reluctantly prepared to try the new drug,
Betaferon. I have been incorporated, initially, into a trial programme prior to it becoming
publically available.

Ambivalence reigns. On the one hand I am heartened; there have been some good results
with this drug lessening the severity and number of attacks for people with MS. However,
Betaferon is still essentially an experimental drug. With all that I have read about iatrogenic
illness, I go into this with my eyes wide open. I know that the dosage is likely to be hit-and-
miss at this early stage and the reported side effects don't particularly thrill me either:
depression, even suicide, have been recorded (a definite concern given my recent mental
health), aggression, "flu-like complex" (aches, fever, general malaise) and skin reaction at the
injection site. Oh yes - it is an injection. I am officially, starting this evening, becoming an
injecting drug user.

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120I note my reluctance to share such personal and stigmatising symptoms. It would have been so easy
to omit these; "forget" them. Lazare (1992: 233) confirmed feelings of stigma attached to diseases associated
with sexual or excretory organs and the anticipated unfavourable reactions of others; this certainly doesn't make
me feel any better about it. I am also struck by the difficulty in sharing the "experience" of these symptoms.
How does one explain to another, who hasn't lived it, what it is like to have no sensation whatsoever over almost
half one's body? Loss of sensation, in particular, is not a problem likely to be taken very seriously by others;
after all, I can still walk can't I? And how does one explain how disconcerting it is to not be able to empty
one's bladder at will? I have no answer. It is easier not to talk about it.
Every two days I somehow have to summon the courage to voluntarily plunge a needle into my thigh or belly. I hear it isn’t much fun: one of my respondents has been involved in an earlier trial and has been injecting herself in this fashion for the past couple of years. I rang her last week to get some moral support. It was a positive, I guess, that from my own research I have been able to draw some solace and support. She didn’t have any symptoms from the drug (although she doesn’t know if she’s taking the placebo or not) except “bruising” at the injection site: one “bruise” never actually went and she is continuously sporting half a dozen marks from previous injections. Just what I need at the moment: another threat to my already battered self-image. She also tells me that she hates injecting herself and that it hurts. Great.

I don’t need to have the flu every second day, become even more depressed, look bruised and battered, and take more medication (paracetamol for the flu-like symptoms or anti-depressants to ward off suicide) to combat the effects of the first! However, I will give it a go. What choice do I have? I think three months will be my limit if I react badly. I am not prepared to forego a complete reversal in quality of life to take a drug that may help, but will not reverse any damage already done or, necessarily, prevent future problems.

The difficulty here, of course, is not just that I have MS: nothing in our lives is getting better; there is nothing to look forward to. Michael is getting worse: slowly, almost imperceptibly, but definitely worse. It is no fun to watch your mate deteriorate. He is not responding to his drug therapy (although the Prednisone also makes him aggressive - what

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121 These marks are injection site reactions; areas of redness indicating inflammation as a result of the serum being rather acidic, rather than a bruise which would indicate bleeding under the skin.
a happy household we’ve become) and a recent review of the literature on neuro-sarcoidosis painted a rather ugly picture. No-one has been reported to have improved markedly, let alone recovered completely. In one study, half died directly after the brain biopsy\textsuperscript{122}; others died later: apparently, the best we can hope for is no further decline.

Life could be better: Michael is deteriorating; the insurance company won’t pay; we don’t have any money; and my own health has deteriorated to the point of becoming a “junkie”. I guess when you think things can’t get any worse, you should prepare yourself for the reality that indeed they can. But I can’t think about that now.

What I will do is have another glass of red wine; "dutch-courage" for that first injection. Then it’s on with the training video and start injecting (Vickers, 1996f).

\textsuperscript{122}Without doubt, the worst day of my life was the day I had to decide whether or not to allow the doctors to perform a brain biopsy on Michael. I knew all the risks: the neurosurgeon calmly pointed out the risk of "a bleed" or of death, in terms of percentages. Of course, I couldn’t have cared less about all the other "statistics" who had survived or not: I was concerned about Michael. I had to allow it, with all the reservations I felt, in order to get a diagnosis. Why? Because administration of the wrong drug (for example, Prednisone, if a malignant tumour remained un-diagnosed) would have been disastrous; a malignancy would have gone rampant. No-one knew what was wrong with him and we had to try and find out. An interesting aside: during the operation for which he was awake the entire time ("No pain fibres in the brain to worry about" said the neurosurgeon), Michael heard the neurosurgeon saying, "Gee, I’ve never seen anything like this before." How comforted he must have been. The surgeon then neglected to come and tell me at the end of the operation whether Michael was alive or dead, let alone what had been discovered. I’m glad that day is over.
Introduction

As we continue the passage of trauma reported by PwIC, I move to themes of ambiguity: a theme characterised by contradiction, inconsistency and uncertainty - stories rife with ambivalence, confusion, complexity and, consequently, trauma. These were findings not anticipated by the researcher, although subsequent reflection on this researcher’s own life confirmed the centrality of this theme. It is a concept not widely reflected in the health, management or human resources literature reviewed to date, nor is it one likely to have been widely addressed in modern times. As with the themes portrayed in the previous chapter, these experiences are iteratively and intersubjectively experienced. Later in this chapter, the author moves beyond themes of ambiguity to authentic stories of survival and, finally, happily, to conclude with themes of optimism and renewal.

Themes of Ambiguity

Consistency is probably an over-used word in social psychology and may be taken to mean "compatible," "similar," "non-contradictory," "conforming," "in agreement" or "congruous"... it may be true that a person’s attitudes are sometimes consistent with his behaviour, but it is likely that as laymen or as psychologists we expect this consistency more often than it is actually present (White, 1982: 3).

Contradictions and inconsistencies in the stories, the reasoning and the behaviour of respondents, have been notable and frequent. In fact, respondents have contradicted
themselves within the same sentence, between questions, between interviews and in word versus deed. The author is not alone in grappling with conflictful stories of illness and work: Pinder’s (1995: 614) study of women with arthritis also demonstrated such a phenomenon.

When considering the stories, one must remember that, on the whole, people want and expect consistency in themselves and others. Individual cognitive consistency was recognised as being tied closely to impression management; indicating that we strive to be, and want others to think we are, cognitively consistent (Kahle, 1984: 31). There is a need for coherence that stems from seeing ourselves as accountable for the meaningfulness of our lives; for coherence of identity (Mann, 1992: 275). There is a presumption that attitudes and behaviour should be consistent (White, 1982: 47) and it has long been an axiom in social psychology that attitudes towards a particular topic become more consistent over time (Foddy, 1993: 66). Consistency is expected in the stories of others (White, 1982: 3) and it is consistent arguments that are valued: ‘Since we expect others to be consistent, we value them when they are so’ (White, 1982: 4). Being consistent is seen as socially desirable (White 1982: 55) and we should be consistent in a manner that is ‘socially accountable’ and ‘rationally visible’ (Shotter, 1989: 140): ‘For, even as adults, our status is a morally tenuous one and if we fail to perform in both an intelligible and legitimate manner, we will be sanctioned by those around us’ (Shotter, 1989: 141). In constructing the self-narrative, the story-teller endeavours to establish coherent connections and describe intelligible events leading to a ‘narrative order’ - essentials for researcher understanding (Gergen and Gergen, 1984: 173-174). ‘Thus, the script is guided by respondent’s wanting to be heard and ‘because we do not want to be seen as not “living up to” what is expected’ (Mann, 1992: 274).
As researchers, 'we may be looking for coherence in our subject's life story in order to maintain our own sense of ontological security' (Mann, 1992: 278), especially likely if one is an 'insider' or 'intimate' (Wilmot, 1975: 59) to the phenomenon under exploration! Narratives are jointly constructed as linguistic devices that are the product of interacting persons (Gergen and Gergen, 1984: 184; Mann, 1992: 273) and are as coherent as possible (Gergen and Gergen, 1984: 183). There is an assumption of truth about narratives, although 'one can be accurate or inaccurate with regard to reporting facts and, second, ... one can be correct or incorrect with respect to the relationship among facts' (Gergen and Gergen, 1984: 182). Many psychological theories have been developed reliant upon the tenet of consistency in attitudes, beliefs, ideas and opinions: Heider's (1946; 1958) balance theory, Newcombe's (1968) theory of interpersonal balance and Festinger's (1957) cognitive dissonance theory (Heider, 1946; 1958; Newcombe, 1968; Festinger, 1957; all cited by White, 1982: 20-27). Finally, expectations of consistency are used to predict the behaviour of others (White, 1982: 3) and to enhance and preserve self-esteem (White, 1982: 5). If we violate our expectations of consistency that are appropriate to the situation and consistent with our self-concept we may feel that we are 'playing a game' (as opposed to 'hiding our real self') (Wilmot, 1975: 52). Whether the assumption of consistency is reasonable or not, 'it allows us to predict other people's behaviour and attitudes, and without it social life would seem incoherent and confused. It can be no exaggeration to say that social life is dependent upon social behaviour being predictable' (White, 1982: 145). Social life is, then, empirically stable, but intrinsically variable (Kouzmin, 1997).

However, inconsistency may not necessarily be problematic (Burgess-Limerick, 1995: 20). Contradiction may be argued as being a necessity, belonging to the very nature of human
thought even though conventional wisdom tell us that contradictions are illogical (Marcuse, 1964: 142) and consistency is "good." Games may be played based on the deliberate concealment by the actors during interviews (Perinbanayagam, 1985: 14), with misinformation being intentional (Goffman, 1969: 2) and masks being indicative of the "truer" self one would like to be (Goffman, 1969: 17). The individual may be reflexively using narratives to reconstruct a sense of self (Young, 1989: 154); the contradiction may be a result of the ontological struggle being had between the researcher and teller (Mann, 1992: 278) or just the inaccuracies that arise from the process the teller must be involved in, of stepping outside themselves and "seizing" perceptions, memories and fantasies that constitute one's subjectivity and welding them into a form derived from, but other than, oneself" (Mann, 1992: 278); creating discrepancies from reality (Bruner, 1986: 147) on both the researcher's part, and the teller's.

Ambiguity may be based on the creativity involved in everyday discourse where 'irony, sarcasm, paradox and purposive ambiguity are not merely literary techniques but aspects of everyday discourse' (Perinbanayagam, 1985: 55) and would be correctly regarded as a measure of grace, not just deception (Perinbanayagam, 1985: 56-57). There may be a vast disparity between the intended message and the perceived message (Young, 1989: 153), which may be affected by 'multiple selfings' of the storyteller (Goffman, 1974b: 521; Young, 1989: 154) or the 'frame analysis' employed by the listener (Goffman, 1974b). Whatever the reason(s) for the ambiguity and inconsistency observed here, for this researcher one thing is certain - it is indicative of a highly complex, interwoven, unresolved set of problems faced by PWI CI.
Within the organisational context, ambiguity and uncertainty may be amplified. Contradiction and conflict in organisations (indeed all social systems) is often denied with the portrayal of social systems as neutral, rational and instrumental agencies (Kouzmin, 1980: 148; Shrivastava, 1986: 366; Argyle, 1989: 215) and yet many of the most significant events and processes in organisations are ambiguous or uncertain (Bolman and Deal, 1991: 244). Contradictions are inherent in modern social institutions arising in the midst of current social ideologies, such as technical rationality (Denhardt, 1981: 68-69). The greater the volume of ambiguity and uncertainty 'the harder it is to use rational approaches [for] analysis, problem solving and decision making' (Bolman and Deal, 1991: 244). With rational responses not being ultimately helpful and being faced with uncertainty and ambiguity, the response from PwICl may be to create symbols to resolve confusion, increase predictability and provide direction - to make illogical events seem otherwise (Bolman and Deal, 1991: 244).

For the story-tellers in this study, the need to increase predictability and resolve confusion is stark. The symbols? - their stories. The inconsistencies found here were indicative of more than just personal presentation management or of organisational inconsistency and idiosyncrasy. The stories are indicative of a turbulent, constant, inner-conflict; of wrestling, consciously, and unconsciously, with issues that have no right answer, no best approach, no easy solution.

About Illness

Illness Disclosure: The issue of illness disclosure is a complex one for PwICl. The literature indicates that few with stigmatising conditions would willingly disclose their existence (Goffman, 1963; Becker, 1963; Jourard, 1971; Scambler, 1984; Nijhof, 1995; Philip, 1993: 232
14; Jones and Stone, 1994; Vickers, 1996a; in press) unless, perhaps, sufficient trust and intimacy exist to encourage this (Crispin, 1993: 300). This reluctance for 'negative self-disclosure' (that is, disclosure of negative information about the self) (Crispin, 1993: 302) may be for various reasons: realistic concerns about discrimination may exist (as supported by, for example, Aikin, 1989; Crispin, 1993: 300; Philip, 1993: 14-15; Jones and Stone, 1994: 3); sick people may feel shame (Scambler, 1984; Nijhoff, 1995; Lazare, 1992: 227) or humiliation as a result of their condition (Lazare, 1992: 227); they may not feel sufficiently courageous to share such personal and negatively perceived information about themselves (Crispin, 1993: 299); the time or circumstance may not be right (Crispin, 1993: 303; Philip, 1993: 4); they may not trust the other person sufficiently (Crispin, 1993: 300; Philip, 1993: 3); the bearer may prefer to diminish the importance of the condition in their life (Rosner and Ross, 1992: 149); or they may prefer to remain in their 'private place', especially given the loss of privacy in institutional life (Jourard, 1971: 70).

Given all of these concerns, understandably, contradiction was often apparent with regard to the issue of disclosure. For example, Daphne asserted that she doesn't mind people knowing (Daphne, #1: 3) and, yet, as was described in the previous chapter, she has not told most of her family and very few of her colleagues: she will not relay the "real" reason to colleagues for her using the telephone rather than walking to see team members and, when asked, admits only to being 'lazy' (Daphne, #2: 4). Similarly, Beverley asserted that she doesn't mind people knowing that she has MS; that she's 'not embarrassed by it' (Beverley #1: 12) and that 'it's much easier to just say "Look, this is what it is. Here's how it affects me and when I'm affected, please, you know, behave in such-and-such a way"' (Beverley #1: 16). Indeed, Beverley reported a phase of telling everyone about her MS, a 'compulsive urge to be honest
about it' that was awful' (Beverley #2: 17). Yet, Beverley also asked me to 'talk softer please' when a neighbour in the garden adjoining hers (where the first interview was being conducted) might have been able to overhear our interview conversation (Beverley, #1: 4).

What the researcher is hearing is that perhaps some PwIC want to be able to disclose easily: they don’t want to feel ashamed, embarrassed or "different". The discrepant reality arguably exists.

Some are demonstrably less keen on others knowing. Reasons given for not wanting to disclose to others, especially a potential employer, varied: other people didn’t need to know (Shelley, #1: 3 and 5; Beverley, #2; Shirley, #1); they did not want to be treated 'differently' (Shelley, #1: 3; Beverley, #2: 21); that it was no-one else’s business (Shirley, #1: 13); that they had a 'female problem’ and a male boss (Shirley, #1: 8); they did not want any special treatment or sympathy (June; Shelley; Daphne); they did not want to admit a problem existed in case it showed weakness (Rodney, #1: 16); or, perhaps, most incisively, they wouldn’t tell because it couldn’t be seen (Fred, #2: 14). However, these seemingly plausible reasons were also, frequently, contradicted. For example, Shelley reported initially:

Shelley: I don’t tell anybody because I guess they don’t have a need to know. I feel they don’t need to; it doesn’t make me any different a person and I’ve found that in a lot of ways people tend to treat you differently if they know (Shelley, #1: 3).

and yet, later, in the same interview she admitted:

Shelley: I guess in a way they had a right to know if one of their staff, I mean we all
work as a team, so in that respect maybe -- It's probably better that they did know so that when I came back they were aware, to sort of help me with things that I couldn't do. The lifting and stuff like that (Shelley, #1: 4).

What does this kind of contradiction mean? The complete answer continues to elude this researcher, however it is likely to be indicative of the inner turmoil, conscious or unconscious, that resides in the minds and hearts of PwICI. It is arguably also part of the construction of the story as it is being told (Gabriel, 1991: 857-858); of making visible the 'rationally invisible' to the story-teller (Garfinkel, 1967; Shotter, 1989: 141-142); the fruition of a perspectival truth based on personal interpretation which is a result of social negotiation (Gergen and Gergen, 1984: 184) between teller and listener; of narratives being used to reflexively reconstruct the PwICI's sense of self (Young, 1989: 154); with the telling constitutive of an inner phenomenological stream of consciousness and an outer interactional stream of experience (Mann, 1992: 272). Whilst the self-narrative is a story constructed from self-relevant events that have unfolded over time, requiring the storyteller to maintain some coherence and intelligibility so the listener may understand (Gergen and Gergen, 1984: 174), one should note that telling the story may change it (Bruner, 1986: 146, my emphasis) and, in this case, the telling of the 'life-story' (Burgess-Limerick, 1995: 23; Nijhof, 1995: 195) may have involved addressing experiential truth (Burgess-Limerick, 1995: 23) confronting issues never before consciously dealt with.

As the stories were constructed by respondents, evidence of inner conflict about issues of import presented itself. For example, when Shelley described the 'underlying worries' that she has with leukemia 'that other people aren't aware of' (Shelley, #1: 15), the researcher asked her what she would like them to do. The turmoil is evident in this uncertain response:
Shelley: I don’t know. I mean there’s not a lot they can do really, because it’s not really so much, at the moment it’s not physical, it doesn’t bring me back physically, except for the lifting business. I guess because I look well they tend to just forget or I don’t know whether they just ignore or forget. I’m not really sure, I mean, I don’t know (Shelley, #1: 13).

Work Performance: Much conflict was reported in the stories about illness affecting work performance. The influence of Weber’s ‘protestant ethic’ (Whyte, 1956/1963: 9; Perinbanayagam, 1985: 94; Argyle, 1989: 111; Beilharz, 1991: 225; Kets de Vries, 1995: 47) and its attendant moral imperative (Whyte, 1956/1963: 11) invoking guilt and shame (Perinbanayagam, 1985: 94) was evident in many of the stories. Respondents were often inclined to deny that their conditions affected their work, perhaps not wishing to admit weakness or any loss of functionality. This may be due, in part, to deployment of various Freudian defence mechanisms (Bowlby, 1980: 140; Kline, 1984: 20; Carr, 1989: 30; Parsons, 1989; Oldham and Kleiner, 1990; King and Singh, 1989: 63), especially rationalisation (Goffman, 1969: 183): respondents may have believed what they were saying, having rationalised or repressed the "truth", or responses could be symptomatic of ‘impression management’ (Goffman, 1969: 183; Forgas, 1985: 180; Young, 1989: 153; Turner, 1991).

For example, Daphne explained that she doesn’t think that having MS affects her work, that she still does her job (Daphne, #1: 4) and yet when discussing travel to client sites: ‘There are some problems. We have company cars that we usually take and I try not to do the driving even though they are automatic. So one of the other people drives’ (Daphne, #1: 6). She also reported her inability to type now with her left hand (Daphne, #1: 9) and problems with fatigue. When explaining what it is like to have MS and go to work she confessed:
Daphne: I think probably its mostly frustrating because I can’t do as much as I used
to in that I get tired more easily . . . . I tend to be careful not to go out, like before I would
go out at lunch for an hour, even a long walk or to the shops or whatever. I try not to go out
at lunch because it shortens the afternoon. I get tired more easily (Daphne, #1: 7).

Similarly, Shelley (#1: 2 and 17) reported that ‘it doesn’t really’ affect her. Shelley
subsequently outlined: her compromised immune system (Shelley, #1: 2); problems if she
contracts an infection (Shelley, #1: 2) involving swift hospitalisation; a great deal of trouble
lifting, an iatrogenic result of numerous lumbar punctures she has endured\textsuperscript{13} (Shelley, #1: 2);
the need to go home if she has a headache to avoid them escalating into migraines (Shelley,
#1: 8); and a day off every three months (Shelley, #1: 18) for medical treatment. Similarly,
June reported that the glaucoma hasn’t affected her at work yet (June, #1: 14): this after
describing three months off work, laser treatment in both eyes, a major operation on one eye,
as well as difficulty reading and writing up reports. June also regularly asks people at work
to read things for her (June, #2). Rodney assured me that his back problems do not really
affect him at work (Rodney, #1: 3) and that ‘day to day at work I don’t really notice it.’
Rodney then portrayed the usefulness of the keyboard support on his desk, the care he must
take in choosing a chair with adequate back support, how he cannot lift boxes or printouts,
and difficulties he experiences sitting for long periods. Finally, Shirley (#2: 5) vehemently
denied the pain associated with her endometriosis not stopping her from working. ‘If it
stopped me from doing my job, I would do something about it. But it does not stop me. It
just makes me feel discomfort and you just, and I’ve been feeling discomfort all my life. You

\textsuperscript{13}The term ‘endured’ is chosen carefully. A lumbar puncture or spinal tap is ‘a procedure in which
cerebrospinal fluid is withdrawn by means of a hollow needle inserted into the subarachnoid space in the region
of the lower back (usually between the third and fourth lumbar vertebrae)’ (Martin, 1990: 396). This is a
procedure that both Michael and I have experienced. For Michael, having this procedure at age 43, the pain was
excruciating, reducing him to tears. I ask him as I write this note of his recollections. He comments, with some
feeling: ‘It was worse than the brain biopsy.’
just put up with it. I just take Panadol" (Shirley, #2: 5); this after describing in the first interview problems with vomiting, not able to stand (#1: 2), being white in the face and 'really, really heavy bleeding' (Shirley, #1: 1) during menstruation.124

**Illness Progression:** Ambivalence and ambiguity can be clearly felt toward the illness and its possible outcomes. The uncertainty and unknowability of living with a chronic, potentially disabling or life-threatening condition was reflected in many stories: Fred (#1: 36) described still going to bed at night and thinking about what might happen; a poignant comment from Beverley: 'It's really scary isn't it?'125 (Beverley #2: 9) whilst, simultaneously, feeling that the MS had helped her self-confidence (#2: 14), helped her to prioritise (#1: 17) and that she is even admired by others for qualities that she doesn't believe she has (#1: 19). Shelley reported worrying about what will happen in the future, what the doctors are going to do for her (Shelley, #1: 16-17) and yet, later,

Shelley: I let [the doctors] do the worrying and, in a lot of ways, mum does the worrying for me. Even temperatures I ignore and shouldn't, and mum does a lot of that (Shelley #1: 17).

The notion of, and beliefs surrounding, "disability" also presented ambiguity. For example, Shelley's comments about disability reflect the widely held view that disability encompasses wheelchair use or some other suitably visible impairment; that her problems do not constitute a "disability":

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124 It is vital to note that the researcher was not trying to invalidate or question any aspect of respondent stories by uncovering inconsistencies: there was a concerted attempt to understand their life-world with ICI and this seems to include inconsistency.

125 The researcher's response to this? 'It's really scary. Yes. Yes.' (Beverley, #2: 9)
MV: Does your organisation have any policy about illness or disability for employees that you’re aware of?
Shelley: Not that I know of. No. I think it would be very hard to work in a child care setting with a disability. I really do. No. [What does she think she has???] Because there is so much lifting and bending, sitting down on the floor, getting up, running around with the children, it would be very hard with a physical disability to work in a situation like that. I think I would probably, if I was to do my back, or something like that, I’d probably have to find another job in that sphere. I don’t know. I don’t know if they’ve got any policy though. I’m not really aware of it (Shelley, #2: 13).

For Rodney, attitudes about disability changed over the course of the two interviews:

MV: You don’t consider yourself disabled in any way?
Rodney: Hell no!! [A strong reaction, almost an over-reaction to the question.
Respondent seemed somewhat offended or annoyed] (Rodney, #1:7-8).

and yet, in the second interview, when asked about disabilities that can’t be seen and a possible example, he responded:

Rodney: Mine [Laughter]. Well, walking around the office no-one would know I had a back problem (Rodney, #2: 5).

Confusion and uncertainty about the disease progress adds to the melange of uncertainty. Shelley reported confusion over the course of her illness; that the doctors don’t know what to do next and how her illness hasn’t followed a predictable course for leukemia:

Shelley: Theoretically, what should have happened the first time, my doctor went for a cure first time around with the chemotherapy and it didn’t work. It lasted 18 months. That was off chemotherapy. So I had two years of chemo and then I had 18 months in remission, which was really good going. That was when I was first diagnosed. Then I relapsed. They
got me back into remission with more chemo and I went two and a half years. In theory, I should have gone shorter than the last one, but after coming off treatment I went 18 months. The second time, I went two and a half years, which should have been shorter than the 18 months. Don’t ask me why, I don’t know (Shelley, #1: 10-11).

**Medical Expertise:** Reliance upon the medical profession was tainted with confusion, and ambivalence, over perceptions of expertise. Stories reverberated with evidence of a lack of faith and yet of having little choice but to place their lives and abilities in the hands of others. From Shelley:

Shelley: They’ve taken my stem cells and frozen those and now they’re saying they don’t want to use those because that could carry the cancer. I mean, there’s so many things happened that you think “You don’t really know what you’re doing with me” (Shelley, #1: 16).

**Expectations of Self**

One of the apparent conundrums of ICI is the ambiguity in expectations of the self: there are degrees of self-awareness (Wilmot, 1975: 35), ‘multiple selves’ (Wilmot, 1975: 40) and yet, simultaneously, consistency of self may be used to preserve or enhance self-esteem (White, 1982: 5). Self esteem is based on significance, competence, virtue and power (Coopersmith, 1967; cited in Miller, 1992d: 397) and yet chronic illness may be viewed as a loss of self (Miller, 1992d: 405). The management of information about such a failing as ICI is a difficult one: ‘To display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and, in each case, to whom, how, when and where’ (Goffman, 1963: 57). Expectations of the self must necessarily be influenced by the individual’s perceptions, attitudes, motives and feelings about the ICI. Their reaction may be mediated by their perceptions of themselves, their body images, how they feel significant others and society view them and
their illness' (Mead, 1955; cited in Lambert and Lambert, 1979: 2). Similarly, the affective response of individuals towards themselves upon perceiving and evaluating their own behaviours and attributes (Kaplan, 1980: 3) should be considered. Given the complex psychological responses noted earlier in response to illness, for example, anxiety, denial, questioning, ambivalence, suspicion, hostility, regression, loneliness, rejection, depression or withdrawal (Lambert and Lambert, 1979: 5-15), it may be argued that similar expectations of self may also be similarly diverse and potentially confusing.

The PwIC1 may be placed, especially in a work situation, in a situation of "role insufficiency", where some disparity in meeting role obligations is felt in that one's role performance is inadequate as perceived by oneself or by others. Similarly, problems of role conflict may be experienced, where contradictory expectations cannot be met simultaneously (Lubkin, 1990a: 53) with ambiguity in expectations of self possibly stemming from a lack of role norms for the chronically ill (Lubkin, 1990: 55-56). For example, the PwIC1 may feel that because they are unable to work ten and twelve hour days that such performance at work is inadequate, particularly when their colleagues do. Managers and colleagues may also indicate that a shorter working day is not acceptable. Feelings of conflict and insufficiency may also become vivified for the PwIC1 in their home life as they struggle to maintain a career, an illness and a home life. Finally, group membership may also be germane in setting self-expectations for the PwIC1: we recall the need for an ability to satisfy requirements of the group being a requirement for psychological health (Maslow and Mittleman, 1981: 49-50).

The literature notes the difficulties perfectionist, careerist women have in asking for help: Biaiker described the "Type E Woman" who strives to be "Everything to Everybody" - the
wife, gourmet cook, gracious hostess, skilled homemaker, tasteful decorator who stays calm, cool and pleasant at all times. 'I would be a terrific therapist, researcher, teacher, consultant, and writer - and show no signs of strain. Eventually I planned to have a family, as well as remaining a devoted daughter, friend, sister, all-around confidante and pillar of strength to everyone who would need me and love me. And while I was at it, I wanted to be thin and beautiful too' (Braiker, 1986: 14). When the 'Type E Woman' also has an ICI the results may be devastating. Shelley hated to ask for help, preferring to cope alone in many respects. Not only did she say that 'I don't like asking [for help]' (Shelley, #1: 15), she then continued by blaming herself for not asking for help!

The expectation of wanting to be "normal" permeated the stories: Shelley (#1: 5); Linda (#2: 13); Beverley (#2: 21); and Fred (#2: 16) commented about just wanting to be a "normal" person, not "different" and desiring "normal" treatment. Yet, this conflicted with their complaints about a perceived lack of support and understanding from colleagues. It is argued that an excruciating desire to be "normal" overshadows the reality of illness limitations in PwICs minds (for some of the time) making expectations of self, unrealistic, even unbearable. This discomfort and confusion when placed in a position of "not being like everybody else" was ubiquitous: Shirley refused to wear a hearing aid because of her perception of its stigmatising impact: 'People will stare at me more. I'll have that many stares now it won't be funny... I don't like them staring at me because, oh, I suppose my impression is they think "Oh, She's deaf - stupid"' (Shelley, #2: 22). Shelley portrayed consternation when deciding whether to go in to work or not when feeling unwell (Shelley, #1: 15). Rodney indicated embarrassment at possibly not being able to do what is normally expected of what, by outward appearances, constituted a young, healthy male. His response to requests for
physical (lifting) help from female colleagues was telling:

**MV:** So if you had to explain about not being able to help someone lift something how would you feel about explaining it to someone?

**Rodney:** I'd probably feel a little bit embarrassed upfront. But nothing-

**MV:** And why would you feel embarrassed?

**Rodney:** I guess it's an admission that you can't do something that *prima facie* you would expect someone of my age to be able to do. But it's not something I would agonize about particularly (Rodney, #2: 2).

Finally, expectations from others put pressure on some PwICI: for June, expectations that others had of her were a big hurdle, especially when looking "normal" in that they added to pressure she may have put on herself:

**MV:** What do you think is the biggest problem for people with invisible conditions?

**June:** Probably expectations that people put on you and you've got to explain. People expect you to be able to -- because you look normal, people expect you to be able to do things the same as what they can do. It's sort of, "I can't be bothered to explain" and I don't think they understand anyway and I don't expect them to understand it. So it's that trying to say, "Well, I can't drive at night. I don't see so well. I really can't attend that function . . ." (June, #1: 17).

**Expectations of Colleagues**

Conflictual stories existed, specifically about expected, actual and desired support in the workplace: each is addressed distinctly, noting discrepancies between the three. It is suggested that the conflict between expectations of others may serve to reinforce personal confusion: PwICI don't seem to know what they should do nor what to expect from others.

**Expected behaviour:** There seems to be a mythical expectation or perhaps desire of
humanitarian concern from our fellow human beings. However, the literature indicated that organisationally-based inhumanity is likely given managerialist, economic rationalist, organisational ideology (Rees, 1995a: 15; Rees, 1995b: 197; Kouzmin et al, 1997: 21) - one driven by efficiency (Landau and Chisholm, 1995: 67) - that it may be a profoundly painful experience when responsibility is denied, no apology offered and no regret expressed (Erikson, 1994: 238). Organisational ethics and morality are likely to be upheld only if instrumental or profitable - benefiting shareholders (Jones, 1995: 417; Quinn and Jones, 1995: 23; Stubington and Cohen, 1996). This 'pride' in efficiency has been described as 'the most pernicious constraint ever laid on a public organisation' (Landau and Chisholm, 1995: 67): 'We expect a certain amount of callousness in modern organisations. The preponderance of efficiency, at any cost, has become a guiding truth - that's business; it's capitalism; it's survival' (Vickers, 1996a: 1).

Interestingly, respondents demonstrated an almost universal (initial) portrayal of a workplace replete with support and understanding, but closer inspection revealed anomalies. It was almost as if there was a belief or hope that humanitarianism would prevail. Beverley described her colleagues as 'very supportive. They were great' (Beverley, #1: 4) when discussing the time she was initially diagnosed with MS and yet, later, concluded that they 'don't really understand how bad it is to be always tired' and that they really can't 'empathise with that sort of overwhelming "Oh, I can't go another step"' (Beverley, #1: 14). Daphne also described her manager as very sympathetic towards her and tolerant (Daphne #1: 8) and yet, conversely, spent time explicating her manager's impatience with her in some situations - for example, her slowness getting in and out of taxis or her needing to have a day off work for medical reasons: 'When we need to get something done and I have to have the day off,
and even though I’ve told him why ... he doesn’t sort of appreciate that there’s no way that
I could’ve come in that day’ (Daphne, #1: 7).

Shelley’s expectations of others were ambiguous: she specifically reported not expecting
special treatment; of wanting to be treated "normally", like everybody else. And yet, she
reported, with some bitterness, the lack of physical assistance from colleagues:

Shelley: Because we’ve moved rooms now, our craft room or our activity room,
where all the larger toys are - big, huge lego blocks; there’s heavy toys, cots, all sorts of things
for the children to play with are down one end of the building. Now there’s three
demountables to walk through with all this stuff. OK. Now, in between that there’s doors and
there’s baby gates to lift up and open. So things have to be put down, opened, picked up, put
down, turn around, you know, all this stuff. Now, I went through all three rooms numerous
times with heavy things and not once did any staff member ask me if they could follow me
through the building and open or help me with anything. So, nothing’s changed [laughter -
bitter]. Yes.

MV: And you don’t do anything as a result of that?

Shelley: [head shaken] (Shelley, #2: 6, with Shelley’s emphasis).

There was a definite expectation on Shelley’s part that help should be offered by others and
yet she wasn’t prepared to ask for help, even though she acknowledged needing it. Much of
the cognitive behaviour therapists suggest that assertiveness skills (Maltz, 1960; Ellis and
Harper, 1975; Smith, 1975: 88; Lindsay and Marler, 1989: 33; Sellick and Bolton, 1989: 176-
177), self-advocacy (Lindsay and Marler, 1989: 33) and an internal locus of control (Shroeder
and Miller, 1992: 185) are helpful coping strategies, especially in overcoming feelings of
powerlessness associated with altered health states (Shroeder & Miller, 1992: 179). Some
may say that the problem may be getting others to listen (Lindsay and Marler, 1989: 33) and
yet, clearly, for some, there is considerable difficulty asking for help, perhaps reinforced by
an individualistic culture.

Whilst June admitted that she didn’t expect others to understand (June, #1: 17), she simultaneously credits colleagues with possibly unrealistic levels of understanding; that they would be there for her if she needed them:

June: If it became really bad and I couldn’t see or if it affected my work, I know I’d have all the support, certainly from my immediate colleagues. I’m not sure about the bosses, but the immediate colleagues I know would (June, #1: 12).

Yet, simultaneously, she described a seemingly inhumane organisational culture, describing the plight of an intellectually disabled man who lived at the hospital where she works and no-one taking responsibility for his physical or emotional well-being or his personal hygiene:

June: I don’t think they want to know. "God is Love" is on the front of the gate and all that, but inside the gate you are there to do the job and he can’t do the job. They don’t want to know. I think that’s probably the bottom line, although they wouldn’t preach that (June, #1: 15).

Stories of organisational support expected (or hoped for), reportedly experienced and actually experienced were contradictory and conflictual. On the one hand the support received was said to be ‘great’: deeper analysis revealed a discrepancy. A variant story came from Linda who, although had also experienced much cruelty and thoughtlessness from colleagues (especially her senior manager), reported being given paid leave above and beyond what she was entitled to, every third week off on full pay for several months and, additionally, was paid in full for the first four months of her seven months leave (Linda #2: 6-7). This
generosity was seemingly at the discretion of her individual manager.\textsuperscript{126}

\textit{Actual Behaviour:} Shelley, unfortunately, described the vast discrepancy between reported and actual managerial support. Early in the first interview Shelley (#1: 7) reported that her manager was very supportive and, yet, this same manager reportedly 'flies off her handle' if anybody asks to go home because they are sick (Shelley, #1: 8). Shelley also reported feeling 'used' by her manager to cover staff numbers when required (Shelley, #1: 9). The confusion evident in Shelley's mind about support received is evident in this passage:

Shelley: I think she does [support me] to a certain extent, but in another one it's like "You're here to work" I guess, you're employed, so -- [pause] I'm not sure how to put it. It's like, you've got a job -

MV: You get on with it.

Shelley: Yes. So that's what I feel. Whether it's -- I'm not sure, I guess that's how I feel. It comes across as even though she is supportive in some respects, if I was sick or got a bad blood result or something on the telephone, she would be there. If I was in tears, she's there for me in that situation. But on the other hand it's like, "You're here to work, do it" sort of thing (Shelley, #1: 9-10).

It is little wonder that evidence of confusion was reported in the stories: PwC's didn't seem sure what they should do, how to behave, what was going to happen to them or what they expected of other people; including colleagues, medical officers or friends and family. If this

\textsuperscript{126}Co-incidentally, my husband worked for the same employer and was given no additional paid sick leave. In fact, when his sick leave ran out we waited for many weeks for this same organisation to process his temporary disability pension (for which we had supplied the paperwork and relevant medical reports many weeks earlier) and over the period received no income. This same employer solved the problem by dipping into Michael's holiday pay rather than having the paperwork ready in time. In addition to this, at a time of clear financial hardship the same employer, through a general reassessment of staff salary packages that involved interest rate changes on home loans, actually reduced Michael's take-home pay. This necessitated a letter from me to point out to the employer the rather cruel and discriminatory anomaly affecting anyone who was already financially disadvantaged, through being temporarily disabled. Clearly our expectations were that this high-profile financial institution, which profess such a deep concern for staff, would substantiate their claims with some consideration. We were sorely disappointed.
is so, this confusion about their life-world could serve to further alienate relationships, create conflict and discord in the workplace and exacerbate inner turmoil and confusion in a life already fraught with turbulence.

Finally, a variant on this theme. Maryanne also reported supportive behaviour from her manager. She described a phone call with her manager about a meeting where she had to drive to the mountains from Westmead (about 30 km) when she was very unwell with endometriosis:

Maryanne: And so I just said to him, "Look Barry, I'm just having really, I've got my periods today, a very difficult time, I'm feeling very unwell and look, I just really can't make it up there."

MV: And what did he say to you?

Maryanne: He said "Fine, I'll come down there." ... 

MV: Right. Now how did you feel when he offered to come here?


MV: Humbled. You thought it was a really - Is there any other course of action that you would have preferred that he took?

Maryanne: No. I just felt blown away actually.

MV: You thought that was really -

Maryanne: Great.

MV: OK, that's great.

Maryanne: Because, the other thing I could have done is not, the easy way out would have been to stay home sick, wouldn't it? But I didn't.

MV: He didn't suggest that you go home?

Maryanne: No. No. No.

MV: And that was OK?

Maryanne: Yes (Maryanne, #2: 3).

This researcher's consternation at this response is evident in the transcript: I was having trouble understanding why she thought her manager's response was positive when I could only
view it as terribly insensitive. Maryanne had impressed upon me just how unwell she was feeling - surely if someone is feeling too sick to drive a car any distance, they are too sick to stay in a meeting and concentrate? Perhaps Maryanne did feel good about the response from her manager; perhaps she is endeavouring to appear consistent with earlier comments made about her very considerate boss; perhaps she is so unaccustomed to reasonable consideration that any token is greedily devoured; or, perhaps, the answer lies in the last sentence, where Maryanne demonstrably felt that staying home sick would have been a "soft option". Her own and perhaps her manager's assumption is that the 'easy way' is to give in, to take time off, even when you are sick.

**Desired Behaviour:** Confusion is evident when PwICl were asked what they would like for others to do; how they would like them to behave - they just didn't seem to know. From Shelley:

Shelley: And I guess there are days as well when I do go into work looking like I'm half dead, but I still turn up whereas somebody else would have a headache and take the day off and I don't know why I don't. But I guess when I do go in looking like that I guess the support is not there. I still have to carry on, which -- that, I suppose is my fault. I shouldn't probably go in that way then... So that's my fault as much as theirs I think. People don't offer if I'm not well and you can see when I'm not well. I'm usually very pale and look like I've had a hard night. So you can tell, but people don't jump out and say "Let me do that" (Shelley, #1: 16).

Shelley's difficulty and confusion is evident not just in what she is saying, but in her apparent difficulty in articulating her point. The tumult continued in the subsequent interview, as did the apparent strength of individualism and the Protestant ethic in our culture:
MV: You mentioned last time, on a couple of occasions, that you feel that support is not really available at your work now when you’re not acutely ill. Specifically, that you look OK and you’re not in hospital. How do you feel about that?

Shelley: Well, I guess its something I have to accept because I’ve chosen to go back to work. . . . It’s upsetting sometimes that people say “Can you do this?” And I won’t ask. . . . I’d rather knock myself about which is silly, but I guess the other way I look at it is I did choose to go back to work and so it’s my responsibility I guess. Otherwise, if I can’t do it I shouldn’t be there (Shelley, #2: 5).

Linda similarly reported anger and frustration with her colleagues, her wish that they would ask her about the cancer so they could better understand her situation (Linda, #2: 15). This, whilst her bewilderment and discomfort is also clear, as are further individualistic notions that the disease is *her* problem:

MV: How do you feel about the fact that no-one understands?
Linda: Maybe, too, I’m expecting too much of people to have to understand.
MV: What makes you say that?
Linda: Well, its my problem, that—. The disease I’ve got is my problem and some people mightn’t even want to know about it, which is their right really. Maybe, also, some of the people at work, I don’t know, they might have had somebody go through it in their family and, you know, it sort of brings it all back to them. I don’t know that. But, so, I shouldn’t really judge people because they might have a good reason why they don’t want to understand. Or maybe they do really understand, but they don’t want you to know that they really understand. So I just feel—. I don’t know how I feel (Linda, #2: 14).

**Uncertainty**

A whisper of uncertainty pervaded the stories: Shelley (#1: 15) was uncertain as to how her boyfriend would respond when he saw her when she was ‘really sick’; Beverley and Daphne were both uncertain as to how and when the MS would progress (Beverley, #1: 20; Daphne, #1: 7); Maryanne was uncertain as to how her work life with endometriosis and interstitial cystitis would be affected with the arrival of a new manager (Maryanne, #2: 14); and Linda
sometimes wondered whether she was actually sick or not (Linda, #2: 6) and, concurrently, whether it would get easier living with cancer (Linda, #2: 12) and whether she would tell a future employer about the cancer or not (Linda, #1: 17). Shelley voiced uncertainty as to why she didn’t like to talk about her leukemia to other people, even though she has previously indicated that others are naive about it and don’t understand.

Shelley: -- I’m not sure. Maybe it’s my way of dealing with it. I don’t, I guess I just go on every day as if it’s not there. It’s hard not to. People ask questions when I am sick and you can see that I’m sick. It’s hard not to explain then. But when I’m like this I get, the way I deal with it is to ignore it. So people don’t know about it because there isn’t a need to [laughter] know at the moment. Yes (Shelley, #2: 3).

Themes of Survival

Defence Mechanisms

Noted earlier was the likely employment of Freudian psychological defence mechanisms as have been widely reported in the literature: denial; amnesia; avoidance or repression; rationalisation or intellectualisation; splitting or projection; and regression (Bowby, 1980: 140; Kline, 1984: 20; Carr, 1989: 30; King and Singh, 1989: 63; Parsonson, 1989; Oldham and Kleiner, 1990; Sinclair and Haines, 1993). Individual actors may employ a range of defensive strategies, distancing themselves when things go wrong (Sinclair and Haines, 1993) with defences providing a way of leeching anxiety from circumstances in order to continue working (Sinclair and Haines, 1993). Even at an organisational level "denial", "wait and see"
and "band-aiding" are common responses to a protracted crisis (Jarman and Kouzmin, 1994; Korac-Boisvert and Kouzmin, 1994: 68). Evidence of defence mechanisms was widely found in the stories, for example, understandable avoidance or repression from Shelley especially evident from the "unspeakable" in the text:

MV: And how do you feel about this impending bone marrow transplant?
Shelley: I guess I don't worry about it. I can't afford to worry about it you know. Gosh, they told me I shouldn't -- I remember when I was diagnosed the doctor, I heard him say to mum "She shouldn't be alive." And they told me I wouldn't see sixteen.
MV: They told you?
Shelley: Well, the surgery is sort of, we were in this room; the surgery is the next room. And there's only a wall. You know, I was in the toilet doing a urine sample thinking "I know that there is a conversation going on now." So I listened and I heard him say everything. When I was diagnosed my spleen was enlarged, everything, my heart was racing; I could feel my heart pounding, my pulse was racing. I knew I was sick. But I heard him say that. So I guess in the same respect now I can't afford to worry about it. I mean, if I shouldn't have seen sixteen and I'm still here. Gosh if I thought I was going to die tomorrow -- I can't, you know? (Shelley, #1: 16).

Intellectualisation or rationalisation was used often to deal with incongruous life experiences.
Shirley explained that she didn't wear a hearing aid because she didn't need it: we have seen the more likely reason became obvious later; that she believed people would stare at her (Shirley, #2: 22). Similarly, she vocalised her decision not tell her manager about endometriosis as being of no benefit to her and none of his business:

Shirley: And I'm going to tell nobody either because it's not their business. The endometriosis would only be a problem if, if I got really really sick and had to have the hysterectomy and I had to have four weeks off. I, but then I still wouldn't tell them. I would just tell them I had to go in hospital for an operation. If anybody asked me I would say "None of your business." [MV laughing.] ... I just won't tell them. I don't have to tell them. As long as I supply a medical certificate there's no need for me to tell them. It's, it's not
beneficial to tell them. Like if I went to Greg and said “Look Greg, I’ve got endometriosis. Endometriosis is la la la la.” I don’t think it’s going to make any difference to the situation. He’s just going to say “Oh, it’s one of those problems. Oh, you better get it fixed up.” That’s it. So, I mean what’s the point of me going through all that agonising pain of telling him and explaining all about it when I’m going to get no, I’m going to get no satisfaction out of telling him. So I won’t tell him. There’s no point (Shirley, #2: 20).

Shirley had previously admitted to being very uncomfortable talking about an illness involving the female reproductive anatomy; what I have elsewhere described as a form of social discomfort stigma; a social taboo (Vickers, 1996b) especially when talking to a male. She confided during our first meeting:

Shirley: It would be easier for me to be able to go up to Greg and say “Greg? I’ve got endometriosis. Do you want to know what endometriosis is? Endometriosis is - This is why I get a pain in my right side and this is why sometimes I get sick.” That wouldn’t, that would mean he wouldn’t ask me then. He would just know. “Oh [bangs fist on the table] the endometriosis is playing up again.” So I mean in one way, yes it would be - easier probably for me to just tell him and then he’d know, but I can’t do that. So I prefer just to say to him “Don’t worry about it. I’ve just got a pain. I’ve got something wrong with me and don’t worry about it” (Shirley, #1: 31, my emphasis).

Beverley (#2: 17) similarly rationalised her fears for the future and a potential loss of sight from MS:

Beverley: I mean I guess one of my fears is that if I loose my vision I can’t read and I just love reading and it would affect my work and, really, it affects everything that underpins what I value most. So that I find that fearful but again, you know, there’s nothing much you can do about it. You just have to start sort of enjoying different things. I guess you start using your ears more, or, you know (Beverley, #2: 17).

Rodney (#2: 2), as a male in the prime of life, rationalised what was suspected to have been
difficulty asking for help. He reported an incident of moving heavy furniture at his workplace minimizing his "weakness". When asked whether he had ever had to move offices at work:

**Rodney:** I've moved my office around, but I haven't actually moved offices.
**MV:** Including furniture?
**Rodney:** Yes, that thing [Rodney indicates a very large L-shaped desk; very heavy looking].
**MV:** Did you do that yourself?
**Rodney:** No. Well, I helped.
**MV:** Who did it?
**Rodney:** The largest employee I could find.
**MV:** So you actually went and got someone and said "Come and give me a hand."
**Rodney:** Yes, yes.
**MV:** And did you tell them why?
**Rodney:** Yes, I think from memory. I think I did. He knew anyway. I think I did.

It is too heavy for one person to move anyway, so it weighs a ton (Rodney, #2: 2).

Finally, Shelley used rationalisations to cope with a frightening future. She rationalised her choice of not telling a future employer of her condition:

**Shelley:** Maybe it's the way I deal with the illness is denying until I go down to the hospital and then it is reality. "This is for real." But in day to day I don't even think about it. I don't think about my illness, so I guess on employment somewhere else I probably wouldn't even think of telling them because it doesn't enter my mind (Shelley, #1: 5).

Other defence mechanisms were also employed: Shelley reported denial of exacerbation of symptoms and illness, fearing the medical procedures she would face when in hospital:

**Shelley:** I fight with knowing what's right and knowing what's going to happen when I get down to the hospital because you sort of end up in casualty where people don't know what's going on; you're with all the druggies; it's just where you end up. Instead of going straight to the oncology ward you end up in casualty with the drugs... I think that's what I
fight against, but I know it's the right thing but its horrible [nervous laughter] (Shelley, #2: 10).

Similarly, earlier sections have echoed that respondents deny the effects of their condition at work as a likely defence mechanism. For example, June (#2: 2) stated that she didn’t do the type of work that necessitating her having to see; Daphne (#1: 9) emphasised that she is 'not in the sort of job where I would need a lot of help'; and Rodney commented that his back problems at work were 'rarely an issue' (Rodney, #1: 5).

Coping Strategies and Resources

Coping is defined as 'constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person' (Lazarus and Folkman, 1984: 141). Coping is a dynamic process affected by numerous variables (Lazarus and Folkman, 1984: 142; Dewe, 1989: 995), with multiple functions (Lazarus and Folkman, 1984: 148), including dealing with social and environmental demands, creating the motivation to meet the demands and maintaining a state of psychological equilibrium (Lazarus and Folkman, 1984: 149). Coping can be emotion-focused or problem-focused (Lazarus and Folkman, 1984: 150-154; Dewe, 1992: 160; Miller, 1992b: 43)\textsuperscript{128} with distinctions being made between coping styles, coping behaviours (Dewe, 1992: 147) and coping strategies (Dewe, 1992: 147; Callan and Terry, 1994: 22-24). Coping resources may include health and energy (not always available to PwCI), positive beliefs, problem-solving skills, social skills, social support and material resources (Lazarus and Folkman, 1984: 157-164): they are those personal, social and organisational elements available.

\textsuperscript{128} The delineation between emotion- and problem-focused coping has been deliberately avoided on the basis of a belief by the researcher that, for PwCI, emotions and problems are closely and inextricably entwined as are their responses.
to the individual which influence the type of coping strategy which may be implemented (Dewe, 1989: 1009). Maximising 'patient power resources' (or coping abilities) are achieved through physical strength, psychological stamina (or hardiness), social support, a positive self-concept, energy, knowledge and insight, motivation and appropriate belief systems (Miller, 1992a: 9-14). For PwI CI, the stress they have to cope with is a 'chronic life stress' (Kasl, 1981: 44). For the purposes of this analysis, the coping styles, strategies, resources and behaviours have been grouped here into the broad areas of physical, cognitive, social, spiritual and material coping.

**Physical Coping:** When referring to "physical coping" the researcher is referring to specifically corporeal behaviours or resources. These may be to increase or conserve energy resources (Miller, 1992a: 11-12; 1992c) or increase physical strength (Miller, 1992a: 9) on the basis that improved physical well-being may be used as a personal power resource (Miller, 1992a: 196) and a basic mobility resource (Miller, 1992c: 196) that promotes well-being and allows task accomplishment (Miller, 1992c: 197-198). The literature confirms the ubiquity of fatigue (Wheeler and Dace-Lombard, 1989: 47-48; Miller, 1992a: 11-12; 1992c: 196) and pain (Wheeler and Dace-Lombard, 1989: 47-48; Stephens, 1992: 362-364) associated with chronic conditions, so it was not surprising to find that the PwI CI interviewed often tried to cope with problems not visible to others by increasing or conserving their energy resources, employing varying techniques to do so.

Use of exercise was common. Fred took a proactive stance in helping recover the use of his right arm by squeezing a squash ball, giving himself physio-therapy which had a very positive effect in regaining the use of his hand and arm after radiotherapy (Fred, #1: 10). He also
walked around the golf course on a regular basis, a game Fred loves but had to stop playing for about three years (Fred, #1: 28) due to his cancer. With one lung out of commission Fred was no longer able to jog as he had previously, but walked instead (Fred, #1: 27). Rosalie walked and did light aerobic workouts to assist in maintaining energy levels (Rosalie, #1: 15); Linda returned to aerobics as soon as she could, as part of getting back to normal living (Linda, #1: 4); and Daphne enjoyed walking, in recent times without the dog (Daphne, #1: 9), now finding such games as tennis and squash not so enjoyable being unable to play to her former standard. Daphne also reported difficulties gardening, having reduced strength to pull out weeds and needing to stay out of the sun (Daphne, #1: 9).

Diet was also used to combat fatigue: Rosalie ate special foods to maintain her energy levels during the day, especially when she was out on a client site (Rosalie, #2: 14). Fred changed his diet considerably, including lots of fresh fruit and vegetables, whilst quitting smoking, cutting down drinking and generally reducing his "bad" habits, which included going out most nights to the club (Fred, #1: 23). Special rest periods were incorporated during the day by Rosalie (#2: 17) and Daphne stopped going out during her lunch break because it impinged on her energy levels for the rest of the afternoon (Daphne, #1: 7). Rosalie made a conscious effort not to rush during the day as this further drained her energy resources (Rosalie, #2: 15).

Conversely, variations were reported: Shelley commented that she didn't 'have time for rest': her body simply 'shuts down' (Shelley, #1: 9) and, whilst she concedes being 'fairly good with food', she believes that all the toxic drugs (for example, chemotherapy) she takes cancel out a good diet or additional vitamin supplements (Shelley, #2: 9). Maryanne (#2: 16) reported 'keeping on' as a coping strategy to get through the day.
Cognitive Coping: People can be encouraged to be more proactive and problem-focused (rather than passive) in their efforts to deal with stressful events that threaten their well-being (Callan and Terry, 1994: 34). It was certainly this researcher's observation that the PwICl interviewed were, in the main, employing many successful cognitive coping strategies to enhance their psychological and physical well-being. Personality factors may influence positively, or negatively, on mental health (Roskies et al, 1993: 617), with psychological hardiness being related to successful coping (Argyle, 1989: 272; Miller, 1992a: 5) and personal attributes allowing some to positively cope with stress better than others (Argyle, 1989: 272). Specifically, a sense of control over one's life and the inclination to face adversity with a sense of challenge and a sense of commitment in life, was opposed to aimlessness, purposelessness and meaninglessness (Blaney and Ganellen, 1990: 298). Positive adjustment to chronic illness has been linked to knowledge, coping resources, problem solving attitude, a sense of personal mastery and motivation (Miller, 1992a: 7).

In the respondents stories, examples of "positive" cognitive coping strategies were available: 'positive thinking' was usefully employed by Fred (#1: 11) to help him feel better emotionally and to aid in his recovery, in addition to a change in outlook, which included no longer 'abusing your body with drinking', smoking and not eating properly (Fred, #1: 23). Rosalie used the ME Society to obtain information about her condition (Rosalie, #2: 3), in addition to writing things down to aid her memory and planning her day (and week) very carefully (Rosalie, #2: 15) to best utilise her finite energy reserves. Linda tried to avoid stress through meditation and relaxation exercises as well as pursuing craft and embroidery as a stress relief.

\[129\] The valuation of some means of coping as "positive" or "negative" is recognised as being a highly subjective interpretation on the part of this researcher and others before me.
Linda specifically remarked that having cancer had helped her re-prioritise her life (Linda, #1: 5-16). Shelley also seeks to actively reduce the stress in her life by ‘switching off’ and by not taking extra work home with her any more (Shelley, #1: 12), but recounted special difficulties removing herself from what she described as a ‘burn-out’ situation at her work; her manager ignoring her repeated requests to move (Shelley, #1: 13). Fred, similarly, tried ‘not to get stressed now’ (Fred, #1: 33), remarking that he had become more tolerant of others (Fred, #1: 24). Daphne liked to cook and garden to help her relax although, at times, found these previously pleasurable pursuits a source of frustration, reporting difficulties pulling up weeds and chopping up vegetables due to weakness and coordination difficulties arising from the MS (Daphne, #1: 8). Gardening was also pursued by June (#2: 3) to relieve stress.

Problem solving skills were employed by Rodney, who would carefully assess a situation before attempting to lift any object beyond his perceived capabilities (Rodney, #1) and by Maryanne, who was giving serious thought to the use of incontinence pads to free her from having to be so eternally close to a toilet (Maryanne, #2: 20). June reported overcoming difficulties in asking for help, now requesting assistance from people at work when she needs it, for example, in asking another to read something for her (June, #2: 5).

Cognitive coping skills are influenced by ‘lay’ or ‘folk’ beliefs about illness126 (Freidson, 1970: 283; Fitzpatrick, 1984: 17; Kleinman, 1988; Klonoff and Landrine, 1994: 408; Archer, 1995: 89; Helman, 1995: 18; Nettleton, 1995: 39) which greatly affect individual response to illness. They are heavily ethnically and culturally influenced (Fitzpatrick, 1984: 11-12; Turner,

126 Please refer to full discussion of this phenomenon in Chapter Two.

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gender influenced (Helman, 1990: 130); socially and ideologically influenced (Nettleton, 1995: 46); and may be very complex, multifactoral (Fitzpatrick, 1984: 17) and, frequently problematic, illogical and inconsistent (Fitzpatrick, 1984: 17-18). These beliefs about health and illness were apparent in the stories and were seen to contribute to respondent's 'active sense-making' (Fitzpatrick, 1984: 25) of the situation, whilst possibly also contributing to the problems experienced by PwI CI. For example, Maryanne believed that people with cancer were treated better in her organisation than people with conditions of unknown origin and cure (Maryanne, #2: 1); Shelley (with leukemia) may have disagreed with her on this. Fred (#2: 23-24) would not submit to any form of operation to fix his slipped disk believing that being cut open and the subsequent exposure of his body to 'fresh air' will adversely affect his cancer. Fred also hoped that his back problems, which are 'driving him crazy', will simply 'right themselves' (Fred, #2: 26). Daphne believes that hard work does not exacerbate her condition (Daphne, #1: 10) and both June (#2: 6) and Rodney (#1: 12) have borne out the current community faith in advances in medical science ultimately coming to their rescue (as described in Chapter Two). From June (#2: 6):

**June:** I usually don't think about it because I think medical technology changes so quickly that, that maybe something, you know, a head transplant or something [laughter]. Things are happening so much, but, but I don't, I used to really worry, but then occasionally it'll hit me, and I think "Yes, I will go blind".

Cognitions about illness affect employment decisions. Ignorance about illness from respondents seemed to abate only with reference to one's own condition. Several respondents were asked for a managerial perspective and invariably demonstrated a preparedness to hire
someone with a condition like their own, but not necessarily with another ICI that they did not understand. For example, Rodney regarded back problems (like his own) as less problematic (Rodney, #2: 8) than conditions such as schizophrenia, cancer, epilepsy or HIV, ching reasons of 'putting unfair pressure on that person to keep up with the work' and also placing pressure on their peers (Rodney, #2: 10). Rodney also proposed that his judgement about such a decision would be guided by his estimation, and theirs, of how the condition would affect them doing their job; with his own determinations and 'gut feel, I guess, really', based on trying 'to put yourself in their shoes' (Rodney, #2: 8). Given the limited knowledge and erroneous community beliefs about many illnesses, this type of approach could present problems. Conversely, Daphne (who has MS) volunteered her belief that cancer, epilepsy and MS could be controlled and felt that they would be much less of a problem for a person at work than chronic back problems (Daphne, #2: 10).

Varying attempts at 'normalisation' (Goffman, 1963: 155; Liggett, 1988: 265; De Swaan, 1990: 1; Johnson, 1991: 19; Branson and Miller, 1992: 19; Miller, 1992c: 207; Herman, 1993: 317; Robinson, 1993: 9; Kelleher, 1995: 95-96) were evidenced in cognitive coping strategies: Linda seemed pleased when telling me that she was treated "normally" these days at work; just another team member and, notably, equated 'coping well' with 'being normal', 'everyday things' and an 'everyday life' (Linda, #1: 4). Shelley, similarly, reported the need to return to work; to get back to a normal life as quickly as possible:

Shelley: I was really quite excited about going back to work. I really needed to get my mind off things. I needed to be out of the home environment: the bedroom, the TV, the soapies, everything. I needed to get back (Shelley, #1: 20).
In concluding this section on cognitive coping, a comment on the need for control by PwICI is warranted. 'Intuitively, it would seem that to cope with a situation is to attempt to control it—whether by altering the environment, changing the meaning of the situation and/or managing one's emotions and behaviors' (Lazarus and Folkman, 1984: 170-171). Maryanne specifically reported becoming very controlling of her life, of being 'overly fond of rules because it allows control and rigidity' believing that she 'would have been a totally different person if I'd never had those diseases' (Maryanne, #1: 27).

Social Coping: In this section, social behaviours that are employed to assist the PwICI and the issues surrounding social support are dealt with. Both of these are of special import, given that the illness is invisible. Social functioning is described by Lazarus and Folkman (1984: 183) as 'the manner in which the individual fulfils his or her various roles, for example, as a parent, spouse, job-holder or community member.' Earlier, the potential problems that may exist for PwICI in terms of perceived role insufficiency and role conflict were examined. Fulfilling the social roles with the unseen problems they face may require quite extraordinary and varied social coping skills. These social skills may encompass an 'ability to communicate and behave with others in ways that are socially appropriate and effective', as well as facilitating problem solving (Lazarus and Folkman, 1984: 163). The stories were replete with evidence of specific defensive and protective practices (Goffman, 1969: 12) related to the concealable dimension of the stigma (Jones et al, 1984: 24). Evident were social practices such as covering or hiding (Goffman, 1963: 125; Wilmot, 1975: 52; Robinson, 1993: 16); passing (Goffman, 1963: 92; Glaser and Strauss, 1971: 170); the use of masks (Goffman, 1969: 17; Jones et al, 1984: 136; Parker, 1989: 67); fronts (Goffman, 1969: 19); and other social performances (Goffman, 1969: 21) such as various 'keeping up'
behaviours. For example, Shelley covered her fear, not letting others know:

Shelley: Things are, like, temperatures. They’re things that you think if I suddenly start getting hot, you’ll think "gosh" [nervous laugh]. So, I mean, I don’t show it outwardly that I mind, but I do (Shelley, #2: 10).

Use of a social "mask" was actually mentioned by respondents: Linda spoke of putting her 'best face forward' (Linda #2: 5); Shelley referred to the need for her and others with ICI 'to mask everything' (#2: 14). Shirley (#2: 12) hid her learning disability as best she could during training courses and Maryanne hides her bladder problems, especially from men, being especially scornful of their lack of understanding of women’s bladders: 'It's all right for them, if they get drunk and they want to whack it out somewhere along the road' (Maryanne, #1: 7). Finally, Rosalie described the 'subterfuge' associated with illness and work:

Rosalie: They don’t want to know. They’re there. They’re paying me as a professional. They don’t want to know. They, it’s not part of their issue. I’ve contracted to do a job. That's my issue and my problem and it would contaminate the process enormously if it was otherwise. And I think for me that’s one of the incredible costs of having an illness is, is that, that subterfuge, that's the word I want, subterfuge, that needs to go on, where you are functioning in a world that, that assumes everyone is healthy, well and in control. So, all of sudden my energy has to go into pretending to be something that you’re not and so it’s not just the energy of trying to make sense of the job with your head, but it’s the emotional energy (Rosalie, #1: 15).

Social Support (Argyle, 1989: 277; Blaney and Ganellen, 1990: 300; Dunkel-Schetter and Bennet, 1990: 267; Hobfoll and Stephens, 1990: 454; Sarason et al, 1990: 10; Silver et al, 1990: 397; Hastings, 1992: 236; Ray, 1992; Roskies et al, 1993: 618-619) reportedly has two kinds of health outcomes: main effects and buffer effects (Dunkel-Schetter and Bennet, 1990: 284), although it is important to note that it is not necessarily supportive nor positive (Argyle,
Blaney and Ganellen, 1990: 300; Ray, 1992), with sick people sometimes having trouble getting the support they require (Silver et al, 1990: 397), with supervisors in the workplace being a great source of stress in some instances (Argyle, 1989: 277). In particular, the distinction should be made between available and received support (Dunkel-Schetter and Bennet, 1990: 269), and the problem of initial support dissipating over time (Dunkel-Schetter and Bennet, 1990: 278). The self-presentation dilemma exists for people in crisis of whether to present positively, negatively or provide a balanced coping ability (Silver et al, 1990: 402-405) to encourage support from those around them. This is, naturally, exacerbated when the condition is "invisible".

Positive and negative social support surfaced in the stories. On the negative side, Shelley described the cool distance developed between her and her former "friend": when asking her friend what was wrong? 'She couldn’t tell me anything. She just didn’t know’ (Shelley #2: 4). Didn’t know or didn’t want to say? The author’s earlier analysis of this situation (Vickers, 1996b) suggested that Shelley’s reported experience of enacted stigma could source from a number of possible areas: from her friend’s fear (fear-of-outcome or fear-for-self); from a lack-of-knowledge (ignorance of how leukemia is acquired); how it effects Shelley; how it is treated; the myths and metaphors commonly associated with cancer and it’s outcomes; or even suspicions of malingering given Shelley’s healthful appearance. It could also come from social discomfort about the treatment regimen that has confronted Shelley, for example, hair loss associated with chemotherapy; or, it could have arisen as a result of an assortment of defence mechanisms employed by Shelley’s "friend" and, indeed, most of us. If Shelley’s friend did know and I was able to interview her about the distance that had developed between them, it is unlikely that she would reveal the truth behind her seemingly
unpalatable behaviour (Jourard, 1971) due to secondary elaborative processes, rationalisation (Storr, 1989: 37), repression or denial (Kline, 1984: 21-25) given that, in the West, it is much more fashionable to 'accept' a friend in need (Szasz, 1991: 136). Shelley also noted negative social support (a lack of support at work) on numerous occasions (Shelley, #1: 7, 8, 10 and 15); that over time colleagues lost interest in her condition (#1: 8) - 'I didn't get flowers this time' (Shelley, #1: 21).

Daphne's consternation when wrestling with the issue of disclosure of her MS to family members was described earlier (See Chapter Five) and was presumably based on the expectation that their resulting panic and upset would present more difficulty for her than assistance (Daphne, #1: 3). For Shelley, her manager and supposed friend of the family became a grave source of stress for her. Shelley described how this woman had 'sort of used her' in keeping staff numbers up at the childcare centre where she worked and, yet, this same person indicated to others that she had given Shelley special consideration in giving her work (Shelley, #1: 9). Shelley also found that her grandmother's support was over-protective; stifling (Shelley, #1: 14). Rosalie felt that her problems tended to confront others' vulnerability, so she chooses mostly to 'pretend' everything is fine during social encounters (Rosalie, #1: 23). Some avoided discussing problems with others (Shelley, #2: 3; Rosalie: #2: 8), with Shirley admonishing that it was none of their business (Shirley, #2: 19), perhaps feeling some constraint symptomatic of 'internalized cultural values and beliefs that proscribe certain types of action or feeling and psychological deficits that are a product of the person's unique development' (Lazarus and Folkman, 1984: 165).

However, positive social support was also reported. Linda wondered aloud how she would
have coped if her mother had not been around to act as mediator and information gatherer between herself and the doctors during her time of crisis (Linda, #2: 8-9). Shelley stated that 'my main network of support is my mum' (Shelley, #1: 14), whilst also acknowledging a close friend and her grandparents (Shelley, #1: 14). June relied on Shelley, for example, in helping her shop for clothes (June, #2: 11). Daphne reported being able to share 'war stories' with her friend with diabetes (Daphne, #1: 9) and Rosalie described a particularly dedicated friend who provided meals for her and her family a couple of evenings a week over the period of a couple of years (Rosalie, #2: 16). She also shared the story of another friend who, recently, had been to a seminar on chronic fatigue syndrome and had rung Rosalie, apologised for not understanding before and asked, 'What can I do?' (Rosalie, #2: 9). Fred described the support of his family and how both he and they made a special effort these days to continue to see one another and keep in touch, and how his sister-in-law had driven him to the hospital for radiotherapy treatments (Fred, #2: 5). Fred also articulated the comfort and peace of mind from sharing concerns about treatment and prognosis with other cancer patients met at the hospital (Fred, #2: 4). Beverley indicated that her mother would somehow get her to work if she was unable to drive and/or catch the bus (Beverley, #2: 8). However, Linda’s comments re-affirm the potential contradiction surrounding social support:

Linda: I found the best thing too is, I actually, family and friends are a really good support, but they really don’t fully understand how you’re feeling. Like nobody knows how I feel. Even my husband, he’s just got no idea. He means well. He wants to know how I’m feeling, but it’s, you know, some days I just cry and cry and cry and you just break down at the smallest thing and, you know, other days you can go weeks without crying and, you know, you think sometimes I think he thinks I’m a lunatic or something (Linda, #1: 11).

131 The potential problem here is that Beverley’s mother was 70 years of age; reliance on this person for social support was not going to be a permanent solution.
Positive social support was also received within the organisational context. Fred was able to share cancer stories with several, similarly placed, colleagues (Fred, #2: 20). Beverley reported a supportive work environment; colleagues looking out for her and being good to her daughters (Beverley, #1: 10); even an incident of being sent home early when completely exhausted (Beverley, #1: 14). Linda, who experienced certain callousness at the hands of her manager, also reported tremendous warmth, caring and support from her direct supervisor including, as previously reported, additional periods of sick leave on full pay and special workplace consideration that left her feeling 'really comfortable' about the fact that someone was 'always concerned' (Linda, #1: 13-14). Rosalie described the empathy and understanding between herself and her business partner (also with a PwIC); that the similarities between their respective situations 'make it work' (Rosalie, #1: 17).

It is argued here, however, that some instances of positive organisational support can be questioned. For example, Fred was told to take off all the time he needed to get over his cancer and his job would still be there for him when he got back (Fred, #2: 12); yet, he only took the sick leave accrued to him over many years of service, having to return to work when the leave ran out. He also reported having grave fears for his continuing employment, especially if he permanently lost the use of his right arm (Fred, #2: 16). Beverley reported, initially, that her colleagues were great and that they were understanding and supportive (Beverley, #1: 10) and yet, later, confirmed that they were unlikely to understand (Beverley, #1: 14). Daphne, similarly, described stories of management understanding when she was diagnosed with MS, that it was 'rotten luck' and when she offered to leave, 'they wouldn't

132 Conversely, when one of these people subsequently died and another turned for the worse, it must have been a tremendous source of anxiety for him.
hear of it' (Daphne, #1: 4). As the interview progressed, her manager's "real" sensitivities became evident: impatience with her slowness getting in and out of taxis and disapproval when she took time off for medical consultations (Daphne, #1: 8). Daphne also reported that her organisation had been very good in terms of leave arrangements, being given a few days 'special leave', fully paid, when her sick leave ran out (Daphne, #1: 5). This didn't seem to me to be an extraordinary gesture for the woman who regularly worked 60-70 hours a week!

Finally, Shirley described the apparent concern demonstrated by her manager about her participation in this interview process; his apparent concern was that her privacy would not be considered sufficiently (Shirley, #2: 25). The researcher's assessment was that his concern was patriarchal, patronising and unwarranted: Shirley was a most assertive woman and, seemingly, quite capable of looking after herself.

**Spiritual Coping:** Finding solace through religious or spiritual pursuits (Wheeler and Dace-Lombard, 1989: 182; Shroeder and Miller, 1992: 190) and belief systems (Miller, 1992a: 13; Miller, 1992b: 25) may incorporate beliefs in God to provide strength and ability to cope, as well as beliefs in self, care givers or the medical regimen (Miller, 1992a: 13). For some, 'the spiritual part of us can be thought of as the essence of our being. It is our spirit that searches for the meanings in life and in suffering' (Brallier, 1992: 209-210). It has been argued that spiritual malaise does not assist healing, coping or well-being (Miller, 1992a: 14), with hope being derived (for some) from spiritual well-being (Miller, 1992a: 14). Religion is a frequent source of support to assist the chronically ill person in handling the difficulties they may face (Shroeder and Miller, 1992: 190), with prayer being a common response for many people even if not previously religious, perhaps invoking an omnipotent force to help them (Raphael, 1986: 70). However, an emphasis on spiritual coping was evident in few of
the stories\textsuperscript{133} which may be representative of an increasingly secular society (Gadamer, 1996: 65-66) or that the researcher failed to uncover this coping mechanism sufficiently well. From the stories: Rosalie found comfort in prayer and involvement with the church (Rosalie, \#2: 15), whereas Linda preferred to meditate listening to relaxation tapes (Linda, \#1: 8).

\textit{Material Coping}: Illness and disability are likely to effect what William James termed our ‘material selves’ (James, 1890; cited in Wilmot, 1975: 41); our ‘achieving selves’ (Parsonson, 1989: 219). Material resources refer to ‘money and the goods and services that money can buy’ (Lazarus and Folkman, 1984: 164) and, although rarely mentioned as a coping resource, are demonstrably important when considering issues of economic status, stress and adaptation (Lazarus and Folkman, 1984: 164): ‘People with money, especially if they have the skills to use it effectively, generally fare much better than those without’ (Lazarus and Folkman, 1984: 164). Having money may also reduce the person’s sense of vulnerability (Lazarus and Folkman, 1984: 164). Having money to survive, for many, means having employment; not always easy for PwICI as we have seen. Poverty and physical impairment are correlated (Blaxter, 1976: 89): ‘Financial difficulties may be an obvious, direct and sudden result of an impairment. On the other hand, sickness may begin a slow drift downwards and often a vicious circle may be set up: sickness causes unemployment or underemployment which, in turn, helps to cause more sickness’ (Blaxter, 1976: 89). Blaxter even cited a man with what this author would term ICI: he ‘was not so visibly disabled as to make officials feel they

\textsuperscript{133}When the time came to report on spiritual coping, the researcher’s ‘background’ (Benner, 1985: 6) became apparent: it seems vital to point out that the researcher is an exemplar of an increasingly secular society (Gadamer, 1996: 66); not enmeshing religion or spirituality in her own life with ICI and, consequently, not asking about this specifically during the interviews. Questions directed specifically toward spirituality may have portrayed a different picture than what is evident here, where few respondents mentioned spiritual issues. This outcome, which may be evident of increasing secularism, may also be the result of unintentional researcher induced bias (Kvale, 1994: 154), where the impossibility of value neutrality (Sarantakos, 1993: 19) may have, in this instance, detracted from the findings.
ought to offer him special consideration. He fitted awkwardly into administrative categories' (Blaxter, 1976: 94). Loss of job leads to lost income for most people (Argyle, 1989: 287) with increased expenses in others areas, such as heating and lighting (Argyle, 1989: 287), as well as health additional costs of illness (as explained in Chapter Five).

Rosalie and Maryanne both articulated the problem of lost income; a direct response to their illness. Temporary pensions were an issue: Linda described her good fortune at getting a (work-based) temporary disability pension from her employer which she described as being around 70% of her wage (Linda, #1: 14)\(^3\). Whilst this is recognised as being infinitely better than nothing, mortgage payments still had to be made on top of additional medical expenses. Shelley described the impossibility of living on a government sponsored disability pension (around $300 a fortnight) when she was actively participating in life (Shelley, #1: 21), emphasising it's sufficiency only when she was lying in a hospital bed. As discussed in the previous chapter, perhaps one of the reasons that this issue has not surfaced much in the literature is because people are unwilling to readily discuss their personal financial details.

Themes of Optimism

Temporal effects

Temporal factors of importance include the immanence of the event (Lazarus and Folkman, 1984: 92) (for example, a recent diagnosis or exacerbation); the duration of the stressful

\(^3\) The reader should not necessarily get too "warm" a feeling from this example. Michael, working for the same employer, also received 70% of his Superannuation Salary when going onto a temporary disability pension. The Superannuation Salary figure is used to calculate superannuation contributions and payout figures and does not constitute an employee's "take-home" pay. For my husband, this nice, warm 70% (that the employer brandished with great aplomb) was, in truth, about half of his previous "take-home" salary. The reader will find in the Epilogue that, for Linda, the perceived "benevolence" of this employer was short-lived.
event (Lazarus and Folkman, 1984: 98) which, for PwICI, can be many years; and temporal uncertainty - that is, not knowing when the event is going to happen (Lazarus and Folkman, 1984: 101). For PwICI, not knowing how, what or when a disability, illness or death will overtake them may be very stressful. However, chronic stressors do not inevitably lead to exhaustion: a lessening of arousal may follow with the subject becoming used to the enduring source of stress (Lazarus and Folkman, 1984: 99). Coping abilities may change simply with the passage of time (Watson and Kendall, 1983: 44). Lowered levels of arousal may also be due to increased use of avoidance coping strategies to deal with the threat or simply a lack of concern with the threat (Lazarus and Folkman, 1984: 103). The associated requirements of grieving also require the passing of time. The stories from PwICI demonstrated levels of adjustment; of an inner healing as time passed and the illness became less central in their lives. The shock of a frightening diagnosis is no less grievous for those with "invisible" conditions than for others with more visible stigmata, although others will be less inclined to understand the grief experienced. Coping is a process (Lazarus and Folkman, 1984: 142) with various stages (Lazarus and Folkman, 1984: 143) that shift with the passage of time. The phases of the crisis response and recovery cycle (Montgomery and Morris, 1989), indeed coping with any grief (Montgomery and Morris, 1989: 48), including those associated with losses surrounding chronic illness, requires the passing of time. Elizabeth Kubler Ross's famous phases of 'death and dying' also encapsulate this temporal issue (Kubler-Ross, 1969; Register, 1987: 21; Barbeau, 1987c), with the grieving process encompassing 'tasks of grieving' and 'phases of grief' (Schneider, 1984: 63 and 66). Coping strategies and styles develop as the PwICI becomes more "inflated" in living with their condition. The human capacity for resilience, renewal and regeneration after a crisis has been noted (Raphael, 1986: 27) and cannot be underestimated, but requires the passage of time.
For example, Beverley moved from her initial, compulsive urge to tell everyone (Beverley, #2: 17) to a situation where that wasn’t an issue for her; where the MS was a less central and prominent part of her self-identity (Beverley, #2: 18). June and Fred both reacted with shock upon diagnosis of their conditions and, yet, over time, this information became less invasive in their lives (Fred, #1: 7; June, #1: 11). Linda became less self-conscious with regards her lost breast (Linda, #2: 10); and Maryanne was conscious of the need to take time to come to terms with her losses: lost children, lost relationships, lost career opportunities and financial loss (Maryanne, #2: 21). Rosalie emphasised that the eventual diagnosis of CFS was when she ‘started to come to terms with what [she] had’ (Rosalie, #2: 1) also indicating that the process of ‘coming to terms’ took time.

Hope

The positive effects of hope were also evident in the stories. Thinking positively leads to new concepts, the making of futures (Goossens, 1985: 83): ‘Hope is important because ... what we achieve is less dependent on what we do and our qualities than on how we think, our self-confidence and awareness’ (Goossens, 1985: 92). The generation of hope is regarded as an effective coping resource (Miller, 1992b: 34); an extremely valuable commodity when living with chronic conditions (Robinson, 1993: 25; Miller, 1992e: 417); a power resource (Miller, 1992e: 413); with normalisation used to support hope, even when a price is paid for this (Robinson, 1993: 23). Hope may be mobilised at the individual, family or group level, and functions to assist survival by controlling mood (Raphael, 1986: 70). Evidence of hope can be seen in Rodney’s comments which assist him in coping with a future of uncertainty:

MV: What do you think might happen in the future with your back?
Rodney: Yes, that probably is something which concerns me a bit. Getting into old age and things start falling apart generally. It's probably going to hurt.
MV: How old are you now?
Rodney: 34. It's probably going to hurt.
MV: What have the doctors said is likely to happen?
Rodney: Nothing. There's nothing to do about it particularly, so no point worrying about it yet. Who knows what medicine is going to be like in 20 years time? (Rodney, #1: 12).135

Self Changes

All who experience disaster are likely to be in some ways touched by it; they can never be exactly the same again. But this does not mean their lives are worse. For even when there may be painful emotional scars, there may also be many new strengths and understandings that have resulted from mastery of the challenge. People frequently find that they are far more courageous than they had thought... and the encounter with death makes them reevaluate their own lives and what is important for them, so that interpersonal relationships, especially with family, and significant life goals may play a greater and more satisfying role (Raphael, 1986: 27-28).136

Positive outcomes of surviving a life crisis may result in a re-ordering of priorities (Glaser and Strauss, 1971: 144), either then or at a later date; the development of the 'drive to

135 However, as argued in Chapter Two, the literature historically suggests that unadulterated faith in the medical community is not necessarily warranted, though commonplace in modern times (for example, Foucault, 1961; Freidson, 1970; Szasz, 1970; 1977/1988; 1980; Illich, 1975; Gould, 1985; Turner, 1987; Helman, 1990; Kouner, 1993; Archer, 1995; Dubos, 1995; Garrett, 1995).

136 The fear associated with having MS and what it may bring, is so profound, so all-encompassing, and so constant (even if it fades into the background from time to time), that other areas of my life have become relatively fear-free. This, combined with the trauma that Michael and I have individually and collectively faced over past months, leaves me feeling incredibly empowered (some of the time, anyway).
survive' (Raphael, 1986: 69); new feelings of mastery (Raphael, 1986: 27); empowerment (Maltz, 1960: 198); courage (Raphael, 1986: 27); more problem-focused coping skills to reduce emotional discomfort (Lazarus and Folkman, 1984: 152; Dewe, 1992: 143; Koeske et al, 1993: 320); the adoption of an internal (versus an external) locus of control to enhance feelings of autonomy (Shroeder and Miller, 1992: 183); greater assertiveness (Shroeder and Miller, 1992: 185); feelings of 'being in control' (Kelleher, 1995: 94-95); and, finally, better relationships with significant others (Raphael, 1986: 28).

Respondents similarly reported these kinds of positive impacts on their lives, as well as others not noted in the literature. Improved relationships with partners, friends and/or family were reported by Fred (#1: 24), Beverley (#1: 8), Linda (#1: 11, 15 and 16), Rosalie (#1: 21), June (#2: 11) and Shelley (#1: 14); with Fred also describing himself as generally 'more tolerant' of others (Fred, #1: 24). Beverley, particularly, noted the positive influence in her life of valuing friends more, declaring herself to be 'a completely different person' (Beverley, #1: 19). Rodney (#2: 5) and Fred reported the positive fact that the medical treatment received had worked, with Fred adding that his recovery was regarded as something of a miracle by the medical community (Fred, #2: 14). Beverley reported that others made positive attributions about her (whether warranted or not); that she was 'very brave' and 'really good', and 'Isn't it wonderful [the way she copes]?' (Beverley, #1: 19). Daphne felt good about herself when the diagnosis of MS enabled her to confirm that her colleagues at work definitely wanted her (Daphne, #2: 9) through not allowing her to resign.

Deliberate stress reduction was often employed through various means (Shelley, #1: 12; Linda, #1: 14; June, #2: 11; Fred, #1: 33; Beverley, #1: 3) to improve quality of life, as was a better
life perspective (Linda, #2: 4; Fred, #2: 9); a changed outlook on life (Fred, #1: 23; Linda, #1: 15); and less anger (Beverley, #1: 4). Both Linda and Beverley deliberately reassessed their life priorities and adhered to the changes made (Linda, #2: 4; Beverley, #2: 2) - including improved levels of assertiveness (Beverley, #1: 7; #2: 4).

Finally, several respondents demonstrated an internal locus of control. For example, Fred took it upon himself to squeeze a squash ball to get the use back in his right hand (Fred #1: 10) as well as experiencing a notable improvement in his health and well-being following a change in diet and lifestyle (Fred, #1: 23). Linda decided to take time off work to recover from her cancer and change her style of life (Linda, #1: 6). Rosalie sought literature about CFS from the ME Society (Rosalie, #2: 3) and Shelley decided, against specific and argumentative advice from the Department of Social Security (Shelley, #1: 19-20), that her life would be improved if she stopped collecting her disability pension, returned to work and felt more independent. Finally, there were reports of improved performance at work (Beverley, #1: 3), valuable knowledge and understanding of limitations (Beverley, #1: 3), with particular attention given to planning, time management and interpersonal techniques at work (Rosalie, #2: 15) being successfully utilised.

This concludes the phenomenological model developed from the stories of PwICl. The author moves now to The Final Chapter and The Epilogue with a certain degree of anxiety, as one finds oneself concluding this section, and the project, with few concrete solutions and many more questions than were commenced with.
CHAPTER SEVEN

The Final Chapter: Shattered Lives, Fractured Selves - Revisiting "Voice" During Ontological Despair

What a strange world I am inhabiting. A twilight zone... On the weekend we went to the beach... I wanted so desperately to just walk off down that beach, away, away, diminishing, as in the final frames of a movie and never coming back... My own pain was no longer something I could carry -- this bag of broken glass, and splintered wood, and gravel and shards of steel and bone, this sack of grotesqueries that I dragged clattering and clanging behind me... I lay with this ecstatic, exquisite sense of finality, this final solution... Meanwhile, I haul my bag of trash on and on (Aisbett; cited by Hawley, 1997: 21).

I feel like shit. I am exhausted beyond belief and I honestly don't know how much longer I can continue. I have aches all over, a headache and a slight feeling of nausea from the seventh (or eighth) injection last night, and none of the injection site reactions have gone. I am covered in ugly red blotches, all over my belly, and I still have difficulty summoning the courage to plunge that needle into my own flesh.

\footnote{I feel increasingly uncomfortable about including my perspective on this research process. However, as I review drafts of this work, I am increasingly convinced that I cannot edit all the "ugly" bits - actually, I could - but not without presenting an inaccurate portrayal of my state of mind during analysis. I make another, difficult, return to authentic writing. The chapter that follows begins by arguing, in some detail, the pros and cons associated with making such personal revelations.}
It is 5.30 pm the day following the last injection: I always seem to feel sick and depressed the day after the injection (although I also feel depressed at other times too), which is a bit of a problem when you are trying to finish a thesis, apply for jobs, win a protracted battle with an insurance company, finish a tax return and, somehow, maintain some picture of normality for the outside world. And I have to do it by myself now: I really miss Michael. He used to offer such great insights and suggestions, especially with job applications and he always helped alleviate the agony of putting together my tax return. Not any more. No more. I miss him terribly. To the casual observer, no-one would know there is a problem, after all, he’s still here and he looks fine. But I know. There’s a big problem and it’s not likely to go away (Vickers, 1996g).

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The dark hood of melancholy once again envelopes me - slowing me; constraining me; bringing unimaginable loneliness. As I consider my life, I feel hollow, empty, numb. What seems to have sparked this particular episode of depression (among the many) is that I have just learned from a routine, three month blood analysis that my liver enzymes are all higher than normal: my liver is not functioning properly and it is highly likely that the Betaferon injections are the culprit.

This cruel paradox presents itself during another hour of bleak reflection: the only current treatment available for people with MS (which, for me, is currently heading downhill like a runaway train) that is considered to have any positive effect on slowing the progression of the disease is now effecting other, healthy parts of my body. If this trend continues, the Betaferon
treatment will be stopped. Ambivalence remains about this drug: I seem to have gone through the worst of the manifest "flu-like complex" side effects (although the depression seems worse) but I firmly believe (or want to believe?) that the MS symptoms experienced would be far worse if I wasn't taking it. I feel that I need the Betaferon to mediate the downhill trend the MS seems to have taken and, yet, it is now apparently having nasty effects upon other aspects of my life. I guess the decision will be taken out of my hands anyway: it is unlikely that I will have much input.

Once again this depression comes the day after an injection and, for once, I have the fortitude to sit down at the keyboard and record my feelings. Half an hour ago as I lay trying to meditate, instead of clearing my mind I found myself contemplating a very dismal future. I am not happy any more. I want things to be the way they were; they never will be again.

I exist now. I do not enjoy, rarely feeling anything but a hollow, emptiness. I record another day of unhappiness; another spoke in the wheel carrying me down, but where? My liver doesn’t work so well now. What will be next? What else can go wrong? A lot. That’s the truth. A lot more can go wrong. I may as well just sit back and wait for it to unfold. I don’t tell anyone: I doubt anyone will really understand or care for that matter. I just want to run away, but to where? There is no-where to run, no-where to hide from this.

I cry a lot.

My thoughts are interrupted and the tears are hastily brushed away. I take a phone call from one of the intermediaries from the study: Shelley is not going very well. 'She is the classic
"invisible" chronic illness' he says: 'She looks fine, but she is dying'. She is bubbly and cheerful, but her blood is full of leukaemic cells. How much longer will she be with us? I don't have the courage to call her. I am so sad. What am I doing? More "fabulous" news to contend with.

Michael thinks the tears are for her; the tears are for me; for my pain, my fear, my loss. Not hers, not his - mine! (Vickers, 1997b)
Notes from the 'Survivor-Witness'  

The final chapter is commenced with trepidation: having heard the voices of PwICl I am confronted, as Tal (1996: 247) was, how to finish? There is reflection on the 'worlds of hurt' (Tal, 1996: 1) that have been witnessed: not only have I witnessed existential agony in the lives of PwICl, I have lived it. Recurring existentialist themes of finitude, guilt, alienation, despair and death (Macquarrie, 1972: 17) have been exposed and, concurrently, lived. How is one to effectively (authentically) report this?

One of the most difficult, conflictful experiences in completing this work was knowing where my place as a researcher, 'insider' (Wilmot, 1975: 59), caring person and traumatised PwICl began and ended. How much should be disclosed in this 'psychological ice age' (Wilmot, 1975: 3) in which we live? I remain unsure. It is difficult to know in this situation (as with many aspects of life with ICI) how much to expose, how much to hide - how much is responsible research and how much is cathartic self-indulgence. One is reminded that 'bearing witness is an aggressive act. It is born out of a refusal to bow to outside pressure to revise or to repress experience' (Tal, 1996: 7). Knowing that individual experiences 'are so central to the ways in which we put together a sense of our own identity' (Abrahams, 1986: 50), I consider that whoever reads this work will most likely have their own experiences upon which they may decide where "the line" should be drawn in the sand. Whether this researcher is deemed to have crossed this arbitrary and personal point of demarcation, the resolve articulated in the opening pages of this thesis is renewed. To remain 'an authentic writer'  

128I am indebted to Professor Alexander Kouzmin, once again, for "browbeating" me into having the courage to finish this project the way it should be finished - with a final acknowledgment of "my voice" and its important place in this research process.
(Jourard, 1971: 58) is to accept that research 'must be expanded to include those artist-like processes' (Steier, 1991a: 4) and be a writer of 'personal stories' related to the 'self' (Lemert, 1994: 101). I am prepared to accept the risk that goes with that. It is an acknowledgment that "the truth" that matters is narrative truth, which succeeds if it somehow succeeds in capturing 'real trouble' (Bruner, 1990: 111, own emphasis). A search for "meaning" evoked in Chapter One is recalled: 'meaning is concerned with getting in touch with one's own evolving experiences, with opening one's world to its fullness rather than rationalizing its incompleteness, with facing up the fact that we must live with light and dark, love and hate, joy and sorrow' (Denhardt, 1981: 56). Indeed, this act of self-disclosure is one which allows others to perceive you (Jourard, 1971: 19, own emphasis); as a researcher privileged by insider status this remained an imperative - an unavoidable aspect of this work.

As a researcher who embraced the notion that 'researchers must be included in their own research' (Steier, 1991a: 5), it has been similarly recognised not only 'that reflexivity is a crucial concern' (Steier, 1991a: 5), but that the processes involved are also critical (Steier, 1991a: 5). This notion of reflexivity as a circular process (Steier, 1991a: 2), as 'self-awareness' (Gouldner, 1976: 55; Kouzmin, 1983: 232), is in keeping with Heidegger's hermeneutic methodology (as in the 'hermeneutic circle' described in Chapter Three), necessary to develop an awareness and an understanding of what others are doing (Steier, 1991a: 3) and to recognise the rules to which one submits and by which one is bound (Gouldner, 1976: 55; Kouzmin, 1983: 232). It follows the shift in focus from representational to ontological narrativity (Somers and Gibson, 1994: 38, my emphasis). 'Transparent narratives' (Bruner, 1990: 113) involving 'self-stories' (Bruner, 1990: 112) acknowledge the importance of autobiography, where the form is as revealing as the substance.
(Bruner, 1990: 119): 'The narrative's opaqueness, its circumstantiality, its genre are taken to be as important as or, in any case, inseparable from its content' (Bruner, 1990: 113), enabling the reader to 'enter the world presupposed by the text' (Good, 1994: 153). Abrahams (1986: 54) argued that 'the reflexive dimension of the ethnographic literature has not been well developed'. It is suggested here that the same applies to the phenomenological literature. Similarly, the fact that there has been 'very little address on the part of the fieldworker as to how cultural norms and professional expectations entered into the collection and reporting of materials, much less what was happening to the collector that might have made a difference' (Abrahams, 1986: 54), renews this researcher's resolve to address these potential inadequacies in this report.

It must be noted that such an act of public self-disclosure is not an easy thing. Whilst the experience of being asked during personal interactions to "give yourself away" is not unusual (Abrahams, 1986: 56), to commit publically, and in writing, my own personal trajectory was not something which was undertaken without consideration of the consequences, both positive and negative, and the emotional toll exacted. However, I continued in an endeavour to underscore the importance of "openness" in achieving meaning and purpose in our interpretive scheme and of giving moral weight to everyday experience' (Abrahams, 1986: 58), and remembering the need to focus on ontological dimensions in narrative studies (Somers and Gibson, 1994: 41). Steier (1991a: 3, emphasis in original) suggested 'that we understand and become aware of our own research activities as telling ourselves a story about ourselves': In this case, the author was required to reflect about herself and her story and, also, to tell others what was happening during this research process.
The writings of trauma survivors comprise a distinct "literature of trauma". Literature of trauma is defined by the identity of its author (Tal, 1996: 17). To some extent, the author's identity has been revealed throughout this work. The telling of other people's life stories is recognised to be constitutive of both lives: the teller's and the researcher's (Mann, 1992: 273). People construct their identities through location in stories: "experience" is constituted through stories (Somers and Gibson, 1994: 38) - mine and theirs. Ontological narratives are used by the tellers to make sense of their lives, 'to define who we are' (Somers and Gibson, 1994: 61) - they are not fixed, not a priori, but are basic to agency (Somers and Gibson, 1994: 61). It is through narrativity we come 'to know, understand and make sense of the social world. It is through narratives and narrativity that we constitute our social identities' (Somers and Gibson, 1994: 59).

It is argued here that my identity, as with those I have interviewed, is a 'fractured identity' (Haraway, 1991: 155; Somers and Gibson, 1994: 56), comprising numerous complex constituents - 'multiple, ambiguous, ephemeral or conflicting' (Somers and Gibson, 1994: 61). It is difficult to identify, difficult to articulate, but nevertheless endowed through narrative location (Somers and Gibson, 1994: 61). It is acknowledged here that research tells a story about ourselves (Steier, 1991a: 3) and I am convinced that 'by holding our own assumed research structures and logics as themselves researchable and not immutable, and by examining how we are a part of our data our research becomes, not a self-centred product, but a reciprocal process. The voices of those with who we interact ... are enhanced rather than lessened' (Steier, 1991a: 7). Finally, 'stories about one's own experiences provide an important resource for not only establishing one's place in the community (because of one's special knowledge) but also for establishing one's identity' (Abrahams, 1986: 56). With
these assurances I proceed in the knowledge that I am one of those researchers committed to 'authoring selves', sharing the hope that some 'attention must be paid' (Geertz, 1986: 373).

As a 'survivor-witness' (Tal, 1996: 2), I am faced with the difficulties of bearing the terrible burden for the living and the dead; of sharing what has been seen, lived and felt and, yet, knowing that the testimony will be somehow inadequate (Tal, 1996: 16); that the words are incapable of expressing the horror (Carroll, 1990: viii); of the impossibility of meeting the responsibility of talking about "that" (Carroll, 1990: xxv) and accepting that, in some cases, 'no witness is competent to speak, given the magnitude of the devastation' (Carroll, 1990: viii). In knowing that the understanding of others will be insufficient, how best to bridge the gap between words and experience? How best to convey an 'authentic view of suffering' (Zola, 1992: 13) and callousness? The problem facing the humanist is one of finding a language to effectively 'celebrate the survival of the human spirit' (Abrahams, 1986: 47), especially in organisational life: 'The sterile words which comprise the ethic of organization--rationality, efficiency, objectivity--appear foreign to our actual experience. Those surges of emotion and meaning, those "special moments" which occur from time to time in our lives and our work simply cannot be comprehended in instrumental terms. Yet these are important, vital, experiences, deserving of our attention, for they represent our efforts to break free from the restrictive categories of a rationalized existence' (Denhardt, 1981: 44).

Differences clearly lie between those who have experienced trauma in their lives and those who have not, when understanding the language of trauma. Communication is hindered, not just because the audience refuses to listen (Fussell; cited in Tal, 1996: 16), but because they are unable to comprehend what is being said. Their frame of experience affects their
experience of "reality" - they necessarily have different and pertinent vulnerabilities in framing (Goffman, 1974b: 439) that are insufficient to share meaning:

Traumatic experience catalyzes a transformation of meaning in the signs individuals use to represent their experiences. Words such as blood, terror, agony and madness gain new meaning within the context of the trauma and survivors emerge from the traumatic environment with a new set of definitions. On the surface, language appears unchanged - survivors still use the word terror, non-traumatised audiences read and understand the word terror and the dislocation of meaning is invisible until one pays attention to the cry of survivors. "What can we do to share our visions? Our words can only evoke the incomprehensible. Hunger, thirst, fear, humiliation, waiting, death - for us these words hold different realities. This is the ultimate tragedy of the victims." (Tal, 1996: 16; including a quote from Wiesel, 1990: 33, emphasis in the original).

It is, surely, trivialising for one to try and tell these stories and impossible to truly share my own. One tries to share the anger, the confusion and the fear (among other things) expressed by PwIC: but how does one explain to another who has not experienced it, who has no comparative yardstick, about the experience of losing bodily capacities; of awaking each day wondering what this day may hold; of waiting, powerless, as physical abilities decline; or how it may be to wait for one's own death? How is it possible to explain the notion of "fatigue" to someone who understands the notion as "feeling tired", of wanting sleep or rest, when "tiredness" is irrelevant to those who truly experience the fatigue frequently associated with
chronic illness - the complete, wearisome, shut-down of the body; a feeling of dragging a body through wet sand; a heavy and rebellious body that simply won't continue no matter how much you might want it to and no matter how inconvenient this may be. How does the knowing witness explain to the 'outsider' (Wilmot, 1975: 59) the notions of powerlessness, and fear - tantamount for this writer - whilst acknowledging and explicating that the experience of another PwICI rests more closely with anger and, yet, for another, in frustration and a sense of loss?

How does one accurately portray this ubiquitous existence of fear that has been witnessed in others and lived with so closely, so that others may truly understand it? How to elucidate this unwelcome "life-partner" that simmers gently, just below the surface, out of sight to others, yet always within reach for me? How to explain to another who does not have this identity "additive", this "schizophrenic" multiplicity of their person? How to explain how it feels to keep at bay something that constantly threatens to overwhelm, to overtake, to undo? How is it tolerable one day, unbearable the next and how might one accurately convey this? How does one help others understand what has been witnessed in others and what is recognised in oneself? The emergence from these experiences comes with a new understanding of what it feels to be "traumatised". The shackles tighten: How best to express the shift? The words remain inadequate, the chasm unbridged. Not even close. I am resigned: 'There is, in this case, no substitute for experience - only [B]eing is believing' (Tal, 1996: 15).

This notion of Being is, of course, inextricably interleaved throughout this work. Heidegger's emphasis upon the ontological (Leonard, 1989: 42; Sass, 1990: 126; Cohen and Omery, 1994: 140; Walters, 1996: 94) brings this methodological quest full circle: The author continues to
wrestle with the essential question, "What does it mean to be a PwICl?" The excavation has been necessarily into their lives and my own. The author remains with few answers, many questions and difficulties explaining what has been learned.

The 'fractured identity' (Haraway, 1991: 155; Somers and Gibson, 1994: 56), the aching, ambiguous ontology of being a PwICl was reflected in the stories, mine and theirs. It deserves some comment in light of current social, psychological and organisational discourse.\(^{139}\) That character is still being read from appearance (Finkelstein, 1991: 1) seems extraordinary and, whilst we may decline to endorse such a practice as being superficial and unjust, it remains apparent that we continue to do this (Finkelstein, 1991: 8), even recognising the known propensity of the 'halo effect' (Finkelstein, 1991: 49; Vecchio et al., 1992: 122-123) and the knowledge that appearances manipulate our sympathies and reactions (Finkelstein, 1991: 50) based on an overall impression (Vecchio et al., 1992: 122). It appears that in health, and capability, judgements are similarly made and similarly flawed:

What does it say of us that we readily accept appearances and habits of conduct as revelations of the private self? What does it say of our social relations that we frequently employ a fashioned self-image and a style of acting in order to create a certain impression through which we hope to influence the opinions others have of us or how they will act toward us? (Finkelstein, 1991: 5)

\(^{139}\)Once again, Professor Alexander Kouzmin has alerted me to the potential clumsiness of our sociological processes, including their crude reliance upon the visual senses. This notion is of essential relevance to this work and the following paragraphs are in response to that suggestion.
What does this also say of the quality and depth of our academic endeavours to date, that so little has been learned about what we cannot see; the constancy and primacy of the visual senses as the basis for justification and assumptions of "truth"? That antiquated claims of external physical appearances corresponding with internal psychological and moral predispositions (Finkelstein, 1991: 42) survive is testament to the naivety and the crudity of our sociological processes. Similar misperceptions apply when assumptions about people's state of health are made - there is a continuing, simplistic and flawed reliance on one sense, one dimension.

The notion of identity is complex for everyone: for PwICI it seems more so. The modern individual shows a marked sense of self-consciousness (Finkelstein, 1991: 155) and a degree of anxiety about how one performs in public and what the opinions of others may be (Finkelstein, 1991: 156). The performance is socialised (Goffman, 1969: 30); the mask becomes the truer self, what we would like to be (Goffman, 1969: 17) - happy, healthy and capable. For PwICI, the anxiety in achieving this front is necessarily heightened. For the PwICI who feels shame, anger or fear as a result of their condition, their ontological experience is necessarily and irrevocably different to the person without chronic illness: an unbridgeable chasm characterised by what Goffman (1969) termed a masked life. 'Freud recognised that most of what is real within ourselves is not conscious and that most of what is conscious is not real' (Fromm, 1962: 96). In a capitalistic, individualist work-world, PwICI are required to cover, to repress, to pass - indeed, 'systematic efforts to suppress or deny transcendental consciousness characterises administrative authority throughout the industrial world' (Kouzmin, 1980: 131). 'Those areas of repression which are common to most members of society; these commonly repressed elements are those contents which a given
society cannot permit its members to be aware of if the society with its specific contradictions is to generate successfully' (Fromm, 1962: 96). The quest for an authentic existence (Macquarrie, 1972: 206) is especially difficult for PwICI. For them 'the everyday being-with-others is inauthentic' (Macquarrie, 1972: 118), symptomatic of their especially distorted social relations (Macquarrie, 1972: 118).

Following Heidegger's ontological guidelines, and utilising a phenomenological methodology that celebrates the acknowledgment of 'background' and 'preunderstanding' (Koch, 1995: 831), acknowledges the importance of ontology and provides a methodology for the existentialist (Macquarrie, 1972: 21). I find myself privileged, even emboldened, by method, yet, simultaneously, burdened with it. I ask myself what has this process done to my voice, as I reflect on my own and others' experiences, and the ever widening polarisation of my feelings: I feel defeated, yet strangely empowered; angry, whilst also accepting; more fearful, but also with renewed faith in my abilities to survive; wildly emotional and, yet, often-times numb, with no feeling at all; despairing and joyful; feelings of discontent aligned with those of immense pride and satisfaction. My voice, as with the multiple voices that have been heard, seems heightened in its complexity and ambiguity, and in its need for expression.

I ask myself (yet again) what has been achieved? There is a belief in an "emotional healing" for those who have participated - an acknowledgment of those in pain feeling "heard", perhaps for the first time, and a belief in the therapeutic effects that may hold; the 'narrativization' of illness being part of the therapy (Kleinman, 1988: 53; Fox, 1993: 112). For myself, the same need for validation and desire for affirmation and release is acknowledged: 'Literature of trauma is written from the need to tell and retell the story of the
traumatic experience, to make it "real" both to the victim and to the community. Such writing serves as validation and cathartic vehicle for the traumatised author' (Tal, 1996: 21). There is also recognition that "we are drawn to those projects and activities which we see as best able to provide a context for the fullest expression of our inner desires and potentialities. We seek action contexts in which we can show the world who we are, but also seek those activities which will provide opportunities for growth, ways of drawing forth literally the best that is in us' (Denhardt, 1981: 60). Yet, more questions are raised:

What is the connection between individual psychic trauma and cultural representation of the traumatic event? What does the act of testimony, of "bearing witness", mean to an individual survivor, to a community of survivors? How are testimonies interpreted by different audiences? What does the designation "survivor" mean and who has the right to confer that title? What happens when a survivor's story is retold (and revised) by a writer who is not a survivor? How are survivor's stories adapted to fit and then contained within the dominant structure of social, cultural and political discourse? (Tal, 1996: 3)

At a social and organisational level, questions of old are revisited: Why must experiences with the medical profession be so dysfunctional? Why must organisational life be so difficult for those already in pain? Why must management insist on making managerialist judgements on behalf of other people, and about feelings and situations of which they know nothing, that impact so mightily and nastily on the lives of PwICl? What policy implementations could be made that might ameliorate these situations? How does one get people from the "other"
group to understand? Why do we continue to focus on the instrumental, the rational, the "bottom-line" in the face of such misery? How can a shift to humanity be successfully made in modern organisations?

One thing becomes clear: 'We must seek complexity rather than avoid it' (Tal, 1996: 22) if we are to ever move closer to answers or to understanding. The 'authenticating narrative' (Finkelstein, 1991: 9) is represented here through a representational synthesis of contingencies (Finkelstein, 1991: 10). To achieve this synthesis and some closure epistemologically, methodologically and ontologically, one must return to the beginning, to complete the circle and reflect on what has passed.

A Return to Inception

A return to inception seems essential. A review of the eclectic blend of literature comprising the theoretical framework; the uncovering of the pathological and multiphrenic aspects of organisational life, and life for PwICl; a reliance on the early work of the philosopher and phenomenologist, Martin Heidegger; and reflections upon the personal, intellectual and methodological journey undertaken by the researcher point unerringly to a belated consideration of postmodernism. Simultaneously, aspects of the 'critical postmodernist' standpoint (Boje et al, 1996: 64), particularly the recognition of heterogeneity and multidimensionality, spark interest. So, too, do aspects of 'critical modernism', such as the confrontation of the increasing power of instrumental reason (Hassard, 1993: 118) and the 'dark side of modern rationalisation' (Fox, 1993: 123). Certain aspects of both seem reasonable and helpful; others sound weary, hackneyed; still others fatuous, even silly.
Critical postmodernism (Agger, 1992; Boje et al., 1996: 64) 'begins with everyday experience and discourse, including its own' (Agger, 1992: 278). It is a critical theory of modernity and postmodernity 'so abundant with insights into what is going wrong with the world' (Agger, 1992: 280) and utilised by this writer who is (mostly) unafraid to bridge the social sciences in order to seek understanding (Agger, 1992: 281) and who recognises the problems that arise when theory becomes 'so carved up, so dissected and then mummified by disciplinary museum keepers, it loses its ability to sharpen insight' (Agger, 1992: 279). Additionally, 'critical postmodernism dances between epoch postmodernism, epistemological postmodernism and critical modernism' moving seamlessly between applying postmodernism in a useful way, suggesting the need for organisations to find new ways of working in a postmodern age (Boje et al., 1996: 64, author's emphasis).

Conversely, critical modernism is characterised by Habermas's defence of modernity: 'to confront the increasing power of instrumental reason in social life and in so doing recapture the spirit of enlightened rationalism for later modernism' (Habermas, 1972; 1974; both cited in Hassard, 1993: 118). It is used to decode repressive dimensions and emancipate social actors (Hassard, 1993: 118) encouraging a language of community (Hassard, 1993: 118). Most importantly, critical modernism is the 'knowing of the subject who, through experiencing a network of meanings and, thus, the common sense of ordinary language, reaches the consensus of human understanding' (Hassard, 1993: 118). It is recognised that the actors here are of the modern, romantic sort: 'suffering the existential angst of suffering and mortality' (Fox, 1993: 111).

This work characterises an interleaving of the modern and the postmodern: the (modern)
pragmatic, humanitarian and epistemological imperatives outlined in the first chapter are
followed by a theoretical framework that overarches literature from sociology, psychology,
social-psychology, health sciences and organisational theory. The methodological choices
made were carefully laid out in a rational, modern tradition, followed by a phenomenological
model, which tried to encourage some sensibility, some themes of commonality from the
stories (another modern tradition), whilst still accepting and documenting the unique, the
inexplicable and the multiple in the stories, perspectives and textured lives of the respondents.

A backward glance at the original imperatives driving this project is sought to gauge what
progress has been made. The reader will recall that it was a quiet evening with friends that
acted as the catalyst for this work: the questioning of a fallacy that if you look well, you
must be well. What began as a well-intentioned (and distinctly modernist) search for the
"truth" has ended with a (postmodernist) state of many questions, few resolutions.

The pragmatic, humanist and epistemological imperatives that guided the early stages of the
research have not vanished, but have been submerged somewhat by the voices heard.
Somehow, it matters less now than it did at the outset to justify the existence or the usefulness
of this research: hearing and telling these authentic stories seems justification and reward
enough. Yet, I too am a product of the times and accept that we are all heavily imbued with
the modernist theoretical lens (Farmer, 1997: 117), compelling a frank review of the research
objectives set out in Chapter One. What follows is, hopefully, a useful juxtaposition of
aspects of the modern and postmodern (Farmer, 1997: 117), without being sucked entirely
and without resistance into the quagmire of the postmodernist debate.
Research Objectives: A Return and Review

The research objectives (listed pp. 29-30) have proven a useful directive. The first three objectives have, from the researcher's perspective, been achieved, although it is difficult to gauge if the "truth" has been found - just as "reality" is a slippery term (Farmer, 1997: 113), so too, is "truth". Exploration of the psychically and socially constructed workplace reality for PwI CI has been "heard": multiphrenic, pathological and traumatic stories of life and work with ICI have emerged. The interpretation is theirs, based on their lives, their recollections and their emotions, and relayed through a researcher intimate to the phenomena. The interpretation is also mine and subject to the sensitivities and dynamics of experiences wrought during turbulent times. It is not an interpretation verified through other sources; an important acknowledgment of the PwI CI's authenticity. The interpretation has been a hermeneutic one; a study of the texts to learn of the person in their situation (Benner, 1985: 5), reliant upon and primarily valuing the subjective experience of the respondents. It is fervently hoped that the phenomenological model recorded in Chapters Five and Six describes these individual, and sometimes collective, experiences and responses, as well as uncovering the issues of deepest concern to respondents living and working with ICI.

One outcome not documented early in the process was the need to "hear" PwI CI; for their stories to be told. This omission was, on reflection, a major one and, yet, not one that could have been anticipated without the benefit of hindsight: it would have been impossible to predict the journey that unfolded and, equally, impossible to predict this most important outcome of it. Another objective not sought at the outset was the value of the methodological journey undertaken. This was a subliminal journey; one undertaken without, initially, the
author being aware. It is argued later in this chapter that the excavation of this methodology, with all its potential advantages and pitfalls, is as valuable an outcome from this research process as the stories themselves.

The last two objectives are more macro: to aid in the amelioration of the working lives of PwICl, including the empowerment and emancipation of PwICl in organisations by understanding more about life and work with ICi; what the reported experiences are; what the issues of import may be and why they may exist; and, finally, to assist organisation theorists and practitioners in understanding the issues and problems that exist for a sizeable proportion of the workforce. It is with these final two objectives in mind that I turn now to the postmodernist literature in an attempt to formulate some response.

Postmodernism: 'Pure Silliness' or Valued Epistemological Vantage Point(s)?

Postmodernism as pure silliness . . . . our sense of silliness is there precisely for the reasons that we feel our assumptions of normal and natural life rotting away. For the postmodern perspective is dead serious in suggesting, for example, that once basic assumptions—the existence of objective time and objective space—are fictions for most purposes (Hummel, 1997: 23-24).

Postmodernism is an interesting term with a vast array of meanings, intentions, ideological components and outcomes. Its presence is felt in many arenas which should be distinguished,

\footnote{140}I am indebted to a colleague, Robert Leiversley, for pointing out that being a postmodernist vantage point, there must necessarily be more than one!
such as architecture, the arts and the social sciences. For some, there is concern that it may be ‘pure silliness’ (Hummel, 1997: 23), with its contentions being highlighted as inadequate with respect to organisational analysis (Carr, 1997: 4). The author refers here to postmodernism with respect to the social sciences and what it may offer the twilight thoughts of this work, especially those final two elusive objectives.

The ‘postmodern turn’ (Fox and Miller, 1997: 51) captured the author’s interest initially due to the tenor of this research project and the multiple voices captured by it. The narratives maintained ‘multiple perspectives and the potential for multiple readings’ (Good, 1994: 153) and there was a recognised need to seek complexity (Tal, 1996: 22): postmodernism embraces heterogeneity and questions many of our rationalist assumptions. On this basis alone, further exploration seemed warranted - a quest which proved a formidable task.

128) as well as the death of traditional sociology and social theory (Turner, 1993: 71; Hassard, 1993: 123) signalling 'the end of the grand positivist statements of traditional social theory and, thus, the end of the finalities of social systems analysis' (Hassard, 1993: 123), as well as going the furthest toward 'renouncing Enlightenment reason and all its works' (Norris, 1990: 119).


Postmodernism has been held responsible for many things: the end of ideology (Boyle and Rattansi, 1990: 13; Agger, 1992: 73; Carr, 1997: 12); the death of the subject (Agger, 1992: 296; Carr, 1997: 8); the end of epistemic absolutes and certainty (Carr, 1997: 5), an end to reason (Carr, 1997: 5), even a 'rage against reason' (Bernstein, 1991: 31) and a recession of rationality (Gergen, 1991: 77); an obliteration of history (Agger, 1992: 286); a frontal assault on methodological unity (Hassard, 1993: 111); a loss of trust in science and other grand 'metanarratives' of science, religion and politics (Lyotard, 1979: xxiv; Lecercle, 1990: 76);
the death of God (Turner, 1993: 71); an end of art (Appignanesi and Garratt, 1995: 54); the embrace of chaos (Appignanesi and Garratt, 1995: 109); the death of the author (Carr, 1997: 16); a rejection of narrative structure (Hassard, 1993: 114); a cultural transformation (Hassard, 1993: 116); a dehumanisation of the subject (Hassard, 1993: 114); a 'relentless dissatisfaction with the here and now as well as a bewilderment about the possibility of thinking beyond the here and now' (Siebers, 1994: 2-3); the phenomenon of 'social saturation' (Gergen, 1991: 61), 'populating the self' (Gergen, 1991: 68) and 'multiphrenia' (Gergen, 1991: 73-74); a parody, pastiche, irony, playfulness and celebration of surface depthlessness of culture (Hassard, 1993: 115); a search for instabilities (Hassard, 1993: 123); and 'a shift from truth to fiction and narrative, by a change from the world of experience to that of language' (Lecercle, 1990: 76). Postmodernism is associated with the fragmentation of self-conceptions in response to a multiplicity of incoherent and disconnected relationships (Gergen, 1991: 7): 'the very concept of personal essences is thrown into doubt. Selves as possessors of real and identifiable characteristics--such as rationality, emotion, inspiration and will--are dismantled' (Gergen, 1991: 7). At this point, concerns were multiplying.

The reign of confusion continued upon finding postmodernism described in an abundance of forms: the New York Times (or Affirmative) Postmodernism (Agger, 1992: 76), as opposed to Establishment Postmodernism (Agger, 1992: 280); a mode of critical theory (Agger, 1992: 292; Boje et al, 1996: 62); a culmination and combination of postmodernity and the new individualism (Agger, 1992: 283); 'good' and 'bad' (Agger, 1992: 284); 'hard' and 'soft' (Younis, 1997); 'real', 'false' and 'eclectic' (Appignanesi and Garratt, 1995: 46-48); affirmative or sceptical (Fox, 1993: 128); an epoch (Hassard, 1993: 115; Boje et al, 1996: 63); an epistemology (Hassard, 1993: 115; Boje et al, 1996: 63); a 'hyperreality' (Baudrillard;
cited in Gergen, 1991; Appignanesi and Garratt, 1995: 55; 121; Fox and Miller, 1997: 55); a 'condition' (Lyotard, 1979: 3; Lecercle, 1990: 77; Hassard, 1993: 123); a 'perspective' (Lyotard, 1979: 14; Hummel, 1997: 22); a 'turn' (Gergen, 1991: 99; Farmer, 1997; Fox and Miller, 1997: 51; Younis, 1997); an ideology (Agger, 1992); a debate (Connor, 1989: 18); a new paradigm (Hassard, 1993: 111); a utopian philosophy (Siebers, 1994: 2); and 'like the Toyota of thought: produced and assembled in several different places and then sold everywhere' (Connor, 1989: 19). Whew!

What could such a multiphrenic concept offer to this work other than more questions?

**Insight into 'Wicked Problems'**

As the review of the postmodernist literature was undertaken, it became increasingly obvious that this new epistemology (or whatever one wishes to term it) had something to offer a student of multiple perspectives (Good, 1994: 153), multiple voices and multiple realities, and one endeavouring to somehow incorporate and understand these multiple positions (Gergen, 1991: 85). The postmodernist sensibility of disorganisation, untidiness and flexibility (Hassard, 1993: 115) lends itself well to a 'Final Chapter' replete with unanswered questions, unsolved problems; after all, 'in the existentialist view there are always loose ends' (Macquarrie, 1972: 13), lives that are incomplete and fragmentary. Here the reality that informs the postmodernist perspective is useful: 'That there is no reality except what we make of it' (Hummel, 1997: 22). Depending on your point of view, the postmodernist perspective may offer endless chaos or limitless opportunities (Morgan, 1996: 53). The author does not conclude that the 'postmodern turn' (Gergen, 1991: 99; Farmer, 1997; Fox and Miller, 1997: 51) is one that has little to offer organisational analysis (Carr, 1997: 4), sharing instead the
view that constructivism (which constitutes much of the underpinnings of this thesis' theoretical framework) is not necessarily inconsistent with postmodernism (Fox and Miller, 1997: 55), but, instead, is consistent with the most devastating insights of postmodernist philosophy (Fox and Miller, 1997: 55). Postmodernism also, usefully, recognises that 'there are no certainties, no context-free truths' (Farmer, 1997: 112). The critical postmodernist and the critical modernist value some elements of modernity: modernity is not rejected out of hand. This is not an acceptance of the "end of reason" thesis but, instead, an acknowledgment that the concept of a predictable, viewable, "clockwork" universe, and our lives within that universe, is repugnant and intrinsically questionable (Younis, 1997). Certainly that position is upheld by the stories heard here. The postmodernist is sceptical of history being orderly, rational and sought on the assumption that things will get better, and of the modern notion that history is the path to a relentless improvement of an ordered world. PwICI may be similarly sceptical of this modern concept: there must be no assumption that life is orderly or rational nor that it will necessarily get better.

To reiterate: this is not a chapter debating the pros and cons of postmodernism nor of its critical application to organisational theory. It is a discourse advocating a critical address of some particular elements of postmodernism to this particular set of 'wicked problems'; problems that may be described as 'malignant' (as opposed to benign), 'vicious' (as in a circle), 'tricky' (like a leprechaun) or 'aggressive' (contrasting with docile) (Rittel and Webber, 1973: 160; cited in Harmon and Mayer, 1986: 9).

An Embrace of Heterogeneity and Divergent Voices

Postmodernism is an acknowledgment that real knowledge should be sought from a variety
of perspectives, both modernist and postmodernist (Farmer, 1997: 116). It holds a self-proclaimed commitment to heterogeneity, fragmentation and difference (Boyne and Rattansi, 1990: 9). Postmodernism turns away from homogenising principles: there is an affirmation of difference, of heterogeneity (Siebers, 1994: 20-21); an acceptance of 'heterotopia' (Connor, 1989; 9; Siebers, 1994: 20), the impossible catalogue that makes no sense anywhere else (Connor, 1989: 9); a heteropia of mixed places and themes (Siebers, 1994: 20). It is a turn towards what was originally Heidegger's and, later, Derrida's 'deconstruction' (Carroll, 1990: xiv; Appignanesi and Garratt, 1995: 77; Champagne, 1995: 28); an undoing of traditional thinking; a questioning of assumptions; a recognition of uncertainty (Farmer, 1997: 112); and a recognition that Postmodernism makes explicit 'the possibility that as many interpretations of the world are possible as there are people' (Hummel, 1997: 21). It is a recognition of incommensurability, of otherness, of alterity, singularity, différence and plurality incorporated in a mood of 'deconstruction, destabilisation, rupture and fracture - of resistance to all forms of abstract totality, universalism and rationalism' (Bernstein, 1991: 57, emphasis in the original). 'In a postmodern world of complexity and diversity, divergent solutions (or arguments) are also necessary in order to go beyond technical and instrumental thinking' (Jun, 1996: 116). The 'postmodern turn' (Gergen, 1991: 99) is a turn away from the modern\(^{141}\): a reaction against the impersonal, the homogenous and the functional. It is these concepts that

\(^{141}\)Of course, this does not mean a rejection of all that is modern. Postmodernism accepts a return to the old and an embrace of the new; an acceptance of eclecticism, heterogeneity, difference. Derrida termed the inclusion of difference and deferral 'Différence' (Appignanesi and Garratt, 1995: 80). I am opposed to the aspects of modernism based on processes of differentiation (Hassard, 1993: 121), technicism and reductionism, which encourage social problems of discrimination, prejudice and stereotyping, especially in the organisational domain. This 'systemic modernism' (Hassard, 1993: 117) insists upon instrumental rationality and an emphasis upon systemic and technocratic theoretical knowledge, with theory developed through rational methodologies (Hassard, 1993: 117). 'Critical modernism' on the other hand, such as that proffered by Habermas's 'defence of modernity' (Habermas, 1987; Hassard, 1993: 119), recognises 'it is the knowing subject who, through experiencing a network of meanings and, thus, the common sense of ordinary language, reaches the consensus of human understanding' (Hassard, 1993: 118).
are deemed useful here.

Comfort is found in the postmodernist recognition of multiple interpretations, as one clumsily attempts to give volume to ‘voices of demystification’ (Gergen, 1991: 96), to spotlight a fractured existence, to express the suppressed in lives replete with physical and social pathology. However, the comfort in embracing heterogeneity must be weighed carefully. An affirmation of cultural diversity, a deconstruction of the classical, traditional distinctions such as race, gender and ability presents its own set of problems. Diversity, for its own sake, is not necessarily good, presenting problems that need to be dealt with and which may not have solutions. In this case, the often problematic negotiation between the divergent groups of the "sick" and the "well" in organisations presents problems of the resurrection, indeed the construction, of self for PwIICI.

*The Death of Certainty: Veiled Nihilism or Liberating Gadfly?*

There is some debate that the postmodern turn is a nihilistic one. For some, postmodernism represents a rejection of absolute values, an embrace of nihilism (Agger, 1992: 284-285); an idealism with the portent of nihilism (Hummel, 1997: 31). Conversely, postmodernism is deemed not to be relativist or nihilist (Fox and Miller, 1997: 56); the postmodernist bent toward deconstruction equated with nihilism is simply a misunderstanding (Farmer, 1997: 108); that deconstruction constitutes ‘good reading’, not necessarily a loss of meaning, but a hyper-abundance of meaning (Farmer, 1997: 108).

Postmodernism liberates (Hummel, 1997: 19). ‘Postmodernism affects the psyche, culture, economics, and politics and government’ (Hummel, 1997: 29), and postmodernism accepts
that many of our basic assumptions are fiction (Hummel, 1996: 25). This is precisely the place where this thesis began: a questioning of an appearance of health. Postmodernism offers a useful gadfly: 'stinging us into acknowledging that our intellectual grids are deficient' (Farmer, 1997: 110), offering a 'role where the primary emphasis is on such aims as undermining interpretations, stinging us to recognition of the need for scepticism about our cherished conceptual frameworks, stinging us to appreciation of the value of hesitation about what we think we know, and stinging us to sensitivity about the injustices that result from faulty knowledge' (Farmer, 1997: 110). Additionally, 'the possibility of justice is increased by adopting a gadfly role toward injustice' (Farmer, 1997: 111). This is what has been sought here.

Issues in Storytelling

For a researcher with a declared allegiance to the subjective perspective of the storytellers and who values the primacy of this perspective, difficulties were found in aspects of the postmodernist consciousness, especially the decentring of the subject. Barthes' sensational proclamation of the 'death of the author' (Appignanesi and Garratt, 1995: 74) suggested that all readers create their own meaning regardless of the author's intentions. The postmodernist 'death-of-the-subject' (Carr, 1997: 8), the concept that nothing exists beyond the text (Derrida, 1976: 158; cited in Carr, 1997: 5; Gergen, 1991: 108), that 'there is no reality outside of language at all' (Derrida, 1973; 1976; 1978; cited in Hummel, 1997: 33), proved problematic. It seems that 'concepts of truth, honesty and authenticity now turn strange' (Gergen, 1991: 111). There are problems characterising the person (Gergen, 1991: 111) and 'the very concept of personal essences is thrown into doubt. Selves as possessors of real and identifiable characteristics—such as rationality, emotion, inspiration and will—are dismantled'.
(Gergen, 1991: 7). The hyper-reality described by Baudrillard suggests that each telling of the story influences subsequent retellings (Gergen, 1991: 122). These outgrowths of the postmodern consciousness undermine the modernist project and, simultaneously, subvert romantic visions of the self (Gergen, 1991: 111); faith in objective knowledge about individual persons, their mind, emotion and intention is eroded (Gergen, 1991: 110). What is confronted, then, is the potential nullification of not only the text (stories) from respondents, but of their value, their authenticity and of the researcher’s carefully considered interpretations.

Much of the postmodernist discourse had sidelined the modern humanist and emancipatory discourse, including much critical theory, through this concept of the 'death-of-the-subject' (Carr, 1997: 9). This notion suggests that 'the self or individual is no longer conceived as a user of language to express one’s inner feelings and intentions but, instead, is the medium through which the culture, in the form of language, gains expression' (Carr, 1997: 8). This notion is rejected here, as Carr has done (1997: 18), arguing that these people are real; they

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142 The modern emphasis on humanity is a point which cannot go untouched. Whilst modernism is responsible for 'the set of visions and ideas that aim to make men and women subjects as well as the objects of modernization, to give them power to change the world that is changing them' (Berman, 1983: 16; cited in Boyne and Rattansi, 1990: 8), a review of the early modern industrial principles, for example, 'Taylorism' and 'Fordism', seem to contradict this theme. Modern humanism (Rose, 1982: 42) was undoubtedly for the benefit of the collective and at some cost to the individual worker. Progress was seen as morally desirable (Rose, 1982: 52). 'Taylorism' (Wren, 1972: 240; Rose, 1982) and later 'Fordism' (Fincham and Rhodes, 1992; Williams, 1992: 9) epitomised the ethics of scientific management, including the social benefits derived from efficiency, such as more and better products, and an increased quality of life (Wren, 1972: 199). They were typical examples of the modernist project: industrialisation and faith in reason, science and the Enlightenment values of equity and freedom which included and preceded utopian emancipation (Williams, 1992: 9). Humanism and 'Taylorism' (Wren, 1972: 240) have frequently been charged with coldness and impersonality (Williams, 1992: 144) as demonstrated in Taylor's thoughts on human relations characterised by a distinctly managerialist tenor: the workers were talked to 'on their own level by those who are over them' about such things as troubles at home or at work (Taylor, Shop Management; 148; cited in Williams, 1992: 144). It is also interesting to recall that these early modern approaches to management were clearly instrumental and not much use to the chronically ill: Taylor's nine qualities for the 'well-rounded' foreman specifically identified 'good health' (alongside 'grit', 'brains' and 'tact') (Williams, 1992: 123).
exist beyond their transcripts, beyond our brief meetings and beyond the investigator’s recollections of them. Their problems are real and whilst the stories were often disjointed, inarticulate, even rambling, 'the modern critique of the sovereign rational subject - atomistic and autonomous, disengaged and disembodied, potentially and ideally self-transparent' (McCarthy, 1987: ix) remains of major interest.

The notion of predictability is, for the postmodernist, a theme to be torn down. Similarly, for PwICl, a life of predictability may be a distant memory: lives, relationships, bodies that cannot be relied upon are what remain. Their stories of life and work are unpredictable, turbulent, poignant (Vickers, 1997a). Their responses are often irrational, unpredictable, contradictory - postmodernist. Paradox, ambiguity and uncertainty are major postmodernist themes and the typical creation of multiple narratives rather than a single infallible narrator, leaving the reader to resolve contradictions or, as is the case here, to accept that the reader (and researcher) be left with an enigmatic experience (Boyne and Rattansi, 1990: 7).

The notion of 'deconstruction' (Champagne, 1995: 28), originally inspired by Heidegger's 'destruktion' and end of metaphysics, inspired Derrida's later deconstruction and Gadamer's hermeneutics (Champagne, 1995: 9). Whilst it is recognised that the 'texts are never simply unitary but include resources that run counter to [the respondents] assertions and/or their author's intentions' (Appignanesi and Garratt, 1995: 80), the recognition of 'meaning' here includes 'identity (what it is) and difference (what it is isn’t)' and, thus, meaning is continuously being deferred (Appignanesi and Garratt, 1995: 80). Derrida's notion of 'différence' combines this difference and deferral (Appignanesi and Garratt, 1995: 80). Whilst 'it is true that deconstruction does hold little promise for reliable knowledge and
reliable judgments’ (Farmer, 1997: 108), it is also recognised that ‘deconstruction is indeed the act of close reading and of breaking through the defences of a text (where text includes not only documents but also lives and actions), showing that privileged terms depend on other, even more significant, excluded terms; it is the act of X-raying a picture (situation) to reveal another picture (situation)’ (Farmer, 1997: 108). From this perspective, the postmodernist deconstruction is helpful, not only in analysis of the texts reported here (which included lives and actions), but deconstruction may allow us to dismantle negative social institutions such as racism, discrimination, paternalism and managerialism. ‘Derrida’s view and the postmodern view encourage a privileging of the unknown and the marginal; it endorses hesitancy because it recognises the limitations of what we know’ (Farmer, 1997: 109).

Another useful postmodernist perspective, especially regarding storytelling, is a recognition of more "realistic" view of time and space: 'We undertake our most ordinary activities—getting out of bed, shaving, eating breakfast, walking, caring and loving, even getting ready the next working move—with no particularly precise sense of location in time and space' (Hummel, 1997: 25). Similarly, the storytellers shifted in time when telling their stories, revealing a perspective of the past which may be, for them, disjointed, discontinuous, fractured; at times frustrating the listener’s attempts to follow it. The storyline was discontinuous, disordered, incomplete; however, if the modernist notions of coherence and order are no longer requisites, one may be left with a pleasing acceptance of inconsistency and disorder - a revised expectation that even incoherence and inconsistency have epistemological value. This is particularly reassuring, given what has been uncovered.
Some Use for The Simulacrum?

Baudrillard’s extreme postmodernist view (cited in Appignanesi and Garratt, 1995: 54) is that the border between art and reality has utterly vanished, having collapsed into the universal simulacrum: 'The simulacrum is arrived at when the distinction between representation and reality - between signs and what they refer to in the real world - breaks down' (Appignanesi and Garratt, 1995: 55). One is left with a surface effect; an end of reality; a reflection of basic reality (Appignanesi and Garratt, 1995: 54); reality becomes redundant (Appignanesi and Garratt, 1995: 55). The postmodernist view looks to the pervasiveness of images. This research has, arguably, demonstrated that much of the understanding of "reality" is through images. The modern belief that seeing is believing (Fitzgerald and Paterson, 1995: 14, emphasis added) has been confirmed here to be an erroneous one.

For PwICl, life is arguably a series of false reflections: images portrayed by them and by others of lives and capabilities that are not real. Paradoxically, many of the problems they experience exist because they are not discussed, not understood and not seen - but they are real. The discourse here does not mark a beginning of the reality of these problems, just because it also resides in text. It marks a beginning of understanding: 'an existence beyond the text and engendering a call for agency!' (Carr, 1997: 18).

A Necessary Return To Heidegger

Before leaving the discussion on postmodernism, and given that this work was an exploratory study using Heidegger’s philosophical underpinnings, it is appropriate to return to Heidegger and postmodernism at this point for several reasons: first, because we know that it was
Heidegger's\textsuperscript{143} work that contributed to and influenced the phenomenology and existentialism\textsuperscript{144} of Sartre, the hermeneutics of Gadamer and the work of the poststructuralists, Derrida and Foucault (all cited by Audi, 1995: 317). It was Heidegger who first posited the notion that 'language speaks us' (Audi, 1995: 319) having a strong influence on Derrida's later deconstructionism (Hassard, 1993: 125) and subsequent commentary about the absence of reality outside language (Hummel, 1997: 33). It was Heidegger who attempted 'to step over the threshold to postmodern thought by internally overcoming metaphysics' (Habermas, 1987: 131). Thus, the roots of postmodernism are in Heidegger's (and also Husserl's) work (Hummel, 1997: 19):

The core of postmodernism originates in France. It is, however, clear that the origins of that core lie in German phenomenology in the work of Edmund Husserl and Martin Heidegger. Postmodernists pursue spin-offs of these serious philosophies in a form that is exhilarating and challenging and with a content that seems to address directly key problems of everyday life on the cusp of what is suggested to be modernity/postmodernity (Hummel, 1997: 26).

\textsuperscript{143}It was Nietzsche, though, who first made inroads into postmodernism. From Nietzsche's philosophy sprang two distinctly postmodernist paths: the first was followed by Heidegger and, later, Derrida; the second pursued by Bataille and Foucault (McCarthy, 1987: xi). Habermas refers specifically to Nietzsche's 'Entry into Postmodernity', suggesting his work acted as a 'turning point' (Habermas, 1987: 83). McCarthy (1987: vii) suggested that Nietzsche and Heidegger 'furnish[ed] the inspiration and set the agenda' for the tendencies to disempowering the purity of reason and its unavoidable entanglement in history and tradition. Habermas (1987: 86) refers to Heidegger and Nietzsche as 'the firstlings' of the postmodern age.

\textsuperscript{144}This influence also extends to the other existentialist phenomenologists that followed Heidegger: Sartre, Merleau-Ponty and Schutz, who all share the same concern for the life-world and the world of everyday consciousness as opposed to the realm of transcendental consciousness (Burrell and Morgan, 1979: 243).
A Return to the Elusive

The benefits of this research are twofold: first, the researcher returning to those elusive two latter objectives now feels satisfied. The amelioration of the working lives of PwICI has commenced, including the empowerment and emancipation of PwICI in organisations, simply by hearing and sharing their stories. The simple act of being heard was, for the respondents participating, a liberating and cathartic experience - they no longer felt alone. The phenomenological model developed is a beginning, at least, of understanding of what some of the issues of import may be for PwICI and why they may exist; it is an acceptance of uniqueness, of multiplicity and an acknowledgment of pain in organisational life:

So basic to agency is ontological narrativity that if we want to explain - that is, to know, to make sense of, to account for, perhaps even to predict, anything about the practices of social and historical actors, their collective actions, their modes and meanings of institution-building and group- formations, and their apparent incoherencies - we must first recognise the place of ontological narratives in social life (Somers and Gibson, 1994: 61).

According to Habermas (1987) 'the defects of the Enlightenment can only be made good by further enlightenment' (McCarthy, 1987: xvii). If one accepts Habermas' (1987) assertion, this work is, in itself, a source of further enlightenment and, as such, a source of emancipation and empowerment, not just for the people kind enough to participate, but for others contemplating the subject matter studied - the researcher included.
Returning to the fifth objective, to assist organisation theorists and practitioners in understanding the issues and problems that exist for a sizeable proportion of the workforce, there is a beginning - a voice - at last. The submission of this thesis and the publication and presentation of papers relating to this work, is this researcher’s best attempt to give voice to the stories that the researcher felt compelled, indeed obligated, to share: stories of survivors of change (Horsted and Doherty, 1994: 53); an attempt to try and convey what is often impossible to tell, impossible to share, what is ‘constitutively undiscussable’ (Stivers, 1997); to find words that perhaps cannot capture the world as it is (Gergen, 1991: 106); to share an aspect of what may be termed the 'survivor’s syndrome' (De Swaan, 1990: 17; Kouzmin et al, 1996); the chaos of lived experience (Somers and Gibson, 1994: 38); stories of lives in flux - indeterminate and subject to further discontinuities (Bateson, 1989: 29) resulting in the constant need for 'self-invention' (Bateson, 1989: 28). It is a recognition that some contradictions cannot be resolved (Bateson, 1989: 187-188) but a rebuttal that they continue to be ignored. It is knowing that a shaping of assumptions about the world shape the contours of intimacy - it is 'to truly know' (Gergen, 1991: 100). Finally, it is realised that to fight something, we must understand it: ‘wishful thinking will not help us. And reciting optimistic formulae will prove to be as inadequate and useless as the ritual of an Indian rain dance’ (Fromm, 1942/1960: 3). Understanding of this problematic area in organisational life has finally commenced.
Future Research

A Transferable Methodology

The literature confirms the existence of many "un-discussable" problems in organisational life; issues that may be recognised as problematic, but which require sensitivity and tact on the part of the researcher to expose the "truth". The previous chapters have explored the notion of an absence of compassion in organisations - both personal and organisational - an absence of humane consideration as has been reported by others, for example, in managerial fundamentalism (Rees, 1995a: 25); narcissistic management practices (Kets de Vries, 1993: 162; Carr, 1994b: 350; 1995: 11; Linstead, 1996: 53); greed and selfishness (Rees, 1995b: 197); bullying (Rees, 1995b: 197); workplace violence (Linstead, 1996: 53; Kouzmin et al, 1996); and organisational conflict (Perinbanayagam, 1985: 14; Argyle, 1989: 200; Lewis et al, 1996).

These sometimes "impossible" situations faced by organisational actors require a new epistemology. One way to increase knowledge is through critical and reflexive method: to uncover narratives; stories that equate with "reality" for the storyteller; reflections from those who perhaps attempt the "impossible" jobs (Glidewell and Hargrove, 1990: 10) or who strive to live and work in "impossible" situations. The stories sought are often those not easily ascertained and will only be revealed in an atmosphere with the requisite amount of trust and where there is an acknowledgment of the sensitivity required to elicit the ticklish and the

145 The notion of "un-discussable" organisational dilemmas is borrowed from the title of a recent conference attended by the author: The Tenth National Conference of the Public Administration Theory Network, held at Richmond, Virginia, USA, 8-10 March, 1997. Some of the ideas contained in this section were spawned by this conference theme and were contained in a paper presented there (See Vickers, 1997a).
thorny in organisational life.

Numerous such "human" organisational dilemmas are worthy of exploration: the pain of redundancy (Temby et al, 1996); job relocation problems (Smith and Wiesner, 1996); failure-avoidance management (Landau and Chisholm, 1995; Chapman, 1996); an aging workforce (Hatchard and Gormley, 1989: 52-53; Vecchio et al, 1992: 7-9); inhumanity and callousness in organisations (Erikson, 1994: 238; Wheelwright, 1995: 30); and the difficulties inherent in organisational restructuring, re-engineering and change management (Carnall, 1986: 105-106; Hammer, 1990; Fried, 1991; Callan and Dickson, 1992; Burke and Peppard, 1993; Towers, 1993; Watkins et al, 1993; Barrett, 1994; Chang, 1994; Coyle and Page, 1994; Horsted and Doherty, 1994; Popoff and Brache, 1994; Hendry, 1995; Sachs, 1995: 36). This is especially important when considering the emotional costs of role conflict and ambiguity (Kahn, 1964/1989: 223) and a subsequent need for workplace transformation or restructuring which recognises communication practices, relationships and co-ordination (Sachs, 1995: 38) and, especially, the tacit quality, style or character of the organisation (Kouzmin et al, 1996, my emphasis), with a shift away from an emphasis on 'machine-people' (Hendry, 1995: 52).

1987; Argyle, 1989: 263; Koeske et al, 1993; Calian and Terry, 1994; Carr, 1994a: 22; Cartwright and Cooper, 1994; Meyerson, 1994; Britton, 1995: 221; Solondz, 1995: 218; Edwards, 1996; Saufi, 1996); that are faced by an increasingly diverse workforce (Vecchlo et al, 1992: 9) leading to the need for flexible workplace practices (Stewart and Spatz, 1993: 105) and the valuing of diversity (Shepherd, 1996) as opposed to the managerialist penchant to 'manage' diversity (Sauers, 1993; Blank and Slipp, 1994: 11; Pringle and Scowcroft, 1996: 29; Steiner, 1996; Woldring, 1996).

These themes of organisational suffering may contribute to the current 'organisations of emptiness' which resonate with a meaninglessness, futility and absurdity, where people are left feeling cast adrift, afloat; searching through life like eternal wanderers (Kets de Vries, 1995: 77). Organisational prejudice and discrimination may be experienced by disabled and sick individuals (for example, Nothdurft and Astor, 1986; Akin, 1989; Noel, 1990; Rayner, 1992; Blank and Slipp, 1994: 97; Jones and Stone, 1994; Klimoski, 1994; Susman, 1994), especially with highly stigmatised, yet invisible, conditions such as HIV or AIDS (Cacioppe, 1988; Kerr, 1992; Stone, 1994; Small, 1995), and schizophrenia (Leonard et al, 1989; Milburn, 1996), but may also be felt by other organisational "misfits"; for example, homosexuals (Blank and Slipp, 1994: 138; Woods and Lucas, 1994: xiv), ethnic minorities and migrants of non-english speaking background (Blank and Slipp, 1994: 77; Woldring, 1996: 5), even women (Blank and Slipp, 1994: 151; Burgmann, 1995: 89).

Qualitative research (including methodologies such as Heideggerian phenomenology) is essential to knowledge development. An urgent need has been recognised in the nursing and health sciences, for example, to re-examine the current theoretical base and to develop more
relevant concepts and theories for practitioners (Morse, 1994a: 2). The same imperative (and the same traditional reliance on the positivist paradigm) exists for organisational research. Both Heideggerian phenomenology (Leonard, 1989; Sass, 1990; Wilkes, 1991) and Husserlian (descriptive) phenomenology have been successfully utilised in the nursing and health sciences (Omery, 1983; Benner, 1985; Swanson-Kauffman and Schonwald, 1988; Osborne, 1990; Wilkes, 1991), along with Gadamerian hermeneutics (Walters, 1996: 92) and other, often innovative, qualitative, reflexive, methodological combinations including phenomenology, ethnography, and/or grounded theory (for example, Kvale, 1983; Field and Morse, 1985: 19; Swanson-Kauffman, 1986; Steier, 1991a; 1991b; Brown and Williams, 1995) - they, too, are likely to be successful in organisational research. Street (1996b: 48) confirmed that, in this postmodern age of few certainties and numerous bounded options, methodological choices should incorporate a philosophy and a method: 'an important part of the researcher/consultant's job is to discover what special circumstances obtain in the community that would prevent the lessons learned from being successfully transferred to other communities' (Ravn, 1991: 110). Uncanny resemblances exist between organisational research imperatives and those of the nursing and health sciences: both have modernist foundations and fundamentally rationalist, objectivist, positivist underpinnings and both require a new emphasis on the tactful, the considerate and the reflexive.

Why is Heidegger's hermeneutical phenomenology so relevant to organisational analysis? It was a methodology and philosophy that supported a rejection of the rationalist and objectivist in favour of the subjectivist and ontological - a means to expose the "un-discussable". The notions of rationality and objectivity espoused, for example, by the managerialist ethic and the medical model were rejected for this study, just as Heidegger rejected the notions of
objectivity espoused by the traditional, Husserlian phenomenology. In a study that valued the subjective, the authentic and the personal it was Heidegger's (as opposed to Husserl's) methodological and philosophical maxim - 'to the things themselves' (Heidegger, 1927/1962: 50) - that was embraced with enthusiasm. It was felt that the successful address of the problematic issues of this research journey might provide direction to other scholars intending to expose the "un-discussable" in organisational life. The methodological vehicle should be a philosophical choice, upholding the aims of the research and, in the case described here, allowing people's hitherto silent "voices" to be heard whilst incorporating suitably sensitive logistical guidelines that respond to the difficulties of accessing a potentially "hidden" population. The outcome may, hopefully, lead to a new, valuable epistemology to be utilised in the capture of previously "unheard" organisational "voice".

Whilst noting the value of Heidegger's 'methodological conception' (Heidegger, 1927/1962: 50), some commentary is also directed toward the possible pitfalls for the future researcher. First, there remains some question as to whether the researcher's "insider" and "intimate" status was actually worthwhile. The pros and cons of the researcher's special vantage point were considered prior to and during the research, and have been discussed at some length in earlier chapters. It seems that in this study, the researcher's "insider" status did have several advantages. It was certainly the case that these advantages assisted in some respects, for example, in gaining access to the population and securing the trust of respondents.

However, it would be irresponsible not to vivify the possibility that this proximity to the research question, especially given the painful context in which the research was carried out, could, in this instance, have also hindered the research process. Qualitative research is
difficult under the best of circumstances, especially for the naive researcher. In this project, there arose a need for the investigator to seek counselling to "survive" the interview and analysis process (see Chapter Four), and of becoming increasingly conscious of a growing distance between herself and the respondents during the main study (after her partner's seizure), whilst deliberately not allowing herself to become too "close" to respondent's pain in an effort to minimise her own. An earlier footnote has flagged the possibility that the stories were, perhaps, more sanitised than anticipated; less raw, less emotive - and correspondingly less representative of the experiences they attempted to portray. Longer passages being extracted from the transcripts may have served to give more impetus to the voices and will be considered for future publication purposes. A researcher embroiled in a personal crisis that is so closely connected to the area of research should, necessarily, be aware of the pitfalls prior to commencement. It is entirely possible that the highly-valued, researcher proximity has been, in some respects, counterproductive. The question to be canvassed, then, is whether someone less "close" to the phenomena could have been more "successful" in eliciting a more representative model. This researcher thinks not, but others may disagree.

What is clear is that careful consideration should be given (as much as is possible without the benefit of hindsight) as to what the possible ramifications of proximity to the research process may be, especially from the perspective of the researcher and the research outcomes. It is not necessary that "objectivity" be sought but perhaps contemplation that, under certain circumstances, the researcher's proximity may actually detract from the research process; certainly, the novice (or the experienced) researcher may find it more arduous.

Finally, it is acknowledged that the "voices" of the researcher and her partner are, necessarily,
stronger than those of the respondents. This comes as no surprise to the investigator given
the events that unfolded and her proximity to them. Naturally, more emotion and more detail
was available to be reported about personal responses of the researcher and her partner. Two
or three hours spent with a person does not compare to living through a personal health crisis
and living with someone who is also doing the same. The decision to include the researcher’s
personal perspective alongside the narratives captured during the research process could also
be questioned. Whilst advocating responsible research and respecting a methodological
imperative compelling restraint from the "bracketing" of personal experiences, perhaps if the
decision had been taken not to report personal events, the respondents voices would have
appeared stronger or would have been stronger.

A Vital Excavation

Phenomenological research is done with an eye to the consequences for action.

Based on the research results, try to formulate recommendations that might
lead to more possibilities for human autonomy, a better situation for those on
whom a decision is to be visited (Barritt et al, 1984: 15).

A vital excavation has begun. Authentic stories have been exposed and whether one wishes
to argue from a critical modernist or critical postmodernist perspective, and whether one
agrees with the researcher’s chosen methods or not, the stories resonate with an undeniable
"truth": life and work with ICI is fraught with 'wicked problems' (Rittel and Webber, 1973:
160; cited in Harmon and Mayer, 1986: 9), brutal problems - problems with no easy solution.
These are not 'administratively soluble technical problems' (Habermas, 1970; cited in
Denhardt, 1981: 65) and require us to widen, not limit, our focus. They are problems to be
grappled with; not necessarily solved. From an epistemological standpoint, there is a beginning, at least, of increased understanding of the rigours of life and work with an ICI: after all, social research should be a reality constructive activity that attempts the betterment of the human condition (Ravn, 1991: 106, own emphasis).

It has been argued that it is surprising that 'so many [organisational] crises derive from the ambiguities, serendipities and banalities of organizational life' (Korac-Boisvert and Kouzmin, 1994: 72). As this work reaches its conclusion, this researcher is not surprised - many of the problems exposed in this work have been so derived. A review of current literature demonstrates numerous difficult organisational problems, personal and organisational crises; difficulties that may well have commenced through ambiguity, misunderstanding and serendipity. Unfortunately, these 'wicked' problems are frequently answered with 'tame' solutions (Rittel and Webber, 1973: 160; cited in Harmon and Mayer, 1986: 9); solutions that are prescriptive, structured and readily distinguishable from other problems and from their environment (Harmon and Mayer, 1986: 9). For example, simplistic recipe-like solutions are proposed: how to effectively deal with people with hearing impairments (Ayala and Lederman, 1994); how to deal with gays and lesbians in the workplace (Blank and Slipp; 1994: 150) or 'dismantle the closet' (Woods and Lucas, 1994: 223-252); and how to handle sexual harassment (Blank and Slipp, 1994: 167). Naive, elementary guidelines of "how to" and "what should be done" are routinely proffered in answer to hugely complex, difficult situations with the underlying notion that if the parties involved simply did what they "should" the problem would evaporate.

As social scientists analysing more complex areas, with more complex conceptual apparatus,
one should acknowledge that "solutions" are not so readily available and that the problems themselves can be defined in rather different terms (Silverman, 1972: 26). The problems confronted by PwICU in their day-to-day existence are not particularly malleable and, sometimes, no amount of common sense or ingenuity will solve them. These are 'wicked problems' in that they frequently have no definitive formulation and, hence, no agreed-upon criteria to tell when a solution has been found' (Harmon and Mayer, 1986: 10). The storytellers presented 'an aching picture' (Somers and Gibson, 1994: 68) of their experiences in organisational life: their experiences as workers were 'inextricably interconnected with the larger matrix of relations that shaped their lives' (Somers and Gibson, 1994: 67) and clearly presented daily dilemmas: Who should they tell? What may one expect from others? Is this reasonable? How do they feel? How should they feel? How might they behave, especially at work? What might life hold for them in the future? How might they respond to that?

Conversely, for colleagues of PwICU, equally difficult questions from another stance: How should one respond to the person at work with, for example, cancer? What should one say? What should one do? How would one feel? How does the other person feel? Should those responses change from day-to-day, even from minute-to-minute? Is this reasonable? How will this affect their work? Students of management and organisation need to explore, reflect upon and debate such issues.

The author set out, artlessly, naively, to find answers to such perplexing and impossible questions. What is concluded is something quite different; something far more powerful: **authentic voice.** This work is 'an analysis rather than a solution' (Fromm, 1942/1960: x). Whilst having no 'management recipe' (Kouzman et al, 1997: 20) to solve these problems,
something far more important is offered: a measure of understanding of ontological despair.\textsuperscript{146}

Some Final Thoughts: Implications for Organisation

What is it that forces man to adapt himself to almost any conceivable condition of life, and what are the limits of his adaptability? (Prome, 1942/1960: 12).

To conclude, one must provide some commentary upon the usefulness of this study to the scholarly fields of management and organisational behaviour. The level of contribution this work makes is at a number of levels and the framework of Chapter One is revisited to explore them - the pragmatic, the humanitarian and the epistemological.

First, to the pragmatic motives discussed in Chapter One. The increasing numbers of PwI/Cl make the study of this group increasingly an issue for those charged with managing human resources. That there have been no previous organisationally-based studies about PwI/Cl at a time when chronic illness is increasing seems neglectful, especially given that it has been argued by many authors earlier (See Chapter One) that having a disability (even an invisible one) makes one's working life more difficult. Additionally, the (Australian) increase in legislative requirements would also seem sufficient to prompt interest in a group that are currently protected and yet remain relatively misunderstood in the community and in organisational life. Highlighting areas of discriminatory practice (as was found in the stories), even unknowing discriminatory practice, seems a useful starting point.

\textsuperscript{146} Once again, the author is indebted to Professor Alexander Kouzmin for introducing the notion of ontological despair for exploration.
Secondly, a return to the humanitarian. The modernist period has frequently been credited with the discovery or rediscovery of the real intensities of experience (Connor, 1989: 4). This thesis addressed itself to this very task, a theme that is upheld in the recent (and modern) proliferation of phenomenological, existential and ethics literature (for example, Heidegger, 1927/1962; Sartre, 1943/1969; 1948/1980; Kaufmann, 1956/1975; Schutz, 1932/1967; Macquarrie, 1972; Singer, 1993; Raphael, 1994).

Organisations are human creations that seem to take on a life and legitimacy of their own (Harmon and Mayer, 1986: 14). Unfortunately, they often allow the individual to absolve themselves of personal responsibility by following the artificial and impersonal rules, roles and procedures put in place by other individuals: modern "rational action" has come to be identified almost solely with what one does within an organisational setting and especially with what one does to further the goals and objectives of that organisation” (Harmon and Mayer, 1986: 15). The postmodern contention that all of us operate as a result of external forces acting upon us, has a number of important ramifications: one may conclude (adopting the now forbidden, linear, causal thinking) that this would suggest an end to personal responsibility and a passivity of human spirit, making actions of empowerment and self fulfilment apparently futile. It would also, necessarily, suggest an end to organisational responsibility and a perpetuation or a refusal to consider these impossible organisational problems.

Further to this, a shortage of personal responsibility adds to the "un-discussable" issues of organisation and are frequently set against a backdrop of achieving 'more with less' (Rees, 1995a: 19), the recent managerialist trend to 'downsizing' (Davis, 1995: 125), 'lean' and
'mean' organisations (Davis, 1995: 125; Kouzmin et al, 1996), the narrow reductionist managerialist interpretations of terms such as 'efficiency' and 'excellence' (Solondz, 1995: 212) and the rise of 'the generic manager', loyal to the managerialist philosophy and eager to impose it (Easton, 1995: 39).

The anti-humanist tenor of the managerialist ethic and economic rationalism exists, not only within the operating organisation, but in the research arena. Much organisational research has been epistemologically and intellectually "high-jacked" by this virulent strain of positivist "science" - economic rationalism (Kouzmin et al, 1997: 22). The terminological and methodological capture of much management research continues through patriarchal and coercive structures that reside within organisations and in the (Australian) academic arenas where favoured techniques and poorly elaborated theories have been purveyed to uncritical clienteles (Leivesley et al, 1990: 367). These clienteles have, in turn, "captured" institutions in pursuit of quick bureaucratic fixes and pragmatic solutions to problems (Leivesley et al, 1990: 367) - problems that are, arguably, notoriously beyond "recipe" solutions. The absence of reflexive thinking or an address of the subjective, the qualitative or the human in organisational analysis and its traditional, positivist, methodological paradigm is stark. This lack of humanism is consistent with the view that actors are living in a psychological 'ice age' (Wilmot, 1975: 3) and the expectation that managers should proffer organisational prescriptions that are consistent for all (as opposed to a response to the unique), apply to all (rather than available only to those who need it) and be unilateral (in the absence of respecting the abilities of those in question to articulate their needs).

The question of the organisational and personal capacity for compassion has been reiterated.
'Reliance upon the inherent decency or honesty of public officers appears to be an inadequate basis for organizational accountability and control within a predominantly Western culture where the primacy of individual actors, and thus individualism, is dominant ideologically and institutionally' (Korac-Boisvert and Kouzmin, 1994: 72). There, perhaps, should reside a recognition of personal responsibility for one's actions: 'Without this, generalized external standards can be (and often are) used to mask otherwise morally reprehensible action. Such personal responsibility entails the public administrator's recognition of the existential nature of all action: ultimately, it is always personal, even when cloaked in external standards of legitimacy' (Harmon and Mayer, 1986: 52). This has been seen in the stories of PwICI in modern organisations: colleagues treating them in a manner that is morally reprehensible under the guise of organisational efficiency. One wonders, for example, how Linda's manager would have felt if it had been his daughter (rather than a colleague) that had been told to find herself another job - fast - in the midst of her life-threatening and harrowing ordeal with cancer. That organisational actors can shed their humanitarian "skins" so easily demands further thought, debate and exploration.

It is the epistemological imperatives canvassed in the introductory chapter that have delivered the most important organisational outcomes. Attempts to understand and apply interpretive, hermeneutic, social constructionist or broadly phenomenological approaches to organisation study have been rare in Australia (Leivesley et al, 1990: 368). This work provides a step in this direction. The reader is reminded that this work commenced with the questioning of the fallacy that the majority believe to be true - that if you look well, you must be well. By questioning this, one must necessarily question many of our shallow and crude organisational processes which are, similarly, guided by falsehood and myth: our appearances shape what
others believe about us. This is not a new concept and yet it continues to be central to organisational processes: hiring of new staff; closing the sale; demonstrating one’s interest in the job; one’s perceived "professionalism" on the job.

"Appearances" go beyond the physical: they include one’s emotional stamina; one’s ability to induce or suppress feeling in order to sustain the required outward countenance (Hochschild, 1983: 7). Our emotions signal our secret hopes, fears and expectations - they are impaired when management of feeling is socially engineering in organisations (Hochschild, 1983: x). This is the "emotional labour"; the commercial use of one’s feelings (Hochschild, 1983: 17) now routinely expected in organisations and part of the management of outward appearances to the satisfaction of others - the rise of the 'cheerful robot' (Mills, 1970/1994: 396) - and the expectation that the robot will also be healthy. The commodification of our feelings and the continuing encouragement of organisational automata are not new concepts, but that the problem remains after 40 or 50 years of scrutiny is a comment on organisation that one should be gravely concerned about - and one that has been underscored by this work.

The exposure of "organisational unreality" has been threefold: first, the "performance" of organisational actors with illness and their demonstrated ability and desire to "mask" their truer selves (in this case, frequently, a masked perception of deviance); secondly, that healthful appearances in the workplace are not necessarily an accurate representation of Being for PwICl; and, thirdly, the reflection that organisational members continue to subject their colleagues to a one-dimensional scrutiny that is neither appropriate, reasonable nor accurate. There needs to be a retreat from the concept of 'machine-people' (Hendry, 1995: 52) and the Tayloristic work models embodied in modern organisations and a recognition, instead, of the
part that "human-ness" - and illness - plays in organisational life. Organisational and administrative analysis, contrary to conventional wisdom that it may be too theoretical, is far too parochial, and too closely linked with the immediate and instrumental orientations of practitioner perceptions (Leivesley et al, 1990: 384).

This thesis has also attempted to be overtly non-positivist in philosophy and methodology, whilst attempting to question some of the normative and ideological "baggage" that continues in many organisations unchecked. Ideological forces continue to dominate organisation analysis generating an unreflexive succession of rationalistic and formalistic theories which derive many of their claims for relevance from overt references to science (Kouzmin et al, 1997: 21) with positivism having claimed to have manifestly authoritarian consequences (Kouzmin et al, 1997: 22). Scientism is the prop of much modern social theory (Kouzmin et al, 1996) - one is reminded that "normal science" can be conceived of as a cognitive pathology (Gouldner, 1976: 48) and objectivism is a cognitive "deviance" produced and reproduced through an effort to conform with that rationality's requirement of self-groundedness. Objectivism and the critique of objectivism, then, are both produced by the grammar of modern rationality, and are symptomatic of its numerous internal contradictions (Gouldner, 1976: 50). It is suggested that one of the purposes of a reflexive analysis would be the discerning of the functions of unacknowledged dogma (Kouzmin, 1980: 131). Here, the unacknowledged dogma of organisationally derived "machine-people" who look well and (supposedly) must be well (and happy) has been challenged through both a critical reading of much current management literature and by the stories reported in Chapters Five and Six.

The professional ideology of science (Yearley, 1988: 45) has been described in terms of
producing 'a favourable image of their objectives and a justificatory account of their activities' (Yearley, 1988: 45-46). This, unfortunately, encourages a 'stunted reflexivity' (Gouldner, 1976: 48) where 'objectivism is that pathology of cognition that entails silence about the speaker, about his interests and his desires, and how these are socially situated and structurally maintained' (Gouldner, 1976: 50). Positivist epistemology is 'in essence based upon the traditional approaches which dominate the natural sciences' (Burrell and Morgan, 1979: 5) and unreflexive rationalistic theories derive relevance through claims to science (Kouzmin et al, 1996). Frequently, when human "issues" are explored in organisational life, they may be done so using positivist approaches that value "objectivity". These are not always the appropriate lenses for researchers to use.

Whilst it is recognised that dyadic relations serve to provide intimacy, social interaction, opportunities for nurturance, reassurance of worth, assistance and guidance (Wilmot, 1975: 6) and that the quality of interaction and dialogue is improved by feedback (Kakabadse, 1991; cited in Kouzmin et al, 1996), as are levels of trust through face-to-face communication (Kouzmin et al, 1996), the dark-side of organisation remains insufficiently and inappropriately investigated. Jourard (1971: 65) posited that one of the most powerful determinants of (voluntary) self-disclosure is the relationship between the two people. Trust is viewed as a necessary prerequisite for successful adult relationships - 'a precondition of partnership and responsible participation' (Bateson, 1989: 18) - a necessity in the workplace and for a successful research outcome when exploring intimate and stigmatising problems. What could be more intimate than revealing a tendency to violence? or a dependence upon alcohol? or the feelings of failure and betrayal following retrenchment? Researchers need to be able to build trust and to report the data gathered with appropriate sensitivity and it is underscored, once
again, the need to hear the previously unheard "voice" of organisational actors, especially about the numerous un-discussable issues cited above. The previous sections advocating future research agendas illustrate the breadth and variability of thorny organisational problems that may be difficult to expose, ticklish and hidden - that could be and should be open for debate.

Finally, this work exemplifies what Winner (1972; cited in Leivesley et al, 1990: 388) argues is largely absent in conventional organisational theory: imagination and an ability to conceive of utopia. Here lies one small contribution to a developed imagination, an encapsulated desire to say no to limited and ideologised solutions, and a work that exemplifies the need for less data and more debate (Leivesley et al, 1990: 388) - a step forward. As one moves to conclude this research one is reminded:

It is only minor decisions, upon which nothing of great importance hangs, that can proceed serenely from such detached deliberation: the genuine, critical dilemmas of the individual's life--and to Kierkegaard individuals alone were real--are not solved by intellectual exploration of facts nor of the laws of thinking about them. Their resolutions emerge through conflicts and tumults in the soul, anxieties, agonies, perilous adventures of faith into unknown territories. The reality of every one's existence proceeds thus from the "inwardness" of man, not from anything that the mind can codify, for objectified knowledge is always at one or more removed from the truth. "Truth", said Kierkegaard, "is subjectivity" (Mairet, 1973: 6).
EPILOGUE

Human life--that is, a life of consciousness and self-awareness--is unimaginable without suffering. Without pain and sorrow, there could be no pleasure and joy; just as without death, there could be no life; without illness, no health; without ugliness, no beauty; without poverty, no riches (Szasz, 1977/1988: xvii).

It is with some trepidation that I submit this work for examination hoping, above all else, that the stories collected have been suitably dealt with. For the people whose lives the reader has glimpsed, who have shared of themselves and their fears, the journey with ICI often never ends, except in death. I feel obligated, having accepted from the outset the risks inherent in what Jourard (1971: 58-59) has termed 'authentic writing', to mark, for the reader, a pause; a semi-colon; some semblance of closure. Indeed, it is imperative that the reader not conclude by thinking that such stories have a happy ending - sometimes they do not and for me, exposing my story, letting other people know my voice, occupied the chief risk, the chief difficulty and an area most exposed to procrastination.

The reader may recall that the research journey began with some private thoughts over a shared bottle of wine. Little remains of that life now. Michael's seizure spotlighted symptoms of memory loss and cognitive difficulties that had been troubling him for weeks prior to that catalysing event. Michael has not recovered, but neither has he deteriorated significantly of late. In fact, some good news recently: the lesions that occupy his brain, disturbing function for him (and life for us) have reduced. The bad news is that this has in no way been related
to the medication given. The disease, seemingly with a mind of its own, waxes and wanes of its own volition. Michael continues to have good days and bad. He worries that it can flare up again at any time; his concern is reasonable. If it flares up again, it can continue to damage other aspects of his brain and body. If the sarcoïd presents in his heart or hypothalamus (the part of the brain that controls body temperature, thirst, hunger and autonomic nervous functions such as regular heart beat or intestinal movements), he may well die. Given that the sarcoïd has already presented in his lungs, joints and brain (that we know of), this is of much concern.

Many of the symptoms of his neurological illness are subtle, although their impact on our lives is not. Michael remains with significant memory problems; we all do. However, it is not that Michael forgets to buy the newspaper when he goes to the shop, it is that when he gets home he has no recollection of having been asked. There is simply no recall of that particular event. Other events stick. There seems to be no rhyme or reason; no pattern which the modernist can't help but seek. Michael remains with difficulty taking in new information, whether this be through written or spoken word and, once digested, has difficulty remembering it. He has similar difficulties relaying his own thoughts to others. This reduced ability to comprehend complexity reveals itself in many ways: he becomes disoriented easily; he is less sophisticated and demonstrates less insight. There are shifts in personality and intellect: the man who was once punctilious, even obsessive, about time, is now often late and completely unconcerned about this. The man with an incisive grasp of numbers, of tax

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147 We are often asked if it is Michael's short-term or long-term memory that is affected. I see so clearly evidence of a social construction here; a medicalised category that has absolutely no bearing on Michael's problems. He has problems with both, and with neither. The categories of "short-term" and "long-term" are simply irrelevant.
legislation and of financial matters, now leaves the wrong money when paying the bill at a restaurant. The man who, before, carefully corrected the dripping tap, now leaves one running full-on for hours - the result of a momentary distraction. Some things are remembered, some are forgotten. Some things are understood, some are not. And day-to-day, there is no way of knowing which are which - but we are grateful for some improvement.

Michael remains grieving for the loss of his "mind": for the person he was. So do I. We ache for the loss of abilities most take for granted. Michael is in many respects a different person: we both are. How could we have experienced what we have and remain the same? Few around us comprehend this and it is so painful. The cruelest irony is that no-one would know, to look at him, that Michael is sick: his is another "invisible" chronic illness. He remains, in many respects though, the Michael of old: humorous, gentle, generous and almost eternally good-natured and cheerful, especially given what he has endured. Some aspects of Michael's intellect remain relatively untouched, making for a very confusing situation for us both and one which few would understand. Most assume that Michael is just "getting better" now; that the crisis has passed. Others assume Michael is an idiot. They-speak-ver-y-slow-ly and can be extremely patronising.

We have learned much over the past year, about ourselves, about one another and most pointedly, about other people. Many of the lessons have been harsh, the changes unwelcome; and we have learned first hand of the stigma surrounding intellectual disability. Michael has retired from work permanently. Thankfully, he was never forced to return to his former place of employment.
My own condition has also worsened significantly over the past year. After completing interviews for the pilot study (around the time Michael was hospitalised) the MS exacerbation reported on at the commencement of Chapter Five left me exhausted and despondent. I could not look at this project, let alone complete it. I was sick of sickness, sick of doctors, sick of the implications of it all and fearful for both our futures. Somehow, though, I did return. I don't know how, except that I felt a compulsion, a need, a desperate burning, stronger than ever, to tell these stories. I also needed something sufficiently engaging to occupy my thoughts as a diversionary tactic. This task has certainly provided such a diversion and has remained one of the few constants in a life marked with change, turmoil and difficult choices. It has also remained one of the few links back to "the old life".

As I complete this thesis, the MS remains unstable. The sensation lost in my right side did, mostly, return, seemingly of its own accord but other MS symptoms remained and worsened. Several months of high dose oral steroids (Prednisone) were only reluctantly acknowledged by the MS necessitating another "pulse" of Prednisone in hospital. The "pulse" evoked a face swollen like a volleyball (worse than the first "pulse", due to the long-term oral prednisone use preceding it), ten pounds gained in a month, a body puffy and blotchy, purple facial blotches, acne, palpitations, hot flushes and general and complete malaise for a couple of weeks. This was, however, cheerfully accepted given that this dose of medication had some impact on the disease process. The relief was palpable: a definitely failing body resumes reasonable working order once again. As I write one of the final drafts, symptoms begin quietly, stealthily to reappear. Perhaps they won't get any worse.

As I near the end, I reflect again on the "So What?" question underlying all that we do as
researchers. I believe I have "pushed the peanut forward" even though many questions remain unanswered, and new, insistent and troubling ones have emerged. The journey continues for PwICl and so, presumably, does the pain. I reflect on my ability to have shared the fractured lives of others given the one I live: the grief and tragedy that has surfaced in many of the respondent's lives has continued to surprise and, at times, overwhelm me, as does my own sense of loss.

Our dear friends at the beginning of this thesis are still with us: I have the greatest admiration for anyone who "sticks it out" with us. A recent dinner with these two friends found me once again reflecting on the dilemmas faced by the four of us: Katherine still sees a psychologist on a regular basis since her accident. She has a bad year in her sales work, and has resumed account management responsibilities to reduce the stress. Don, fortunately, reports much better health and a much lower dose of Prednisone these days (only 10 mg per day). Michael no longer works and is plagued with headaches, arthritic joint pain, confusion, fatigue, clumsiness and an ever-present threat of seizures. However, he is not getting worse currently and, given the outlook we pondered a year ago, this is a very positive sign. Hopefully, this spontaneous remission will continue.

I no longer see a psychologist: whilst very helpful during a period of protracted crisis, in the end, I felt that she was unable to "fix" my life - that was up to me. Michael and I are more settled financially and emotionally now but I continue the battle to get a frightening disease to "settle down", fervently hoping that it hasn't shifted to a more progressive form. I feel a changed person: hardened, cynical, traumatised; finding, also, that these words hold new meaning for me now. I am often surprised at the harshness evident in some of my comments,
my actions, my thoughts. I also find myself surprised at my continuing emotionalism. In the final analysis, though, I have survived. The dark mantle of depression that has periodically overtaken my life, for days and sometimes weeks at a time, is finally receding. I have learned that I am extraordinarily capable and have been startled with what has been achieved. I remain unable to contemplate what that future might hold.

The purpose of this epilogue is also to report an "afterwards" on the lives of some of my generous respondents. As is the general tenor of this note and of life with ICI, the news is sometimes good, sometimes not-so-good. As with the four of us at dinner at the outset, for the respondents who participated, there is variability in outcome. For some, there has been an improvement in their lives: Rosalie has reported some improvement in her condition, chronic fatigue syndrome. She reports feeling better, more in control and having better energy levels than she has had for years. I'm glad for her.

Unfortunately, there is also bad news. Of the ten people interviewed last year, three have left their places of work. Daphne has left her job indefinitely on unpaid leave. I understand that her boss was making her life at work so miserable that she couldn't deal with him and her deteriorating MS, choosing to take some time off to get her life back in balance. The reader may recall this is the same boss who was initially described by Daphne to have been "great" and, yet, was suspected by the researcher to be unkind, thoughtless and inconsiderate. I wish those suspicions had been wrong.

\[146\] That is, that I am aware of. The truth is, I haven't had the courage or the stamina to make personal contact with each of the intermediaries to find out. I simply was incapable of hearing that things may have been getting worse. This may seem an irresponsible end to this research project, but I just could not.
Linda has, like Michael, retired from work permanently. She has recently been found to have more secondary cancers. In a young woman, two metastases are indicative of a rather poor prognosis. Linda also complained, at some length to her intermediary, about how bad her employer had treated her and how insensitive they were to her needs, failing to reveal to her when she would find out about her retirement, how much money she would receive and when she would receive it. My suspicions during the analysis process have again, and unfortunately, been confirmed. This doesn't make me feel any better.

Finally, there is Shelley. Shelley spoke hesitantly during our interview, early last year, about her fears for what would happen to her when August 1996 arrived. Unfortunately, she didn't have to wait until August: in July, Shelley's acute lymphoblastic leukemia relapsed, necessitating a lengthy hospital stay in the bone marrow unit. She had to choose whether to have a bone marrow replacement (if they could find a donor) or a brain stem cell transplant (of her own brain stem cells previously taken and frozen). She chose the latter, insuring a period of no contact with the outside world for several weeks due to the risk of infection. She must have been terrified.

Unfortunately, the transplant did not "take". I was informed in November that Shelley's normal white cell count was slowly dropping. She was dying. Shelley then faced choices, every day, of balancing how much she could do without over-tiring herself and compromising her already weakened immune system, against the vivid pressure of living every day to the fullest. I wrote to tell her I was thinking of her.

When I last spoke to Shelley's intermediary in April 1997, I was told that she was very sick:
vomiting, diarrhoea, infection; a very low normal white blood cell count. On Sunday, 27 April, at around 4 pm, Shelley died quietly in her home. I think of her, of her life and the loss her mother June must be feeling. I also recognise the blatant confrontation of my own fears: of fear and lost control, over life, over illness; my own and Michael's.

A final word: this project has encompassed a most extraordinary turn of events. Not only have I had the opportunity to witness and report the respondents’ passage of trauma with "invisible" illness, I have concurrently witnessed my partner’s crisis with illness unfold, and my own. I truly feel like a survivor-witness: privileged, traumatised and exhausted. In the meantime, as I turn away from this endeavour and move on to the next, more fervently than before, I dare not consider what the future might hold. Michael and I live in 'the parallel world of illness: oppressive, consuming, difficult' (Jennings, 1997: 17). Like others before me, I have no idea sometimes how I continue: 'One day at a time, I suppose . . . you can’t do anything but live one day at a time' (Jennings, 1997: 18). I am also conscious of being 'wise beyond [my] years, filled with resolve' (Jennings, 1997: 18).

I conclude, though, on a positive note as the analysis did, referring to some thoughts from June; words that echoed with me during my own pain, continuing to inspire and epitomising the resilience and renewal that is possible. Knowing that she was losing her sight and (then) facing the prospect of losing her daughter to leukemia, having already lost her husband to a senseless murder, she said:

But I’m still here. I’m still living. I’m still laughing. I’m still enjoying life (June, #2:1).

And, somehow, so am I (Vickers, 1997c).
APPENDICES

Appendix 1 - Advertisement in *Inside AHRI*, November (1995: 8)

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‘Invisible’ illnesses

RESEARCH into the work life of people with chronic “invisible” illnesses (such as diabetes, epilepsy, HIV, migraine, etc) is being carried out by the University of Western Sydney, Nepean.

The researcher is seeking participants for the project who live or work in the Sydney metropolitan area.

To find out more about participating, send your contact details to:

‘Life at work with an invisible chronic illness’ project, M. Vickers, Department of Management and Administration, Faculty of Commerce, University of Western Sydney, Nepean, PO Box 10, Kingswood NSW 2747.

This research has been approved by the university’s ethics committee and all responses will be treated in the strictest confidence.

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DO YOU WORK?
DO YOU HAVE A CHRONIC CONDITION?
IS IT DIFFICULT FOR OTHERS TO "SEE" THAT YOU HAVE THIS PROBLEM?

An "invisible" chronic condition\textsuperscript{149} is one that others cannot readily observe, even though it may affect you at work. Examples of such invisible conditions may include asthma, diabetes, epilepsy, HIV, cancer, migraine, schizophrenia, multiple sclerosis, cystic fibrosis, chronic pain, depression and many others.

Research is being conducted into the life at work for the individual with an invisible chronic condition over the ensuing months. If you have a chronic invisible condition, I would be very interested in talking with you and learning about your experiences with this condition at work if you LIVE OR WORK IN THE SYDNEY METROPOLITAN AREA.

To find out more about participating in this research, please respond in writing with your name (or an alias if you prefer), the invisible chronic condition that affects you, your postal address and contact phone number to:

\begin{flushleft}
'Life at Work with an "Invisible" Chronic Condition' Project  
M. Vickers  
Department of Management and Administration  
Faculty of Commerce  
University of Western Sydney, Nepean  
P O Box 10  
KINGSWOOD  NSW  2747
\end{flushleft}

This research has been approved by the University of Western Sydney Nepean Ethics Committee and all responses will be treated in the strictest confidence.

\begin{footnote}
\textsuperscript{149}The reader will note that in the formative stages of this work, reference was made to "invisible" chronic conditions rather than "invisible" chronic illness. This shift was made as understanding grew and, consequently, it was felt that the term "condition" was less appropriate than "illness". A full explanation was made in a footnote in Chapter One (p. 9).
\end{footnote}
Appendix 3 - Informal Survey Outcomes

Three potential notices were developed and presented to three PwCI known personally to the investigator. Semi-structured (informal) interviews about the advertisements and their ability to attract potential respondents to the study were undertaken. Questions included:

- Which notices were preferred and why?
- What was liked about them and why? What was not liked about them and why?
- Would they respond to their preferred (or any) notice? Why or Why not?
- What would influence their decision to participate in such a study?

It was felt that, after the initial lack of response to the Inside AHRI notice, careful consideration should be given to future notices, especially their wording and placement.

Outcomes

Two out of the three people interviewed found the Notices 2 and 3 (attached) to be intimidating and assumed they were trying to sell something. Neither would respond to these notices. Another problem identified with these notices was that respondents felt that they would only respond if they had one of the conditions actually listed in the heading (see Notice 2). The problem of defining the term "invisible chronic condition (or illness)" was discussed at some length. The term "chronic" was felt to be misunderstood by many in the community, even by those interviewed.

Notice 1 was felt to be more informative than the others. Particularly preferred was the fact that the address showed the University affiliation. The ethics committee validation was felt to be important by all respondents. The more credibility being supplied in the notice, the better, and the more likely those interviewed would be to feel favourably towards the notice and, perhaps, respond.

Suggestions made included: making the notice more informative to respondents, for example, giving some information about what might be required and how it may help others in the future. It was also suggested that survey data be collected at the end of the interview process as potential informants may be discomforted with such questions early. [The reader should note that it was subsequently decided to collect survey data, in writing, prior to the interviews to save time and make it available to the interviewer for review.]

Finally, the issue of why people who qualified may or may not respond was found to be related to the time involved. Time involved in participation, fatigue and other physical problems associated with being chronically ill made careful selection of every activity a must. Responses indicated that the difficulties of surviving a full-time job and the problems of chronic conditions made response unlikely. It was suggested that appealing to potential respondent's altruistic motives may be a helpful approach in securing participation of informants.

Interviews were conducted on Sunday, 26 November, 1995.
DO YOU WORK?
DO YOU HAVE A CHRONIC CONDITION?
IS IT DIFFICULT FOR OTHERS TO "SEE" THAT YOU HAVE THIS PROBLEM?

An "invisible" chronic condition is one that others cannot readily observe, even though it may affect you at work. Examples of such invisible conditions may include asthma, diabetes, epilepsy, HIV, cancer, migraine, schizophrenia, multiple sclerosis, cystic fibrosis, chronic pain, depression and many others.

Research is being conducted into the life at work for the individual with an "invisible" chronic condition. If you have an "invisible" chronic condition I would be very interested in talking with you and learning about your experiences with this condition at work if you LIVE OR WORK IN THE SYDNEY METROPOLITAN AREA.

To find out more about participating in this research, please respond in writing with your name (or an alias if you prefer), the "invisible" chronic condition that affects you, your postal address and contact phone number to:

'Life at Work with an "Invisible" Chronic Condition' Project
M. Vickers
Department of Management and Administration
Faculty of Commerce
University of Western Sydney, Nepean
P O Box 10
KINGSWOOD NSW 2747

This research has been approved by the University of Western Sydney Nepean Ethics Committee and all responses will be treated in the strictest confidence.
Q: What do ASTHMA, BACK PAIN, DIABETES, DEPRESSION, EPILEPSY, HIV AND MIGRAINE have in common?

A: They create problems for people at work.

Research is being conducted into the working life for people with long-term medical conditions that cannot be seen. If you have any condition like this and you work I would be very interested in talking with you and learning about your experiences at work if you LIVE OR WORK IN THE SYDNEY METROPOLITAN AREA.

To find out more about participating in this research, please respond in writing with your name (or an alias if you prefer), the chronic condition that affects you, your postal address and contact phone number to:

'Life at Work with an "Invisible" Chronic Condition' Project
University of Western Sydney, Nepean
C/- P O Box
WILLOUGHBY  NSW  2068

This research has been approved by the University of Western Sydney Nepean Ethics Committee and all responses will be treated in the strictest confidence.
Do you have ASTHMA, BACK PAIN, DIABETES, DEPRESSION, EPILEPSY, HIV or MIGRAINE?

Research is being conducted into the working life for people with long-term medical conditions that cannot be seen. If you have one of the above conditions or any other chronic condition and you work, I would be very interested in talking with you and learning about your experiences at work if you live or work in the Sydney metropolitan area.

To find out more about participating in this research, please respond in writing with your name (or an alias if you prefer), the chronic condition that affects you, your postal address and contact phone number to:

'Life at Work with an "Invisible" Chronic Condition' Project
University of Western Sydney, Nepean
C/- P O Box
WILLOUGHBY NSW 2068

This research has been approved by the University of Western Sydney Nepean Ethics Committee and all responses will be treated in the strictest confidence.
Appendix 4 - Revised Advertisement for The Sydney Morning Herald

Planned for inclusion in The Sydney Morning Herald, Public Notices
Saturday, 20 January 1996

DO YOU WORK?
DO YOU HAVE A CHRONIC CONDITION?
CAN OTHERS "SEE" THAT YOU HAVE THIS PROBLEM?

An "invisible" chronic condition is one that others cannot readily observe. Examples include asthma, diabetes, epilepsy, HIV, cancer, migraine, schizophrenia, chronic pain, depression and many others.

Research is being conducted into Life at Work with an "Invisible" Chronic Condition. You can help by participating in two private interviews, each taking about 1 hour. If you have an "invisible" chronic condition and you LIVE OR WORK IN THE SYDNEY METROPOLITAN AREA please respond in writing with your name (or an alias if you prefer), the "invisible" chronic condition that affects you, your postal address and contact phone number to:

'LIFE at Work with an "Invisible" Chronic Condition' Project
Department of Management and Administration
Faculty of Commerce
University of Western Sydney, Nepean
P O Box 10
KINGSWOOD NSW 2747

This research has been approved by the University of Western Sydney Nepean Ethics Committee and all responses will be treated in the strictest confidence.
Appendix 5 - Sample Covering Letter

(Department of Management and Administration,
Faculty of Commerce
University of Western Sydney, Nepean
Letterhead)

Cipant Name
Cipant Address
Cipant Suburb and Postcode

<Name>

LIFE AT WORK WITH AN "INVISIBLE" CHRONIC CONDITION

you for allowing me to contact you about my research project: Life at Work with an ble" Chronic Condition.

d is an INFORMATION SHEET which will explain what this research is about, and s anser any additional questions you may have thought about since our earlist sation.

ake a moment complete and return the CONSENT FORM and the DEMOGRAPHIC EY as soon as possible so I will have a chance to review your details before we meet.

rm that our first meeting is scheduled for:

Date: ________________________________

Time: ________________________________

Place: ________________________________

have any questions about participating in this research, please call me on (02) 411 6462 on 9.00 am - 6.00 pm, Monday to Friday. I will be pleased to explain any part of the dings you are uncertain about or answer any of your queries.

forward to meeting with you.

faithfully

aret Vickers
Investigator
Appendix 6 - Sample Information Sheet

(Faculty of Commerce,
University of Western Sydney, Nepean
Letterhead)

Date

<Participant Name>
<Participant Address>
<Participant Suburb and Postcode>

Dear <Name>

INFORMATION SHEET FOR PARTICIPANTS

Purpose of Research

The purpose of this study is to find out what problems exist for people with an invisible chronic illness who work and whether there are problems in common between people with different invisible illnesses. The study is undertaken as PhD research with the Department of Management and Administration, Faculty of Commerce, University of Western Sydney, Nepean.

Definition of “Invisible” Chronic Condition (ICC)

A person with invisible chronic condition is someone with a medically diagnosed condition where symptoms associated with the illness cannot readily be seen by other people. Examples of such conditions may include: arthritis, asthma, depression, epilepsy, heart disease, back pain, cancer, schizophrenia, chronic fatigue syndrome, diabetes, hepatitis, nephritis, migraine, malaria, cystic fibrosis. This list is not exhaustive and many other conditions not listed here may be included.

This study is designed to investigate and understand the problems experienced by people who have an ICC and who find that having this condition presents problems (and possibly benefits) for them at work.

The Interview

The research will involve you being asked a series of open-ended questions about your work and your illness, and your experiences with the two combined. Each interview will be expected to take approximately one hour, and will be scheduled at a place of your convenience (in the Sydney Metropolitan Area.) I am uncertain as to exactly how many interviews will be required: at least one and possibly two, with the outside chance of a third conversation which you may find more convenient over the phone.

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I am prepared to travel to a pre-arranged venue that is convenient to you such as your home or place of work (if a private office is available), a coffee shop, bar or perhaps the foyer of a hotel. What is important for the interview is privacy, quiet and lack of interruptions. If none of these places are suitable, you may prefer to attend the interview at an office at the University of Western Sydney, Nepean. Campuses are at Westmead or Werrington that may suit you. I will be happy to organise a room.

You may, at any time, terminate the interview or decline to answer any question.

With your permission, it is my intention to tape record the interview as well as make short notes during the interview itself. This will allow me to listen carefully to whatever you are telling me during the interview, so I can better understand it. You are assured of absolute privacy and confidentiality. All tapes, transcripts and notes will be securely held in a private home and will not be made available to other persons for review. A copy of the transcribed interview will be made available to you as soon as possible after the interview and may be referred to during subsequent interviews. You may telephone me if you have any questions, comments or thoughts to add after the interview.

Counselling

You may find that recalling events about your chronic condition makes you feel upset, angry or anxious. This would not be unusual and you may wish to get some counselling to help you work through the issues of concern to you. I will be happy to refer you to professional counsellors.

Any other information

If you have any other questions or need any further information please contact me on (02) 411 6462.

PLEASE COMPLETE THE CONSENT FORM AND BRIEF SURVEY AND RETURN TO ME AS SOON AS POSSIBLE. THESE DOCUMENTS WILL BE REQUIRED IN ORDER TO PROCEED.

Yours faithfully

Margaret Vickers
Chief Investigator
Appendix 7 - Sample Consent Form

(Faculty of Commerce,
University of Western Sydney, Nepean
Letterhead)

CONSENT FORM

I __________________________ agree to participate in the research project entitled Life at Work with an Invisible Chronic Condition conducted by Margaret Vickers, 153 Penshurst Street, WILLOUGHBY, NSW, 2068 in conjunction with the Department of Management and Administration, Faculty of Commerce, University of Western Sydney, Nepean.

I understand that the purpose of the study is to find out the attitudes, experiences, perceptions and behaviours of people with invisible chronic conditions who work, and to find out the issues that concern such individuals. I understand that this is NOT a study of occupational illness or injury, but of invisible illness brought to the workplace by the individual.

I understand that my participation in this research will involve participation in one or two in-depth interviews lasting approximately one hour at a venue to be agreed upon between myself and the chief investigator, Margaret Vickers. The interview process may be supplemented with telephone conversations that will take place at my convenience between myself and the chief investigator Margaret Vickers.

I understand that participation in this interview may be emotionally or psychologically taxing and may result in emotional or psychological discomfort before, during or after the interview takes place.
CONSENT FORM ...

I give permission for the chief investigator Margaret Vickers to use a tape recorder to tape the interview and make brief additional notes during the interview to clarify understanding and to assist with her later analysis and interpretation.

I agree that the research data gathered from this project may be published in a form that does not identify me in any way.

Name: ______________________________________
Address: ____________________________________
          ______________________________________
          ______________________________________
Ph (Home): __________________________________
Ph (Work): __________________________________
(This number will be used with the strictest discretion. No mention of this study or your illness will be made to anyone who may answer your telephone.)
Email: _____________________________________
Fax: ________________________________________

Invisible Chronic Condition: ________________________

__________________________________________ / /
(Signature of participant)

NOTE: This study has been approved by the UNIVERSITY OF WESTERN SYDNEY NEPEAN'S Human Ethics Review Committee. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Ethics Committee through the Human Ethics Officer (Ph: 047 360 169). Any complaint you make will be treated in confidence, investigated fully and you will be informed of the outcome.
Appendix 8 - Demographic Survey - Pilot Study

DEMOGRAPHIC SURVEY

Please fill out this short questionnaire and return with your consent form.

If there is any question you do not wish to answer please feel free not to answer it. Participation in this research is entirely your choice.

PERSONAL

1. What is your age? ________________ (years)

2. What is your gender? (please tick one)
   □ Female
   □ Male

3. How many people live in your household? ________________

4. What are each of their relationships to you? (Please describe each relationship, for example, partner, child, parent, friend, spouse)

5. Please describe your ethnic background?

6. What is your highest achieved level of education? (please tick one)
   □ Commenced High School
   □ Completed High School (HSC, Leaving Certificate or equivalent)
   □ Technical Certificate
   □ University Degree
   □ University Postgraduate Degree or Diploma
   □ Other (please specify): __________________________

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EMPLOYMENT

7. What is your income range? (please tick one)

☐ $0-24,999
☐ $25,000 - 49,999
☐ $50,000 - 74,999
☐ $75,000 - 99,999
☐ $100,000 - $124,999
☐ $125,000 or higher

8. In what employment sector do you work? (please tick one)

☐ Private industry
☐ Government/Public sector
☐ Non-profit organisation
☐ Self-employed
☐ Other? (please describe)______________________________

9. In what industry do you work? (please tick one, and specify further if you think appropriate, for example, Computing/Technology - Telecommunications; Health Care - Physiotherapy).

☐ Banking/Finance______________________________
☐ Education_________________________________
☐ Health Care_______________________________
☐ Public Administration________________________
☐ Computing/Technology_______________________
☐ Retail_____________________________________
☐ Service Industry____________________________
☐ Other? (please describe)_______________________

10. What is the title of your current position?

__________________________________________________________________________
11. How long have you been in your current position?

12. How long have you been with your current employer?

HEALTH

13. What is the name of the invisible chronic condition that you have?

14. When were you diagnosed with this condition?

Thank you for filling out this survey. The information on this form will be stored securely and may be referred to during the interview process.
Appendix 9 - Demographic Survey - Main Study

Please fill out this short questionnaire and return with your consent form.

If there is any question you do not wish to answer please feel free not to answer it. Participation in this research is entirely your choice.

PERSONAL

1. What is your age? ___________ (years)

2. What is your gender? (please tick one)
   □ Female
   □ Male

3. How many people live in your household? ___________

4. What are each of their relationships to you? (Please describe each relationship: eg partner, child, parent, friend, spouse)
   __________________________________________________________
   __________________________________________________________

5. Please describe your ethnic background?
   __________________________________________________________
   __________________________________________________________

6. What is your highest achieved level of education? (please tick one)
   □ Commenced High School
   □ Completed High School (HSC, Leaving Certificate or equivalent)
   □ Technical Certificate
   □ University Degree
   □ University Postgraduate Degree or Diploma
   □ Other (please specify): ____________________________________
EMPLOYMENT

7. What is your income range? (please tick one)
   □ $0-24,999
   □ $25,000 - 49,999
   □ $50,000 - 74,999
   □ $75,000 - 99,999
   □ $100,000 - $124,999
   □ $125,000 or higher

8. In what employment sector do you work? (please tick one)
   □ Private industry
   □ Government/Public sector
   □ Non-profit organisation
   □ Self-employed
   □ Other? (please describe) ____________________________________________

9. In what industry do you work? (please tick one, and specify further if you think appropriate, for example, Computing/Technology - Telecommunications; Health Care - Physiotherapy).
   □ Banking/Finance ____________________________________________
   □ Education __________________________________________________
   □ Health Care _________________________________________________
   □ Public Administration _________________________________________
   □ Computing/Technology ________________________________________
   □ Retail _______________________________________________________
   □ Service Industry ______________________________________________
   □ Other? (please describe) _______________________________________

10. What is the title of your current position?
    _________________________________________________________________

11. How long have you been in your current position? ____________________
12. How long have you been with your current employer? 

13. Please briefly describe what you do at work: activities you may perform or tasks required of you on a regular basis.

14. What mode of transport do you use to get to work?

HEALTH

15. What is the name of the invisible chronic condition that you have?

16. When were you diagnosed with this condition? How long since diagnosis?

Thank you for filling out this survey. The information on this form will be stored securely and may be referred to during the interview process.
Appendix 10 - Sample Focused Interview Questions

[The reader should be aware that these questions provided, especially for the early interviews, a point of focus; some direction for the investigator and were derived from the theoretical framework. As the interview process progressed, question foci necessarily shifted as new categories were explored and current ones reached saturation.]

1. PHYSICAL LIMITATIONS IMPOSED BY THE CONDITION
(Refer to Survey Data from Respondent - Employment and Health Sections)

What kind of limitations does having this invisible chronic condition place on you at work? Using a scale of one to ten (one being the lowest), how would you rate the negative physical impact that your condition has on your work life? Are there any benefits? What are they?

2. PSYCHOLOGICAL, SOCIO-CULTURAL, COGNITIVE PSYCHODYNAMICS AND BEHAVIOURAL AND PHYSIOLOGICAL RESPONSE

Can you think of a situation where having this invisible chronic condition presented a challenge for you at work? What happened? Why do you think this happened? How do you feel about what happened? Why? What did you do? In what way has this incident affected your behaviour since then? Did this have any impact on your chronic condition?

3. BEHAVIOURAL RESPONSES - DISCLOSURE, PASSING, COVERING; PSYCHOLOGICAL/SOCIO-CULTURAL/COGNITIVE PSYCHODYNAMICS AND BEHAVIOURAL AND PHYSIOLOGICAL RESPONSE

Have you told anyone where you work of your condition?

Yes - Why did you tell them? Who else knows about it? How do you feel about others finding out if you have not told them? How do you feel in situations at work where you are uncertain who knows and who doesn’t? What do you do? If you went to work somewhere else, would you tell anyone about your condition? Why do you say that?

No - Why did you decide to tell no-one at your work? Under what conditions might you change your mind? How do you think your colleagues would respond if they knew? What makes you say that?

4. NEGATIVE ATTITUDES ABOUT ILLNESS; STIGMATISATION; STEREOTYPING, DISCRIMINATION; MYTHS AND LAYPERSON’S BELIEFS ABOUT ILLNESS; LACK OF UNDERSTANDING

Can you think of a situation where having an invisible chronic condition has disadvantaged you at work? What happened? Why do you think this happened? How did you feel about this situation? What did you do? What might you do in the future to avoid such a situation happening again?

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5. NEGATIVE ATTITUDES ABOUT ILLNESS; STIGMATISATION; STEREOTYPING, DISCRIMINATION; MYTHS AND LAYPERSON’S BELIEFS ABOUT ILLNESS; LACK OF UNDERSTANDING; MOST IMPORTANT ISSUE FOR THE PwICI; PSYCHOLOGICAL, SOCIO-CULTURAL, COGNITIVE PSYCHODYNAMICS AND BEHAVIOURAL AND PHYSIOLOGICAL RESPONSE

What do you think is the biggest problem for people working with invisible chronic conditions? Why do you think this is a problem? How do you feel about this problem? How has this problem affected you? Can you give me an example?

6. COGNITIVE PROCESSES, PSYCHOLOGICAL COPING STRATEGIES, DEFENCE MECHANISMS USED TO COPE WITH HAVING AN ICI AT WORK

People employ sorts of coping behaviours to help them deal with having a chronic illness or disability at work. These can be used at home or at work.

What sort of things do you do to help you cope with your work life and having this invisible chronic illness? Can you give me an example? Why do you do this? How does it help you (or does it make things worse)?

7. ISSUES OF IMPORTANCE TO RESPONDENT NOT YET MENTIONED BY INTERVIEWER

Are there any other things that you think are important when considering the lives of PwICI at work that have not been discussed? Why do you think this? Can you give me an example?

8. ADDITIONAL DOCUMENTARY EVIDENCE

Do you have any documents related to anything you have told me here today? What are they?
Appendix 11 - Telephone Information Used

Criteria for Selection of Case Study Participants

1. Person must be working or have been working in the past 12 months
2. Person must have a chronic medical condition that is not visible to the casual observer.
3. Examples cited: arthritis, epilepsy, asthma, MS, migraine, nephritis, depression, chronic pain, cancer, diabetes, heart disease.

Information about the Researcher

1. Researcher is currently working full-time on her PhD in Management at University of Western Sydney, Nepean.
2. Researcher also has an Invisible Chronic Condition, Multiple Sclerosis.
3. Researcher has received full approval from the University of Western Sydney, Nepean, Ethics Committee.
Information about the Research Process

1. Researcher will send out INFORMATION SHEET, CONSENT FORM and brief DEMOGRAPHIC SURVEY.

2. CONSENT FORM and DEMOGRAPHIC SURVEY to be returned prior to interviews.

3. Likely to be required 2 x 1 hour in-depth interviews. Interviews to be taped if the participant agrees to this. Brief notes also to be taken. Copies of Transcripts made available to participant as soon as available. Second interview arranged at completion of first if required. Alternatively, phone calls may be used to clarify or inform further if second interviews prohibited.

4. Participants may ask about the researcher, outcomes of the study, counselling or anything else that they think is relevant to their participation in this research.

5. Participants will be informed where and when research is later published (this could be in more than one year’s time) and is likely to be after the completion of PhD dissertation.

6. I am interested in studying the experiences, feelings, perceptions of the PwICC at work.

7. All participation is completely voluntary and participants may withdraw at any time or decline to answer any question at any time. They will also be invited to ring me if they have any questions about the research now or in the future.

8. All information will be kept completely confidential.

What I Would Like the Intermediary to Do

1. Ask their friend/acquaintance/colleague if they would interested in participating in this research.

2. Ask permission for Margaret Vickers to make contact with potential participant and explain all necessary details and, perhaps, if they agree, organise an interview time.

3. Get contact phone number(s), Name and Address and give the assurance that work contact numbers will be treated with the utmost care.

4. Inform Margaret Vickers as to how well they know and trust this person vis-a-vis the safety of Margaret Vickers going to their home to conduct an interview.

5. Inform Margaret Vickers of any success or lack of success with permission granted from the potential respondent as quickly as possible.
Appendix 12 - Sample Contact Summary Sheet

Daphne (One); 19/2/96; Interview #1

(Typed 21/2/96 and 27/2/96)

1. What People, Events or Situations Were Involved?

People Involved Included:

Husband, Manager, team leaders/members who work for her, sisters, mother, father, mother-in-law.

Events Included:

Initial attack of MS 8 years ago. Suffered a migraine then lost vision in her right eye.

About a year ago her right hand and leg got numb and tingly.

Vertigo experienced about 3-4 weeks ago. Still with her.

Trouble with the left side now. Hand worse than leg. Feels like "I can't control it". Goes a different way.

Diagnosis in May 1995. One month consisting of lots of tests in order to get diagnosis. "Good to know exactly what it is so you can deal with it."

Wears anti-glare glasses used because her right eye aches and feels like it will fall out of the socket.

Inability to carry coffee tray at client site. She is unable to carry the tray for fear of dropping it.

Inability to type with left hand now. She is normally a proficient typist. Now writes out work long-hand (with right hand) and gives to another to type up [without explanation].

2. What Were the Main Themes or Issues in the Contact?

Stress Effects/Responses

Right hand tingles when she is angry or upset.

Reports a tendency to bottle-up her feelings rather than letting them out.

Working 16-18 hour days for several months prior to first attack.
Physiological Response

Loses her balance.

Can’t control her left side of her body.

Vision lost completely in right eye. 80% returned over a six year period.

Right side has gone numb and tingly. This happens more when she is angry.

Vertigo over last 3-4 weeks. Nearly fell when near the tea room.

Work Life

Avoids incidents where she may be embarrassed or her failings become obvious, for example, not carrying the coffee tray when visiting client sites.

Works very long hours.

Doesn’t ask for help or explain to colleagues why she engages in some unusual behaviours due to her condition, for example, ringing rather than walking to see people.

Feels indebted to her employers and wants to stay working for them. She reports wanting to do a bit extra to make up for time lost when sick.

Psychological Response

Feels inadequate, as though she’s not doing her bit when she can’t carry the coffee tray when it’s her turn. She will make an excuse to avoid doing it, for example, that she’s too busy. She tries to get out of it.

Does not want special treatment.

Feels as though people are staring at her when she walks, even though they may not be. Feels self-conscious, conspicuous.

Doesn’t ask for help in opening the photocopy paper.

Reported thinking that when she took time off last May (only worked 7 or 8 days in that month) that this was a great deal of time to have off. Reported feeling very badly about this.
Behavioural Response

Avoided walking up the long hall to her colleagues (team members) because she felt conspicuous, that people would be staring at her even though she thinks that they probably weren’t [Covering/Passing].

Made an excuse when asked about ring them up all the time [Covering].

Makes an excuse when not able to carry the coffee tray rather than explaining her predicament.

Still opens the photocopy paper (with one hand) even though this is difficult. Does not ask for help.

Gets typing done by another, as she has difficulty typing with her left hand now. Writes work out long-hand. Has given no explanation for this and not been asked for one.

Goes up and down stairs slowly, avoiding them when she can. Holds the hand rail to steady herself.

Doesn’t work weekends any more. She used to, but now feels that she needs the two days off to recuperate sufficiently to work the next week.

Doesn’t think that hard work hurts her [Compare with her reported emotional stress and anger and the physiological response of tingling and numbness].

Had to have her husband drive her to work recently for a couple of weeks due to her inability to get herself there.

Response from Others

Team members [who apparently know?] have asked her why she always rings them rather than walking down to see them [Check this].

When she is unable to walk quickly enough to keep up, people just slow down and keep pace with her [How does she feel about this?].

Manager told her it was terrible luck. Seems to hide his impatience from her now.

The "admin lady" is sympathetic, motherly.

Husband doesn’t talk about it much (apparently) but frowns and looks concerned when something happens, for example, if she drops something. She just "knows" he is worried.

Husband is very protective of her. Will make an excuse to come with her and help with the shopping or walking the dog.
Relationships with Others

Support from her husband, close girlfriend and sisters.

Support from two team members (analysts - girls) at work. They drive the car to client sites and offer to carry the coffee tray at morning tea without her having to say anything much.

Coping Behaviours

Does not go for a walk now at lunch time to conserve energy for the afternoon.

Asks the admin lady to type her work. Writes it out longhand first because she is no longer able to type.

Uses the telephone rather than walk to see colleagues.

Avoids situations where there might be a problem (by her own admission).

Does not tell certain family members, apparently to protect them and because of a language problem. She perceives having difficulty making them understand the situation whilst speaking in Greek.

Avoids using the stairs whenever possible.

Puts her husband on her right-hand-side in shops to avoid bumping into racks of clothing whilst walking through department stores, due to her vision being gone in that eye.

The Organisation

Has given her special leave when her sick leave has run out.

Have encouraged her to stay even when she gave them an option for her to voluntarily leave. [Perhaps they didn’t understand what the future might hold!] She feels indebted to them now. Wants to stay there and work longer hours to make up for the time she has had off.

Disclosure

Has told boss and team members. Says it isn’t a secret from others, although she thinks that many others at work don’t know (except for admin lady). [This seems to be in contradiction to her disclosure policy with family members - she keeps the existence of her MS a secret from many of them!]

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Relationships with Others

Support from her husband, close girlfriend and sisters.

Support from two team members (analysts - girls) at work. They drive the car to client sites and offer to carry the coffee tray at morning tea without her having to say anything much.

Coping Behaviours

Does not go for a walk now at lunch time to conserve energy for the afternoon.

Asks the admin lady to type her work. Writes it out longhand first because she is no longer able to type.

Uses the telephone rather than walk to see colleagues.

Avoids situations where there might be a problem (by her own admission).

Does not tell certain family members, apparently to protect them and because of a language problem. She perceives having difficulty making them understand the situation whilst speaking in Greek.

Avoids using the stairs whenever possible.

Puts her husband on her right-hand-side in shops to avoid bumping into racks of clothing whilst walking through department stores, due to her vision being gone in that eye.

The Organisation

Has given her special leave when her sick leave has run out.

Have encouraged her to stay even when she gave them an option for her to voluntarily leave. [Perhaps they didn’t understand what the future might hold!] She feels indebted to them now. Wants to stay there and work longer hours to make up for the time she has had off.

Disclosure

Has told boss and team members. Says it isn’t a secret from others, although she thinks that many others at work don’t know (except for admin lady). [This seems to be in contradiction to her disclosure policy with family members - she keeps the existence of her MS a secret from many of them!]

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Medical Profession

Business Analysts she works with have a nursing background so she thinks they understand more than, say, the technical people.

Originally, when her sight went many years ago, she was told it was a virus.

Limitations on a Day-To-Day Basis

Feels very tired.

Can't type with left hand.

Left leg doesn't go where she wants it to.

She feels drunk when walking sometimes.

Difficulty taking the stairs. Has to hang on to the handrail.

Vertigo causing difficulty. Almost dropped her tea in the hallway. Had to stand propped against the wall until the vertigo passed.

 Doesn't catch the train during peak hour. Thinks that she might lose her balance in all the bustle and rush.

Heat affects her greatly. [OBSERVATION: respondent had a fan going in her office. Also mentioned after the interview a disastrous holiday recently in Queensland, where the heat made it unbearable for her.]

Had a period recently where she wasn't able to drive. Husband drove her to work. He has now taken a job in Wyong, meaning that he will no longer be able to drive her should that situation arise again. She will get her sister to drive her if need be as they live very close by. [Longer term problems of getting to and from work if she is unable to drive or take the train, and her husband can no longer drive her?]

Employment Elsewhere

Doesn't think having the MS affects her work. She still does her job.

She would disclose or would feel guilty otherwise.

Wouldn't tell them at the interview, but prior to accepting the job.
Protestant Work Ethic

Daphne demonstrated that she was a very hard worker. She cancelled first two appointments because of work commitments keeping her late. The third scheduled meeting resulted in a venue change from her home to her office. The appointment was at 6.30 pm. I left about 8.00 pm and she reported still having some work to finish off before she went home. She gets up in the morning at 5.30 am.

Employer had given her special leave when her sick leave has run out. She feels indebted to them now. Wants to stay there and work longer hours to make up for the time she has had off.

At time of her first MS exacerbation she was working 16-17 hour days.

She used to work weekends, but now she feels that she needs the two days off. Her staff can contact her by phone if they need to.

Discrimination Against PwICC?

She would like to think that this does not occur, but thinks that, yes, they probably are discriminated against.

As a manager, she reports that she would be very understanding now.

Still thinks that one would naturally pick the person that one would get the most productivity from, if all had the same qualifications and skills. [Assumption that sick people are always less productive even though she believes that she still does her job; lots of contradictions here.]

3. What New Questions Should be Addressed in Future Interviews?

Other people’s behaviour and misunderstanding?

Need to get deeper into the affective component of the interview. Risky!

Issues of how this affects her management behaviour? Are sick managers actually better, more understanding, more aware?
4. Questions to Ask at the Next Interview:

1. When you had your first MS attack (8 years ago), you mentioned that you were working very long hours at the time and had been for several months beforehand. Tell me about that. Were you under a lot of stress at work?
   How long had this been going on?
   Were there any other stresses in your life (good or bad) at that time?
   How much time off did you need?
   How did your loss of vision affect you at work at that time?
   Did you tell people at work what had happened?
   How did you feel about that loss of vision?
   What did you think might happen in the future?

2. Did anything happen (with hindsight) in between that episode with your eye and your time of diagnosis?
   Did this affect you at work?
   How did you feel?
   Did you connect this with your eye problem?
   Did you see a Doctor?

3. Around May 1995 (when you were diagnosed) what was your work life like at the time?
   What about over the last month or two? (since vertigo and left side problems)
   What do you think about this?
   What might you do in the future as a result of this?

4. You mentioned that you are currently asking the admin lady to do your typing for you, and that she never asks any questions.
   If someone did ask you why you are doing this, what would you say? Why?
   How would you feel if this happened?

5. Since your diagnosis last May, you mentioned to me a further two MS "incidents": your vertigo, and your left hand and leg problems.
   Did you see a doctor about these?

6. You mentioned in the last session that having MS is frustrating, but that you are thankful that it is not worse. You mentioned wondering how much worse it would get.
   Tell me about that. What do you think might happen to you in the future?
   How do you feel about that possibility?
   Do you talk to anyone at work about your concerns?
   Do you talk to anyone at home about your concerns? (Husband?)
   How do you think others might react if that happens? (Colleagues, Family, Friends)
7. When we talked last time, you mentioned that you haven’t told several members of your family. What would prompt you to change your mind about telling them? How will you feel when you tell them? How will you tell them? (What will you do?) How do you feel about the possibility of having to tell them? Do you think about this a lot?

8. You talked about your frustration with having MS; that you can’t do what you used to do. You get tired more easily. You have adjusted your work day to cope with this. Do you think about this much? What do you think? Tell me more about this feeling of frustration. Would you want others to know about it?

9. You mentioned that when you are emotionally distressed you feel your arm tingling. You mentioned that you tend to bottle up your stress, keeping your feelings inside rather than showing them. Has knowing you have MS made any difference to the way you handle your feelings? What do you do?

10. You told me about not walking down the long hall to see your team members when they were sitting further away from you than they are now. You mentioned that someone asked you why you rang up all the time. Did that person know about your MS? Were you surprised that they said that? How did you feel when you made the excuse about being lazy?

11. When you are walking along (not quickly enough) or others are waiting for you to struggle to get out of the taxi, especially your impatient boss, how do you feel? What might they be thinking?

12. You mentioned that you gave them [your employers] the opportunity to let you go some time ago when you found out about the MS, so they could have gotten rid of you "without them looking at all bad" and that they "wouldn’t hear of it". Why did you do this?

13. As a manager, think back to the time before you knew you had MS. If you had been interviewing someone for a job and you knew they had MS, what would your response to that candidate have been? What about Cancer? What about Back problems? What about HIV/AIDS? Would your response be different now? How?
Appendix 13 - Sample Ideational Category List

KEY

MP: Medical Profession
CI: Chronic Illness
CR: Cognitive Response
Psych: Psychological Response
BR: Behavioural Response
WSR: Western Societal Response
OM: Organisational Management
OR: Organisational Response
OO: Organisational, others (for example, colleagues as opposed to managers)
SO: Social, others (for example, not family or colleagues)

MP-Diagnosis

CI-Symptoms
CI-Disability
CI-Limitations
CI-Stress

CR-Coping
CR-Learning
CR-Confusion
CR-Uncertainty

Psych-Embarrassment
Psych-Self Consciousness
Psych-Emotions
Psych-Values
Psych-Protective
Psych-Fear
Psych-Defence
Psych-Denial
Psych-Coping

BR-Avoidance
BR-Coping
BR-Covering
BR-Adjustment
BR-Passing
BR-Contradiction
BR-Stress Management
WSR-Capitalism
WSR-Influence on PwIC
WSR-Protestant Ethic
WSR-Sympathy

OM-Attitudes
OM-Behaviours

SO-Support
SO-Friendship
SO-Family
SO-Worry
SO-Fear
SO-Emotions

OR-Policy
OO-Support
Appendix 14 - Sample Interview Transcript

Nine: Interview #2 (Alias Beverley)

MV: OK. You mentioned last time that you know your limitations and that you've spent time working out what those limitations are. I want you to think back to that time in your life when you sorted through all of that.

Beverley: Mmm.

MV: When was that? What happened?

Beverley: Oh, it was really an evolving thing, but I think that [pause] probably, I mean I've always been aware that if I get tired then I'm likely to, you know, but it was kind of bigger than just the tiredness thing and it was sort of knowing what your boundaries are and knowing what boundaries of other people are and it was also a great awareness of energy levels as opposed to tiredness. It was kind of the opposite of that and people who sap energy levels and other people who don't and, and so I, I was just, it was really only this year. It was early this year and the kids were away for the month of January so it was just, I was just coming to work and sort of I had the month to myself really. And I just did a lot of reading and a lot of relaxing and it was just, it just all [MV: Thinking about it all?] Yes. Yes. It was really good.

MV: Right. OK. And what, did anything happen to prompt you to spend time working that out? Was there any particular incident?

Beverley: No, just that I had the time to do it I think. Mmm. I mean I think it's something that I had been evolving to anyway and it just all clarified, it was just, because they [the children] weren't there, I had that space at the right time that I was able to actually do that.
MV: Right. OK. And what exactly are your limitations. What did you discover from this little soul searching. Was it just an energy level thing, or?

Beverley: It is, but it's also, outside my work and, I guess, my domestic time and it's when you have a lot of responsibilities at work and you have a lot of responsibilities with the kids and just sort of day to day stuff. So anything outside that, which is kind of my social life or whatever or relationships with other people, you know, be they friends or be they partners or whatever, then you have to make sure that they're worthwhile because they do take up time and they do take up energy and whether I had MS or not I would still have to be doing this same thing, I think.

MV: Do you think you would have done it, though, if you didn't have the MS?

Beverley: Oh, I don't know. I really couldn't tell. I may not have. I think you tend to take things for granted and then when you sort of find a major hurdle in your life then you kind of re-evaluate and you know that, you know, there's a reason for re-evaluating. But I mean I had done a fair bit of that beforehand because I'd come to Sydney and separated from my husband, done all that sort of stuff, but I think that possibly I hadn't taken it as far as I could have. [MV: Right.] I think that you still think that you can do everything and be everything to everyone until you realise that you can't because, physically, you're not able to do that [MV: Yes. Yes.] and so then that makes you set some priorities and work out what your limitations are. I think that's good.

MV: Mmm. Mmm. So do I. Has anyone ever found out about you having MS without you telling them?

Beverley: No. Most people would not know, I mean, they wouldn't.
If I say to them "Oh, I've got MS." They say "Oh you're kidding, have you? Oh. Oh." You know, because things are never noticed.

**MV:** Right. OK. How would you find out about people finding out, then, that you had MS without you telling them? If someone in the office found out, for example, whom you didn’t want to know, how would you feel about that?

**Beverley:** I don’t care. [laughter] It’s not something that matters to me whether people know or people don’t know. [MV: Right.] It’s not, you know, it’s not an embarrassment. It’s not a limitation as far as the things that I decide I want to do so it doesn’t matter.

**MV:** [pause] Oh yes, last time, you told me that someone here at work had told you that there was a bed upstairs that you could use if you felt really tired. I want you to think back to that time, when they told you that, what were the circumstances where they told you that?

**Beverley:** Oh, it was actually the girl who uses this room. [OBSERVATION: This was the same office that alias Shirley invited me to use to interview here. This girl was explained to me to be dyslexic.] [MV: Right.] And she’d had some problems as well that were kind of, I guess they were mental-health type issues really. I mean she’d been fairly depressed. And so we were just discussing the effects of that and the effects of whatever and she said, "Oh," she said "Something you’ll be interested in," and she’s a good friend of mine so she knew all about it and she just said "Oh, something you’ll be interested in is that there is a bed up there if you get tired enough to need to use it." I mean I wasn’t tired at the time [OBSERVATION: spoken very quickly] or anything like that. She was just sharing information with me [laughs - indicating discomfort?].

**MV:** And how did you feel when it was suggested?
Beverley: That there was a bed? I thought it was a great idea if I ever had time to get to it [laughter]. Yes.

MV: Yes. Right. Oh, OK. Yes, it's important whose suggested it isn't it. [MV referring to notes and question schedule]. Have you ever used it?

Beverley: No. I haven't needed to [with emphasis].

MV: Do you think you ever would?

Beverley: Yes. [MV: Do you?] I would, yes. If I didn't go home, which would be the other thing, then, I would go up and use it. I mean as I say I usually tend to be able to know whether, and because I have more confidence with the people I work with and everything and I'm quite confident to say "Look, I need a day at home," if I'm starting to get tired, whereas before I would just keep pushing myself and so I would have needed a bed under the circumstances [laughing], but now, I mean, if I feel that it's going to be that bad then I'll probably just say "Look, I'll work at home today" and, then, have that rest at lunchtime if I need it. Yes.

MV: Yes. OK. When you decide that you'll work at home for the day, who do you tell about that?

Beverley: Oh, just one of the deputies usually. I just say-

MV: Right. What's their relationship with you? Are they your manager or colleague?

Beverley: Oh, they're colleagues.

MV: They're colleagues. Right and you just tell them that you-
Beverley: Yes. Yes. I just tell them so that someone can contact me if they need to. I mean it's not fair if you're working at home that if there is anything urgent that comes in then you need to be available, so I just tell them and I leave my phone numbers with strategic, my phone number with strategic people.

MV: Right. Fair enough. And, think back to the last time that you decided to work at home. What exactly prompted you to do that? To decide to work at home?

Beverley: Oh, there were two things. One was that I was worn out, [MV: Right.] and as it turned out I was sick. Because the next day I had to go off literally sick because I was just, I was, you know, ugh, I just had one of those 'gastricky' things. [MV: Oh, OK] and so, I mean, that may have been all I was working up to when I was feeling tired anyway, but I didn't take the risk and so I just, plus I had appropriate work to do at home for the day too so I just thought well (a) it's precautionary but (b) I'll get more done if I'm there anyway.

MV: Right. OK. Right. Did you think about it at all before you made that decision?

Beverley: Yes. [MV: What did you think?] [pause] Oh, just whether it was going to work out. I mean, I, the only thing I thought about was only just, "Have I got meetings that day? Is there anything I really need to be at the office for?" You know. It was only those sorts of things. It wasn't morally whether I should or shouldn't or anything [MV: No.] like that.

MV: OK. And, you mentioned last time or else it was on your form actually that you filled in, that you travel to work by bus. [Beverley: Mmm.] How do you find that, given that you've got the MS?
Beverley: Oh, I actually sometimes find it a bit awful. Like sometimes I'd really like to have a label that says I'm disabled [laughter] or something. Please give me a seat." And it's only because I don't think my arms are quite as strong. I mean, I, I, I'm not, in my normal state, at threat of not being able to stand up or hold on if we go around a corner or anything like that, but I do feel it sometimes in my arms.

MV: Do you? What, a bit of weakness?

Beverley: Yes. Yes. Yes. I don't think they're as strong as they used to be. [MV: Yes. Yes.] And so I, yes, I'd rather be sitting down. But I'm sure that you probably hit an age in life where you'd rather be sitting down anyway. [Beverley coughs] I mean I don't find it any hassle. It's not a problem at this stage.

MV: And how would you feel if there was a day when you really had to sit down and you used the disabled seat. That was the only one available. How would you feel if somebody challenged you?

Beverley: I've thought, I've often thought of that. [MV: Have you?] Yes. I even thought of it coming in because we were all crammed in and I was standing up this morning. I thought "I don't know how I'd do this if I . . ." and I don't know that I'd be able to or not. I don't know. I mean, because - [MV: Because probably someone would wouldn't they?] Well you'd, yes. I think someone would. I think I'm still relatively, I mean there's a lot of older people who get on who I think I would feel bad about if I didn't stand up for them. But I remember when I was coming in when I first got MS and I was coming in on the bus and you'd have to stand up going home and all, what I'd do was get in and you know where the baggage part is at the front, and I'd kind of sit my bottom on there. And the bus driver said one day "Oh, you've got to move down the back." And I said "Look, I really can't because I'm not very well at the moment and I
need to rest against this." And he was fine, but I mean I didn’t say why [laughter].

**MV:** But you had to *explain* it didn’t you?

**Beverley:** Yes. [MV: Yes.] Well you *do* because you’re being told to move down the back and you’re not doing it. *You’re disobeying an order.* [laughter.]

**MV:** Yes, that’s true. Yes, it’s an interesting one.

**Beverley:** Yes, but I think that’s the most awkward, particularly seeing that you don’t necessarily *look* disabled. I mean I’ve often thought "Maybe I should just buy a walking stick, so that at times when I’m feeling really bad, I can kind of walk along with the walking stick [laughter] so I *look* disabled."

**MV:** Yes. Yes. It’s a good idea actually.

**Beverley:** And I think that probably would sort of solve things a bit. So that *might* be my next thing, if I really need to or there *might even* be an old one at mum and dad’s place that I can borrow [laughing] just for those sort of occasions.

**MV:** Do you have a disabled car parking sticker at all?

**Beverley:** No.

**MV:** And how long does the bus trip take?

**Beverley:** Oh, between 10 and 20 minutes. It’s not that long.
MV: Right. Are you close to the bus stop where you are?

Beverley: Well, I what I have to, what I actually have to do is drive to the school which is, oh, only about a kilometre or a kilometre and a half to drop Alex [daughter] off, because she's there - and I mean it's not really walking distance when you're in a rush in the morning - park the car there and that's at the bus stop. So I just then sort of walk 100 metres or so, take her into school and catch a bus. Yes.

MV: Right. OK. [pause] If you couldn't get the bus, if something happened to your legs, how would you get to work?

Beverley: I don't know [said very slowly and deliberately] [laughter from MV]. I think that there would be two things happening. One, I think that I'd probably go on part time long service leave or something so I was only working half time and the other half I'd have someone here [indicating at her place of work] bringing work home to me or organising that. And I think that would be, that would work for a while, but I mean if, if I'm actually that disabled I can't live where I'm living. I mean I've got stairs, and I can't get in and out and things like that anyway. So, I mean, I guess I'd probably end up having to take sick leave or making some other arrangements. I'm not really sure. But I'd certainly, if I could get to and from work, because I was mentally able to keep working and things, my mother would get me here. [MV: Right, right.] and drop me off. I just know she'd do that. [MV: Yes. Yes.] But I mean that's relying on her at the moment. If anything happened to her then I don't know what I'd do.

MV: Right. How old's your mother?

Beverley: Seventy, nearly. Mmm.

MV: Do you think at all of that much?
Beverley: Mmm. [pause]

MV: Me too. [laughter.]

Beverley: It's really scary isn't it?

MV: It's really scary. Yes. Yes.

Beverley: I mean I guess in, what's Lindsay? Twelve. So in five year's time, theoretically, you know, she could be dropping me off on the way to school or doing that sort of thing because she'd have her licence. But, you know, there's still that time frame of, you know, what could happen and what can't. So.

MV: And no way of knowing what might possibly happen.

Beverley: No.

MV: And it's almost impossible to plan, plan for these sorts of things.

Beverley: I don't think you do. I think, and also if you try to plan for it you just worry yourself and you put, I think, hurdles in front of you that aren't necessarily there. I mean, it may not happen.

MV: Exactly. It may never happen.

Beverley: So.

MV: OK. Just changing tack here, in your job are you ever in a position of interviewing and recruiting other people for the organisation?

Beverley: [Nodding]. Yes [laughter].
MV: Does that happen very often?

Beverley: Oh, all the time [indicates displeasure with this concept].

MV: All the time?

Beverley: There was only this morning that the last lot of people asked me to do it [laughter]. I'm on about, I'm on about four panels at the moment.

MV: Right. Are these for full time or contract positions?

Beverley: Mmm. Full time.

MV: Full time positions. OK. Have you ever had to interview anyone that you've known has had a chronic condition?

Beverley: Oh, I've interviewed someone who was deaf or partially deaf and - I found that really difficult because he was a difficult person to deal with anyway and, but you just had to be aware that he had to be watching you talk. That's all. Mmm. So once you were aware of that, I'm with a, we've actually got a girl [coughs] who works in our branch who's a bit deaf so I mean I'm used to that anyway. I always stand in front of her when I'm asking for things but nothing else. That was all.

MV: Right. OK. How would you respond if you interviewed someone who you knew had cancer?

Beverley: [short pause] Oh, I don't, I mean that again. That wouldn't make any difference to me. Well, I think it would to other, a lot of people though, because they'd be saying "Oh, how long are we going to get this person for?" and "Are they going to be sick?" and all of that sort of thing.
But I mean that’s not how we’re meant to judge people for jobs and that’s not how I would.

MV: That’s right. Yes. OK. What about if they were HIV positive?

Beverley: Same again.

MV: Same again. Why do you think that you think differently to a lot of other people?

Beverley: Oh, I don’t think I have the prejudices that a lot of people have and there’s a lot of people around and I say “a lot” and I, that’s a bit of a value judgement. I really don’t know. But I know there are people who do have prejudices and who would feel uncomfortable with that. But, I mean, if we actually follow through the way we have to interview people then you can’t. I mean, it might colour their judgement but it certainly couldn’t come through as a decision-making thing.

MV: Do you think it happens though, that it colours their judgement?

Beverley: Oh, I’m sure it does. I mean I think that’s just, I think that’s very normal. I haven’t seen it happen. [MV: You haven’t seen it happen?]

No, but I mean I’ve seen people in the interviews who are a bit uncomfortable with gay people or something like that. Yes.

MV: What about if you were interviewing someone and you knew they had MS? How would that influence you?

Beverley: Oh, I might be, I might be coloured the wrong way on that. [laughter] I might feel too sympathetic.

MV: Is that right? Do you think, do you think it would make any
difference?

Beverley: I don’t know. [laughter] No, I don’t think it would make a difference about whether they got the job or not, but if in fact they did get the job then it would make a difference as to how I would sort of responded to them in the workplace. That’s all.

MV: How would you respond?

Beverley: Oh, I’d try and help them as much as I could and make sure they had everything they wanted and, yes. And let them know they had a kindred spirit [laughter].

MV: Yes. Yes. OK. [pause] OK, you talked about, you talked about your need to set priorities quite a bit in the last interview. What exactly are your priorities?

Beverley: - The kids and then my work or, the kids I guess and mum and dad. I feel a fair bit of responsibility to them but obviously the kids first and then getting my job done properly. I don’t think I set myself, for myself, a high enough priority, like things that I should do for myself.

MV: Yes. You didn’t even mention yourself [laughter].

Beverley: No, I know. I mean I do think of myself [laughter]. I just, I guess that, you know, your resources physically and financially run out a bit, but I mean every now and then I sort of screech and say "OK. This is my time" or "I’m going out to dinner with friends" or whatever and do it. I mean I don’t really, I’m not unselfish. I do have a certain amount of selfishness [laughter].

MV: And do you think those priorities have changed at all since the MS
Beverley: No. Not really. I mean its a matter of survival isn’t it?

MV: Definitely. [laughter]

Beverley: So. Yes. [laughter]

MV: OK. You mentioned last time, you were talking about relationships with men and that you avoided men for a while. Do you remember talking about that? [Beverley: Yes.] Can you tell me about that? Was it, was it deliberate?

Beverley: Well, yes, it was. Quite deliberate. I mean I guess I didn’t, I hadn’t worked out how the MS was going to affect me and I guess if you’re going to have a decent relationship then you have to be fairly honest and, you know, I guess they have to be aware of what the outcomes and things are. But a lot of it’s not just the MS. It’s just the fact that you’ve got to work to get them built in or work with the rest of your household and, you know, I’ve got two girls who are ghastly. They hate anyone who’s there. They misbehave dreadfully. [MV: Really?] Oh yes. They’ve really got to, it’s got to be worth fighting that one [laughter] and, yes, I mean I, I just guess that I, I mean this sounds really bad, but I don’t actually find too many men that, I guess, meet my needs intellectually as well as physically and so, and they’re the only ones who I’d sort of spend any time worrying about or trying to fit in.

MV: And they’d be the only ones you’d tell about the MS presumably would they?

Beverley: Oh, no. I’d probably, I’m quite honest about the MS. I don’t, it doesn’t particularly worry me. Mmm.
MV: Right. [pause] So, just so I understand this, you sort of avoided them [men] until you worked out how the MS diagnosis, how you felt about yourself? Is that right?

Beverley: Mmm. Mmm. I think so. I mean I was really insecure and it's taken me a couple of years to kind of get back up again, [MV: yes, yes.] but I'm probably better now than I've ever been in my life as far as security and confidence and things like that.

MV: How does it, how did it influence your self-image? How did affect your insecurities?

Beverley: Oh, look, it affected me, it affected me at work. I was really not doing very good work. I just was being put in positions with people who were, you know, sort of directors or whoever and I'd sort of cringe at the thought of having to go and face them and talk to them about things and, and, it was just, it was really bad. It just threw me so badly for a while.

MV: Just your confidence generally?

Beverley: Yes, [MV: Right] and it wasn't because I have MS. It was just because of what it did to me personally knowing that I had it. It wasn't thinking "Oh, I've got MS, therefore I can't talk to this person," its just that it shook at a much deeper level than that and it took me a long time to work out that I was actually OK and I could do my job because, you see, when I first got it I had about two months off and I just was really disoriented, and while I was getting it and not knowing and then, after that, and, you know, it was just, it was a really bad time. And it did take a long time to sort of get back on my feet again and get my confidence and, as you say, self-esteem back. Mmm.

MV: Mmm. And, oh no, forget that. Do you ever think you've been
discriminated against because of the MS?

Beverley: No.

MV: Do you think it ever might happen in the future?

Beverley: [pause] I suppose it could, but I mean, I guess I know that I do my job really well and, I mean, I think it, I think what would happen would be that if I went and, I mean, I have to . . . really good stuff but, I mean, there are limitations on the fact that I’ve got responsibilities to kids and they’re young or youngish and so I can’t put in long hours, and anything much higher than what I am now would require a bigger commitment and less assurance that I’d be able to get to them both the times that I had to and things like that. So I think it’s limited a lot by that. But I also think that if, you know, I went for any SES jobs, you know, the higher executive jobs and things or if I wanted to sort of take my path up through that then I’d have to be fairly honest and say "Look I have got MS and this" because it does place limitations on you and, whether you like it or not, you know, I think you have to be honest about that. So people do have an opportunity to think "Well, OK. If she’s got MS, I don’t want her," and as I said, theoretically, in the public service they shouldn’t be able to do that but I think that they’d have to. I mean if I was honest with them and told them that there were limitations then they’d have to take that into account. And I mean I think that’s realistic. I don’t know that that’s being necessarily discriminating. I think it’s probably realism, apart from discrimination.

MV: And, and if you told them, you were honest with them and, and then you really thought that it had influenced their choice, a choice against you, how would you feel about that?

Beverley: Oh [pause; indicating discomfort]. It would depend on whether I thought that I could do the job myself and then I’d be pretty
pissed off. But I mean if it was a job I really wanted and I thought I could do it, I mightn’t tell then anyway [peels of laughter from both].

MV: *The truth comes out! I love it.* [laughter]

Beverley: Not before I'd signed on the dotted line anyway.

MV: Right. I understand. All right. When you have an exacerbation, what goes through your mind?

Beverley: It's "Here we go again." It just *really annoys* me. [MV: Does it?] Because I have no *control* over it. I, I mean, even tiredness you have some *control* over; you can do something about it. But once you get it you think [scrunches face indicating frustration, anger.] "This isn’t fair."

But yes, I just-

MV: Any fear in there?

Beverley: Ah, I think there probably *is*, but probably because I've sort of bounced back reasonably well each time then, I guess, I guess I try and stay positive so, I mean, there always is the fear that, you know, if you got it - but I haven't had it badly enough, I suppose, to- I think there's *always* fear but having an exacerbation doesn't make that fear any more or less. There's always fear that next time it could affect you or, you know, you may not be able to get from point A to point B or *whatever*, but because that hasn't happened then I guess I just try and think positively and think "Oh, well." So, whilst the fear's always there. just having an exacerbation, if it's like the eye going again or if it's just the pins and needles type stuff then, you know, it doesn't make me any fearful, more or less fearful of the whole thing.

MV: Mmm. OK. And with the fear, how often, how often do you think
about that? What sort of things trigger it for you?

Beverley: Standing on a bus full of people [laughter] or, I don’t know. I mean I guess one of my fears is that if I loose my vision I can’t read and I just love reading and it would affect my work and, really, it affects everything that underpins what I value most. So that I find that fearful but, again, you know, there’s nothing much you can do about it. You just have to start sort of enjoying different things. I guess you start using your ears more or, you know.

MV: You said last time that you went through a phase of telling everyone about the MS.

Beverley: Oh, it was this compulsive urge to be honest about it. It was awful [MV laughing].

MV: Because you thought it might affect what they think about you.

Beverley: Yes, I still think it was more a compulsive urge as much as anything.

MV: Do you? Yes.

Beverley: Like I could only say three sentences and “Oh, by the way I’ve got MS” [laughing]. It was just really weird.

MV: Really. What do you think was behind that?

Beverley: I don’t know [laughs].

MV: So getting back to-
Beverley: I think it was because I thought it was a bigger part of what made up me than it really was. [MV: Right.] I think I thought it was, [MV: What, it was so big in your mind?] I think it was a far more important, yes, I made it far more important than it really is and that was probably why. And it was also new. It was a new part of me but now it's not. I mean it's not as big as that at all. It's got back to where it really sits now and I've got it in perspective, but I don't think I did then. Because I had, it was all out of perspective and I think that was why.

MV: Mmm. What did you think that they might think about you? You know, how you felt this compulsive need to tell them - What did you think they might think?

Beverley: I don't know. Maybe I wanted sympathy. I don't know. It was just something I had to do [laughs].

MV: Oh, and last time you described the colleague whom you believe understands about your MS and about the tiredness. You talked about someone?

Beverley: Yes, that was probably Shirley. Yes. It was probably Shirley. [She is referring to a person that I believe that I have interviewed, who also works with this organisation. Alias has been used here. It is interesting that the person that she thinks understands her most is another with an ICI. Neither of the respondents knows that I have interviewed the other].

MV: I haven't got the page reference.

Beverley: Yes. It was probably Shirley here, but I, there's, I mean the man who [MV: I thought it was a man. I've got 'he']. Yes it might have been. It was probably Mike.
MV: Right, because the question is, why do you think he or she understands better than other people? Is there any reason?

Beverley: No, I just think he's a kind person.

MV: Right. OK. Last time we talked about your fears for the future and we have today as well and you mentioned the possibility of the dreaded wheelchair. How do you feel about this possibility?

Beverley: Oh, it's just going to be so awkward. Like, how am I going to have baths? How am I going to have showers? My place doesn't fit. Even my parents place doesn't fit, but I think you could probably get around better there. You know, it's just a pain in the bum basically. [MV: Are those?] I mean nothing, nothing's made for it. Public transport's not made for it. You know, my house isn't made for it. Ugh, it would be awful. [MV: What would you do?] My car's not made for it [laughter].

MV: So you'd have to move?

Beverley: Oh, it depends on whether it was permanent or not. I mean those things come and go. I think I'd treat it that it wasn't permanent to start with and see what happens.

[Alarm rings. End of Tape Side One.]

MV: Oh yes, that's right. About moving. Ah, is there anything else that particularly worries you? You've mentioned your eyes today. You fear for your vision? Anything else that is particularly of concern that the MS might bring?

Beverley: No, I mean, it's so unpredictable. You could think of every eventuality. I mean you could think, you know, your bladder going or all
those other things that seem to be, they always ask you about, you know. And you think "Oh God, that hasn’t happened yet. Oh well. It mightn’t happen." I mean, it can affect all of you really so there’s no point. You only worry about the things that, like wheelchairs, because that’s there, that’s kind of, you know -

**MV:** You mean it’s obvious?

**Beverley:** Yes. It’s, well a lot of people end up like that. I mean a lot of people don’t and the eyes, because that’s what has personally affected me.

**MV:** Mmm. Mmm. Oh right [referring now to Interview #1 transcript, p 12] page 12. Oh, OK. We’re talking about the day you went into the office with the eye patch. [**Beverley:** Yes] Do you remember that? And I said "You didn’t feel anything before you were going in? You didn’t feel a little bit self conscious or anything? and you said "No, I think I probably took the eye patch off in the lift because I didn’t want everyone to know that I was -"

**Beverley:** Well, I don’t want people to query me. [spoken very quickly] I mean I didn’t want to be picked out in the lift. There’s kind of, I don’t know, 400, 600 people who work in this building. Probably 400 people who I’ve never met and, you know, another 100 who I only know peripherally so, I mean, it’s none of their business. It doesn’t affect them, so.

**MV:** Right. OK.

**Beverley:** Yes, but no, well I might have said I didn’t do it-

**MV:** What didn’t you want them to know?

**Beverley:** I did once I got in. I thought, "Oh-oh. I do feel worse than
I thought," like I do feel "Oh, here’s Beth with a black eye patch on." [MV: Right. Right.] because, whilst I don’t hide it, I mean, I don’t know who is really aware that I have or I haven’t.

MV: OK. So, what was it that you didn’t want everyone to know that you were -? See, have a look at this first couple of lines and, you just kind of stopped there: "I didn’t want everyone to know that I was-" blank. [MV referring to the previous interview transcript.]

Beverley: Oh, all right. Oh, well I guess that I had MS or that I was afflicted by it at the time or whatever. I mean it’s really that you don’t particularly want people going "Oh, poor Beth." [laugh] Because it makes you different from everyone else. I mean, people who know that I have MS and have a job and have kids and do all that, think I’m a bloody miracle woman. You know like "How do you do it?" and I hate that. You know, you just get on. You have to do it.

MV: Yes, that’s right. There’s not a lot of choice is there?

Beverley: No. You are no different from anyone else that’s put in that position. I mean, you know, I might be good at what I do because I have the abilities that are different to someone else, but the fact that I have MS doesn’t mean that I have any more or less, you know, it’s just, it’s there.

MV: And still referring to that day, oh yes, I was just going to ask you, did you actually wear it [the eye patch] in the office or did you, you said something about covering it with your hand. I wasn’t sure if you had it on or if you took it off.

Beverley: Oh no, I had it, yes, no, well I had, but I was only in and out you see, so what I did literally was walk from the lift-well, pick up something at my desk and come back. And so, I mean, I probably had it on
in the lift but I did this [indicates covering her eye with her hand] just for, I don’t know. I can’t really remember.

**MV:** Right. OK. You’re obviously pretty up-front with people about the MS and you certainly seem to prefer to tell people what your needs are in certain situations rather than try and hide it.

**Beverley:** Mmm. Well if I’m tired and cranky I’d rather people know that there’s a reason for it and it’s not them [laughter].

**MV:** Not a personal attack. OK. Have you, have you ever been in a situation where you’ve explained to someone or to a number of people about what you need or how you’re feeling and then you find yourself having to do it again and again?

**Beverley:** Oh, I think you always do. But I mean I’m so used to that. If you have to tell your children or, again and again, ugh, things, you know. I think my twelve year old now is more sensitive to it, but I mean certainly at six [she] wouldn’t have a clue.

**MV:** And how do you feel when you have to keep explaining it, not necessarily to your children, but to, say, your colleagues?

**Beverley:** Oh, I don’t spend too much time explaining anything to them. I mean, you know the people I guess I’m closest to or who need to know here probably- I don’t, I mean, I don’t think I’d have to explain to them. I just, I just tell them I’m tired and that’s it. I don’t really have to explain again and again.

**MV:** OK. [pause] And do you think that other people with invisible chronic conditions are ever discriminated against, like people with cancer, or HIV?
Beverley: I think they're just overlooked. [MV: Overlooked?] Mmm, [MV: Can you explain that?] I don't, well I don't think people understand how they're feeling or, you know, why they might be acting the way they are. I mean, you know, if, I mean, I get, I guess I wouldn't know how people feel if they have cancer or how sick they feel or whatever, but I know that some are. I mean, I, one of the fellows at the hockey club, one of the fathers there has cancer and they're trying to get rid of him at work because he's had so much sick leave and whatever. Now, I don't know whether that's directly related to the cancer or, I mean he certainly would be driving me berserk if I worked with him, not because he's not there but just because of his attitude. He's very bolshy about it now. He's very defensive [MV: About the cancer?] Yes and I think sometimes that's harder to take into account than the fact that the person's had a lot of sick leave and isn't available to do his job and things like that. So. But, oh I don't, I don't know whether they're discriminated against. Here, I mean, there was a man who had cancer here and everyone was very caring and just took over his work and-

MV: Do you think it depends on the organisation that you're in?

Beverley: Probably. It depends on the organisation and on the person.

MV: The person and the individuals around?

Beverley: Yes. Which is unfortunate, but I think everything depends a lot on interpersonal relationships with people, not whether you're sick or a woman or whatever. I mean, you know, they're sort of doing the anti-discrimination thing here and trying to get women through a bit and what-have-you and, I mean, I've never had to worry about that particularly. I mean I guess I've capitalised on it a bit here, because I've known the situation but, you know, a lot of it is, you know, if you have interpersonal skills and you can relate to people and do that, then you can get by and
even, you know, if you've got MS or he's got cancer or whatever, you
know, you can keep relating to people and keep dealing with people and
probably get treated well. It's people who haven't and people who are
insecure and are, just in everyday life, you can see people out there who
really don't get a fair deal and so, I mean, I try hard, particularly for
women, to get them to believe in themselves a bit more but, you know, I
believe it's more that than the actual disease. I mean, that's why, I think
that's why I think I handle it OK. But if, you know, if there was just
ordinary Joe Blow out there who had MS and may not be coping with it
personally, he may not be coping with it, you know, in a family life or
whatever, and then comes to work and feels really bad about themselves
because they've got it, then I believe that they're discriminated against
because of those sorts of things. I mean-

MV: Rather than the condition?

Beverley: Well, they've got the condition and it's made them a certain
person and they just, and I, I believe should be helping those, but it's also
hard for people to ask for help or to put themselves in the position to say
"Look, I need help."

MV: Mmm. That's true.

Beverley: And I think that's why the invisible illness thing is, it's really
hard for the people who have it in the workplace because (a) you have to
confess to it and (b) you kind of have to tell, yes, you have to be able to tell
people that you have needs or whatever, otherwise it goes there and you
wonder why that person has every second, you know, a day off every second
week or-

MV: When they look fine?
Beverley: Yes, they're just sort of labelled as something else and people don't understand.

MV: Do you have any difficult asking for help?


MV: Just finally, how have you found this interview process?

Beverley: Oh, it's OK. I don't think a lot of people would like it particularly.

MV: Why do you say that?

Beverley: Oh, it's always very confronting and, also, people don't necessarily like talking about themselves one-to-one [MV: Mmm.] or talking about themselves anywhere, let alone one-to-one.

MV: Have you thought about it much in between?

Beverley: No. I do this sort of thing all the time, just for work or for whatever. It's not, it doesn't really make that much difference to me. [MV: And how-] And I mean I can talk about myself personally. I talk about it to friends and, I mean, you know, you get to an age in life where you need to "be yourself" with other people and, you know, there are good friends that you can do that to. You know.

MV: Has it brought up any issues in your mind that you otherwise wouldn't have thought about or hadn't thought about for a while?

Beverley: I think it probably has raised the issue of other people who
might be out there, but it hasn’t brought, I mean, it hasn’t personally as far as me having the illness, it hasn’t raised anything, but as far as the fact that there could be other people out there, I mean, it was like Shirley when she had her depression. I mean that was terrible and I didn’t know about it for ages and then suddenly I did and I sort of said “Oh,” and she said “Oh,” she said “I’ve been trying to talk to you Beth, but I just haven’t been able to.” And of course she was feeling really inadequate. And that was good for her and I guess for me a bit, but, you know, she needed someone who could, she could sort of talk to about things for her.

**MV:** I’m just going to leave it there.

**[Tape turned off. Then turned on again.]**

**Beverley:** There’s one thing: I think if *women* have a chronic illness then there are more likely to be other women out there to help them and I think women are more honest and able to say “I have a need or whatever.” If *men* have it they would see themselves as just absolute failures; wouldn’t confess it to anyone and they’d just sit there, trying to get by.

**MV:** So you think it’s important that women-

**Beverley:** Oh, women have much better networks. They really do. I mean even in an organisation where there’s so few of us, I guess, maybe that’s why, maybe that’s why. **[MV: That’s an important point.]** But even outside, I think women friends are even closer relationships than men. I mean, you talk at a more personal level than if men are good friends. Mmm.

**MV:** Yes, that’s true. OK.

**[Tape is turned off and discussion ensues. Beverley asks me how long I’ve**
had the MS, how it has manifested, etc.]

OBSERVATIONS

- Beverley would be a good respondent to review the chapter I think. She also declined to take the interview notes (interview #1) that I provided for her. I got the distinct impression that she felt a lot more favourably disposed to me than in the first interview - more trusting.

- After the interview during casual (relaxed) discussion, Beverley also revealed the following:

1. That some of her colleagues had got an absolute shock during a discussion when they were talking to her and she assumed that they knew about her MS and so she said something and it became very apparent that they didn’t know. They were totally shocked by it.

2. Another major fear was revealed by Beverley: that if she became disabled, that is, too disabled to work or care for her children, that her children would have to go and live with their father. She believes this would be awful and that he is not a good influence on them.

3. Beverley also revealed that she found the Drug Trial she is involved with confronting. She
was seeing other people with MS at different stages and with different levels of disability.

I found Beverley to be extremely warm during this whole interaction. She was friendly and, during this interview, just the smallest disclosure from me encouraged her to open up enormously. I should do this more often, without monopolising the conversation. I found that this interview was closest to a "chat" between friends with something in common than the others have been. I wish I had done this more in the beginning. The early interviews were too formal. I was afraid of influencing people's answers, but have found that people will heartily disagree if their experience is different to mine.
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Life and Work with "Invisible" Chronic Illness (ICI): Authentic Stories of a Passage Through Trauma - A Heideggerian, Hermeneutical, Phenomenological, Multiple-Case, Exploratory Analysis

by

©Margaret H. Vickers

A thesis presented to the Department of Management and Administration, Faculty of Commerce, University of Western Sydney, Nepean for the degree of

Doctor of Philosophy

October 1997
PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
CANDIDATES CERTIFICATION

I certify that the thesis entitled *Life and Work with "Invisible" Chronic Illness (ICI): Authentic Stories of a Passage Through Trauma - A Heideggerian, Hermeneutical, Phenomenological, Multiple-Case, Exploratory Analysis* and submitted for the degree of Doctor of Philosophy, is the result of my own work, except where otherwise acknowledged, and that this thesis (or any part of it) has not been submitted for a higher degree at any other university or institution.

Margaret H. Vickers

4 February 1998

Date
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DEDICATION

This work is dedicated to the respondents who participated in this study; who shared so willingly, and generously, of themselves, their time and their energy - without their help this research could not have been completed.

And especially to Shelley.
ASSOCIATED PUBLICATIONS AND CONFERENCE PRESENTATIONS

Associated Publications


Conference Presentations


See also: Vickers, M. H. 'Life at Work with "Invisible" Chronic Illness (ICI): A Passage of Trauma - Turbulent, Random, Poignant', Paper currently under review with *Administrative Theory & Praxis*.
ASSOCIATED WORK IN PROGRESS

Journal Papers Submitted for Review


Vickers, M. H. 'Qualitative Research in Public Organisations: A Methodology to Expose the "Un-Discussable"', Paper under review with the Journal of Public Administration Education.

Planned Conference Presentations


ABSTRACT

This research journey began with the author's perplexed reflections on "appearances" and the assumption frequently made that if one looks "well", one necessarily must be well. It is an epistemological, methodological and experiential journey. It is also a very personal journey; one shared in the hope that the risk taken by this author in being 'an authentic writer' (Jourard, 1971: 58-59) would have been worthwhile.

This is research into "Invisible" Chronic Illness (ICI): illness that cannot be "seen" by another, but that can have a major, sometimes catastrophic, effect on the lives of people concerned, especially their working lives. Chapter One illuminates the problem, defines and gives examples of "invisible" chronic illness, and discusses the initial concerns of the author that motivated this study - pragmatic concerns, humanitarian motives, epistemological imperatives.

Chapter Two outlines the complex and challenging life-world of People with 'Invisible' Chronic Illness (PwICI) using a social constructionist paradigm, examining four entitites of influence: illness in a capitalistic, individualistic, Western, social framework; the medical profession; the "invisible" chronic illness itself; and the modern, arguably, "sick" organisation. Of interest when examining the experience of illness in the West are the consequences and constraints of capitalism and individualism, and attendant negative attitudes and judgements about illness, including assumptions of deviance and attributions of stigma. The medical profession, the "doyen" of professions, is examined, including lay perspectives about illness and, especially, the modern application of the medical model, problems of iatrogenic illness and the dominance and patriarchy so commonly confronted by sick people in their dealings with physicians. "Invisible" chronic illness is reviewed in terms of its impact on PwICI: their personal response to illness; the social construction of illness and illness categories, and an analysis of the three socially constructed "perspectives" of illness; "disease", "sickness" and "illness". Finally, the modern organisation is examined in terms of its effect upon "sick" people: one finds a culture intolerant of illness, "rabid" managerialism, organisations as mechanisms of social control and the consequential dilemmas presented to the "sick" person in a "sick" organisation.

Chapter Three assesses the issues, choices and justification for the research methodology employed, especially the chosen path of phenomenology and, specifically, the philosophical underpinnings of Heidegger's phenomenology and its eminent suitability for this particular project. Chapter Four continues the methodological quest by articulating the justification for a multiple-case research design, whilst analysing, in some detail, the sometimes "stony path" to complete this research. The pilot study is reviewed, complete with problems encountered, serendipitous outcomes and consequential amendments to the research design and analysis process prior to the main study being completed.

Chapters Five and Six comprise a comprehensive phenomenological model: a model that ultimately describes a passage of trauma for PwICI. It is an authentic model; one that, it is hoped, captures the essence of life and work with an "invisible" chronic illness. The stories resonate with an aching uncertainty; an ambiguous, fractured existence and one characterised by inconsistency, trauma, poignancy. It is a model that concurrently blossoms with themes of optimism and renewal; of hope, of resilience and of personal growth.

The Final Chapter is a return to voice, not just the voices of the respondents in the study, but to the researcher's voice; a voice glimpsed, necessarily, throughout this volume, as life events which impinged heavily on this research process were recorded en route. It is also a return to voice, not just to the research objectives articulated in Chapter One, but to the voice of the person whose quiet reflections started the roller-coaster ride the reader will necessarily share. In this final analysis, the quest for voice is reconsidered and reaffirmed whilst sense-making of shattered lives and ontological despair is attempted. The epistemological vantage point(s) of postmodernism are valued during analysis of multiple voices, fractured lives and futures of uncertainty, and complete the methodological circle commencing with a philosopher named Heidegger. The research is argued to be a vital excavation - a recognition of authentic and previously unheard voices and a methodology of primary value in researching the incommensurable, the difficult, the nasty in organisational life.
PROLOGUE

The Authentic Writer

Tacitly, or openly, he [she] addresses himself to people who can be enlarged; he wants to enrich their experiences. If he makes money or achieves fame through writing, it is because of the accident that, at that time and in that place, people treasure truth when it is artfully presented. . . . But authentic writing is risky. The chief risk lies in letting other people know how one has experienced the events impinging on one’s life (Jourard, 1971: 58-59).

A Journey Begins

Another excellent bottle of chardonnay is opened. It is about 9.30 pm on Saturday evening and I sit back contentedly after dinner, enjoying the company of my beloved husband and dear friends. Whilst the others chat happily, I withdraw within, momentarily, and reflect. A newcomer to this party would never know, judging by appearances alone, that any of us had any health problems. After all, we all look particularly well, some would say in the prime of our lives; all aged between 29 and 41 years.

We are all far from "well".

Katherine [a pseudonym], though right-handed, is holding her wine glass in her left, cradling her right arm in her lap. About twelve months earlier she was in a car accident, leaving her
with chronic debilitating pain in her right arm, shoulder and neck, and chronic fatigue. She has difficulty writing now for any length of time or participating in any physically demanding activity. Sport is out of the question and any physical activity undertaken by Katherine is now done so with the lavish use of painkillers. At one time she was taking these constantly to cope with the pain, although I understand she has restricted their usage in deference to the future health of her kidneys. I suspect Katherine deserted her part-time degree because of the difficulties her arm causes her, though she has never stated this openly. She has been seeing a psychiatrist (and later a psychologist) since the accident to help her cope with the changes that have been brought to her life, notably depression. Katherine has also experienced cognitive and memory problems since the car accident which have interfered with her job performance; reducing her confidence and sapping her energy. Katherine has decided to pursue a case for damages as her car accident came about whilst driving to a client site in her line of work.

Don [also a pseudonym] mentioned earlier in the evening that he has just increased his Prednisone medication dosage to 75 milligrams every second day. Anyone familiar with this particular "poison" knows that this is a very high dosage of a very powerful drug. The possible negative side effects of this drug are numerous: weight-gain; oedema; hyperactivity; mood swings; bone mass loss; kidney stones. Don has nephritis (inflamed kidneys) and is a possible future candidate for a kidney transplant. The need for increased Prednisone is in direct response to a decrease in normal kidney functioning. Don also has Asthma.

My husband Michael [also taking Prednisone and not using a pseudonym] has sarcoidosis, a particularly rare systemic condition, affecting his lungs. In addition to the iatrogenic effects
arising directly from the Prednisone, the sarcoidosis affects his lung capacity, effecting shortness of breath, tightness in the chest, frequent coughing and fatigue. Since having this condition he is also experiencing inflammation of the joints, resulting in pain in his hands, shoulders and hips. This arthritic pain, whilst not yet debilitating, indicates a future of uncertainty. Michael regularly has his eyes checked, as blindness can also result from sarcoidosis. Some of the iatrogenic effects of the Prednisone that Michael has reported have, in his view, been worse than the condition itself: weight gain; oedema, particularly in the face [commonly called "moon-face"]; mood swings; aggression; two cracked ribs and a kidney stone; all have contributed to the impact of this "invisible" chronic illness (ICI) on his life and work.

I have multiple sclerosis (MS). I live with recurrent periods of overwhelming and inexplicable fatigue; visual problems; bowel and bladder disturbances; balance and co-ordination difficulties; and numerous phantom-like, intermittent, sensory symptoms. I have, in the past, experienced more acute disease episodes which have seriously (and, fortunately temporarily) affected my vision, hearing, balance and co-ordination; even a period of hemiplegia [paralysis to one side of the body]. Unlike the other three, there have been few iatrogenic effects of treatment for me to deal with: there is no ongoing treatment to speak of. Occasional bursts of Prednisone are used in very high doses, for short periods, when acute illness overtakes me, rendering various "bits" unworkable. So far, this has worked for me, but how long will it continue to do so?

Recently there has been talk from the MS Society of a new drug: Betaferon. I try not to give this possibility too much thought. It only dredges up vast amounts of emotion and endless
questions: When will it be available? Will it really help? What will the long-term effects be? My neurologist assures me that this drug is not the one; that it doesn’t alter the course of the illness. Nevertheless, hope not previously dared is undeniably, and unreasonably, born.

I sigh deeply and push thoughts about my future health firmly to one side - as has become my habit. In the meantime, I relish an inner excitement: the PhD that consumes my life has found a new and definite direction. It is time to refill the glasses and rejoin the party. I have a sense that a journey has now begun in earnest: Where will it lead? (Vickers, 1995b).