PAIN: A BIOGRAPHICAL ANALYSIS

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PLEASE NOTE

The greatest amount of care has been taken while scanning this thesis,

and the best possible result has been obtained.
Acknowledgments

- This thesis is a gift to my Dad for his blind faith, love and support;
- This thesis is a gift to my Mum for her love;
- This thesis is a gift to Audra and Matthew whom I love and work for;
- This thesis is for Clinton – to show him that it could be done and for his love, patience and support;
- This thesis is a gift for Vivian, who never questioned decisions and has always been there for me:
- But I complete this work for my friend and sister, Mini May who’s life has been filled with pain, but who has always worked outside herself. I love and miss her.
- I thank my supervisor Colin Holmes for his time, friendship, and patience and mostly for getting me there!
ABSTRACT

An understanding of pain and the lives of persistent pain sufferers presupposes that the sufferer is able to use a language which is shared and understood by all. Pain as an inner sensation and perception, is always described in the language of experience. Because pain language, is culturally determined, descriptors of pain inevitably reflects the dominant discourse and articulates a distinction between the sensation of pain and the behaviours associated with it. Pain as a social medium is established within the discursive elements of the dominant culture, and therefore by creating its understanding legitimates pain as a cultural and personal experience. An experience, which is encountered by all, but lived alone.

This study explores the experiences of persistent pain sufferers. David, Joanne, Vince, Vicki and Steve are persistent pain sufferers who have not had their pain validated by diagnosis, and in consequence have been required to abandon their pre-pain life plans and lifestyles because persistent pain has become the centrepiece of their existence.

The interpretive process, and more significantly ‘interpretive biography’, as described by Denzin (1989a, 1989b, 1989c), provides the framework for this study and the use of epiphany moments illuminates an understanding of the essence of persistent pain experiences, and the significance of these experiences for the life trajectory of the sufferer. Persistent pain sufferers are provided with a voice to tell their own stories of persistent pain as their experiences unfold through events in time. Dolby Stahl’s (1985, 1989) literary folkloristic methodology deconstructs stories in order to
understand the ways in which sufferers make sense of their pain altered lives. In particular Marxist literary theory, Foucault's construct of power and the concept of resistance were applied to stories in order to bring meaning to the lives described.

This study found that the communal folklore of pain remains underpinned by dominant ideological forces and discursive practices which sustain the powerlessness of persistent pain sufferers. Through the quest for meaning and cure of pain the persistent pain sufferer is rendered powerless through medical technologies including the medical interview. These technologies subliminally support dominant ideological practices in order to sustain and maintain the discourse of Western medicine. Through language the sensation and perception of pain is understood and translated in such a way as to create a situation in which the persistent pain sufferer is caused to question the validity of their experience while simultaneously accepting blame for the persistence of their pain and the need to have their pain stop. This contradiction re-affirms the powerlessness of persistent pain sufferers and although Foucault's construction of power necessitates the oppositional requirement for resistance, the positive influences of resistance are not clearly evidenced in the stories of persistent pain sufferers. It was postulated that resistance provides the mechanism through which persistent pain sufferers are able to surrender previously held notions of self to alternate identities, which encapsulate the embodied experience of pain. The ensnarement of this experience permits the sufferer to move beyond accepted paradigms of pain to a position where their persistent pain experience is validated. This has not been the case for participants of this study. They remain ensnared in a life of hopelessness and despair.
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I’m gonna read out to you um, Ok, that was after the 8th October. Because down here it says, (B. Here it is, um 13th October that was in between when she was really suffering after these 3 needles, we went to a doctor at a medical centre here in Southport it’s um. Vicki asked if she could have something to relieve the pain, a shot of pethidine and ah he virtually turned around and told us if that’s all you want why don’t you go down the street and get a shot off the street). Go out and get yourself a hit. (B. Get yourself a hit of the street yes, if you only want a buzz for a couple of hours go and get a hit off the street, that was on the 12th October and this was on the Friday the next day, this is what she wrote in her book, pain level still very high, depressed and very down, still needing to lie down for 90 - 95% of the day, must move slowly because of the pain, still waiting for the legal letter from Dr. W. which was a letter to authorise Pethidine injections until she seen the doctor in Brisbane, mum spoke with him this morning and a letter is definitely in the mail, Dr. W. phoned me I was lying down.

Bill took me down to the medical centre last night for me to get some pain relief instead a doctor gave me a junkie lecture and told me the next best thing to do is go out and get myself a hit that was his own words and also told me to stop moving around, he also said he was not going to give me anything because it would only give me a buzz for a few hours and then I would be out looking for more, I left there holding back the tears not only because of the pain, but because of the way he treated and spoke to me, my mind has passed the point of coping and irrational thoughts towards the doctor and putting him into some serious but not permanent pain, serious but not permanent pain keeps going around and around in my head.

I really have to stop to think of the overall consequences referring police charges he may even take me to court but at even times my thoughts into how to do it are so real and close to doing it, meaning that she was going to go down there and do something to hurt him to put). No. I planned it Joyce, I was so close to actually doing it you know I had planned to go down there book into see him when I had got into his office I was going to pull out a knife because he wears a tie, I was going to tie his hands behind his back, so they hurt and then I was going to tie his feet, and then I was going to make him arch his back up as far as he can and I was going to stick the knife underneath his chest area so if his back got sore and he needed to lean forward he would lean on the knife and let him feel that pain because arching your back like that with no support with your hands behind your back would obviously give you back pain and I wanted him to feel what it’s like to have back pain and have someone there can help but won’t you know, that’s how mad he made me that’s, to make me feel like he didn’t make me feel like a junkie but he, like he destroyed my inner self by treating me like one you know like I had planned all this and it was only the fact of really being happy to be rational, really having to be, like he could take me to court for this and the police would be involved and you know on the news and like I didn’t want that side of it, all I wanted was for him to feel back pain and to have someone there that can stop it and they won’t you know, that’s how mad he made me (Vicki, Verbatim Transcript, October, 1995).

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CHAPTER ONE

INTRODUCTION

1.0 PREAMBLE

The thoughts of Vicki reflect the confusion and anguish of a person entangled in the web of persistent pain. Pain is among the most common reasons for individuals seeking medical attention. Twigg (1970:150-151) asserts that

a pain with no intensity would be a pain to which we paid no attention, and such a pain would be one that we did not feel. The paying of attention, whether it is demanded or not, is a necessary condition for the feeling of all pain, even the pain of low intensity which is usually neither pleasant or unpleasant.

Likewise, it may be suggested that all healers are challenged by pain. Anderson (1990:714-5) states that

people, especially those with chronic illnesses with no cure in sight, are increasingly being called upon to assume responsibility for their ‘self-care’. The expectation that people should be able to assume responsibility for self-care is strongly voiced not only by policy makers but also by health care providers. Health professionals, operate within a social field, and are not exempt from the ideas and practices that permeate the larger health care system.

Health professionals have their own experiences of pain, and pain sufferers must resort to the use of descriptors in order to communicate their pain. Medicine works a transformation in dealing with the subject through this communication. Vrancben (1989) asserts that the way the medical community conceptualises what a pain patient is, and how this individual should be treated, exemplifies how the medical community understands pain. Pain ceases to be an existential state and becomes an experience to be constructed. To translate pain feelings into data, understood by medical discourse, pain, an indicator of pathology must be classified by duration, intensity, site, fluctuation, and position. That is, the experience needs to be verbalised,
visualised, and rated. However, pain is as elusive for investigators as it is immediate for sufferers because the use of scales and instruments in order to quantify pain leads to fundamental misconceptions of the nature of pain; furthermore, any description of pain is liable to pale into insignificance beside the experience itself. Fields (1987:189) claims that verbal descriptions of pain as simply an observable behaviour ignores that the description is, in itself, quite distinct from the pain sensation or perception. The division of pain experience into sensory or perceptual and psychological or reactive components robs it of its intimacy because the experience is correlated to scales which are used to centrifuge the essence of pain out of the sufferers themselves. Wittgenstein (1967) contends that 'uncovering the mechanism of neurological action is one thing but a semiology of pain is not possible'. Kleinman (1988:7) concurs, stating that the inferences derived from the meaning of symptoms are the semiotics of diagnosis. Therefore, symptoms must be transposed to the signs of disease. Thus, the patient's subjective account of their pain experience is not accorded credence until it is quantified and rendered 'objective'. This position is made explicit in the work of Foucault (1973:22), who asserts that Western medicine has precipitated "a syntactical reorganisation of disease", such that the world is seen in terms of commitments to particular aetiological and pathological accounts. Being visible to the examining eye, signs have become the basis of diagnostics, while intrinsically perceived symptoms have come to be regarded as futile (Honkasalo, 1991). Bakan (1968:23) writes

... the attempt to come to an understanding of pain is characteristically met at the doorway by materialist objection that subjective states can, at best, be allowed only a secondary status in the realm of scientific reality. Thus the status of chronic pain- its evidentiary rank- is diminished because it has to do with the self rather than with the medical object. Pain is not explained but spirited away- made into an epiphenomenon.
That is, a sensation which cannot be exclusively traced in all instances to the problem. In this instance the pain sensation induces personal introspection in an attempt to define its antecedents and significance. In the wake of personal introspection the necessity for pain relief is evidentiary: a relief which is dependent upon the detection and validation of a symptom which cannot be measured, seen, or felt by another. This situation is complicated in the case of the persistent pain sufferer who does not have a definitive or consensual medical diagnosis. Health care provision in this circumstance is laden with frustration because the pain being suffered is unpredictable and difficult to objectively validate in relation to its source and severity (Fagerhaugh & Strauss, 1977). Simply, it baffles and defeats medical judgment. Health practitioners encountering persistent pain sufferers become frustrated both by the sufferer and by the failure of traditionally prescribed treatments (Rose & Fitzgerald, 1987). Doctors often write these patients off as hopeless cases, beyond medical help, and the Report from The Working Party On Management Of Severe Pain, contends that medicine, or medical discourse, has become reluctant to treat pain for fear that physicians may be regarded as practising inadequate or unscientific medicine (NH&MRC, 1988:33). Moreover, the Royal College of Surgeons & College of Anaesthetists Working Party (1990) reported that health professionals working in the pain management arena are ineffectual when attempting to establish suppression of distressing symptoms. In consequence, the problem of pain is more often transferred from health practitioners to the pain-experiencing individual, who is held responsible and accountable for their persistent pain because of inherent personal failings (Seers & Friedli, 1996)
Paradoxically, Bakan (1968) suggests that in Western medical discourse the sufferer gives control of personal pain to the healer, or health practitioner, in order to suspend personal volitionary processes. In juxtaposition, when orthodox practitioners fail in their curative attempts the legitimacy of pain is questioned, and pain is then understood as a failure of the sufferer to shift control to the healer. This becomes a significant factor associated with persistent pain, because medical discourse constructs the failure to cure pain as the inability of the sufferer to transfer to others the management of their condition. However, pain remains a reminder to continue the search for assistance. Moreover, Rose & Fitzgerald (1987) assert that sensing the doctor’s hostility, patients respond in similar vein. Often expecting some miraculous cure, they do the ‘merry-go-round’ of doctor after doctor in a futile effort to find relief. Further, Vickers (1969:8) states that the therapeutic success of medicine in the last hundred years has bred in the lay mind the idea that pain is not part of the human condition and the condemnation of health professionals whose job it is to ‘fix things’.

Significantly, pain meanings, in the therapeutic relationship between health professionals and the pain sufferer, are negotiated between individuals of disparate power, on the help-seeking merry-go-round, such that the pain sufferer continues to need to persuade the more powerful other of the intensity of their anguish, and for the need to access pain-reducing resources (Kleinman, 1988). Thus, the management of pain, whether diagnostic or symptomatic is contingent upon medical ideology and its powerful expressions: expressions which view biomedicine as a socio-cultural system, in which the experience of pain is not only constructed as a naturally occurring phenomenon, but also as an artefact of human society, founded in a cultural framework of values, premises, and problematics, explicitly and implicitly taught by

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the communications of social interaction and then enacted in a social division of labour in institutional setting (Hahn & Kleinman, 1983).

1.1 THE NEED FOR RESEARCH

This research addresses the experience of suffering pain by those individuals whose pain is not compatible with the accepted notions of pain care and management. By theorising the construct of the pain experience, and its significance and place in the life of the sufferer, it will be possible to provide an insight into the life of the pain career patient. The first report from the Consumer's Health Forum (1990) into persistent pain identified the sufferer's need for the acknowledgment of their pain as real and the need to be dealt with as 'whole people, who experience pain'. Further, it was contended that those who experience persistent pain hold the belief that difficulties arise in relation to society's attitudes to the invisibility of their pain and because their pain is defined by experts or ignored by families and friends. Vicki explains the position of the persistent pain sufferer in the following:

*Life through tainted glass*

_I live a life you could not conceive, to explain it, you could not believe_

_my life is filled with constant pain I'm existing and I cannot gain_

_My planned life has been cruelly stopped, the world I lived in had just popped_

_I kick and fight and cry my way, through every single waking day_

*Life is so much different now, in every way, - you don't know how._

_I lie down when the pain is bad the pain itself, it makes me sad_

_Believe me its no easy task, to look at life through tainted glass_

_suicide is a daily thought, reasons not to, I have to sought (sic)_

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My life is full of dismay and hatred Oh what precious time I’ve wasted
but I cannot help this person- me so I’m getting professional help, you see
I have a baby on the way, it keeps me breathing every day
I’ve got a future, I have to fight I need to keep that well in sight

I have a special man, he loves my just the way I am.
I had no right to hurl him in- he has seen me at me at my best and worst,
and he hasn’t screamed, or jumped or cursed. He takes it all into his stride
he knows it’s an unfair life I ride

He accepts the life and doesn’t mind, his normal life he left behind
I am a handful to say the least, because it lives inside me, - pain- the beast
I find it hard to live each day, emotions, they change in every way
from day to day and hour to hour, my god, they have just so much power

I hate the person who lives within, if I could tie her up and find a bin
I’d throw her in and SLAM the lid, that’s how I feel, how far I’ve slid
From deep inside I’m saying this, you normal people, you may hiss.
you don’t understand, and that’s O.K., because its my body and mind that is affray

For everyone who is like me too, I know this has made sense to you
I’m writing this to touch the mark, of someone with a bleeding heart
you are not alone!

Vicki (19/7/93).

The poem signifies the sense of betrayal experienced by those on the treadmill of
Western medicine’s promise of the ‘quick fix’ or medical cure. The sorrow,
hopelessness and loss of life’s potential is beautifully captured in the words life
through tainted glass. The feelings evoked by the words of the poem are analogous to
those of Tolstoy (1886, cited in Morris, 1991: 34), who describes the experience as
that of a “slow poison relentlessly destroying one’s sense of satisfaction with life,

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changing them and intensifying their aloneness”. Thus, persistent pain becomes an experience about which there is an increasingly nothing to say, nothing to hope, nothing to do. It casts the sufferer into a featureless landscape (Morris, 1991).

The interpretive process, and more significantly ‘interpretive biography’, as described by Denzin (1989a, 1989b, 1989c), is an approach which enhances an understanding of the essence of the pain experience and the significance of this experience to the life trajectory of the persistent pain sufferer because is provides the pain sufferer with a voice in telling their own story as is unfolds through events in time. Brown (1985:573) suggests it is through the narrative provided that the “the essential features of human existence are expressed through specific events”.

1.2 AIMS OF THE RESEARCH

The aim of the study is to:

1. develop new knowledge through an innovative reinterpretation of existing data and emerging ideas relating to pain;

2. develop a deeper and more relevant knowledge of the issues and structures as they relate to the study of persistent pain in those without a consensual medical diagnosis;

3. make possible the discovery of new ideas relating to the personal and cultural milieu of the persistent pain sufferer; and,

4. elaborate upon existing theories of pain upon through an interpretation and re-interpretation of personal accounts of real people in the sub-culture of persistent pain sufferers.

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1.3 CHAPTERS TO FOLLOW

The chapters to follow will include a review of literature pertinent to understanding the experience of persistent pain without a consensual medical diagnosis, on the life trajectory of the persistent pain sufferer. A discussion of Denzin's interpretative biographical method and its relation to literary folkloristic methodology will be considered in light of the experience of pain. The pain stories of David, Vince, Steve, Vicki and Joanne will be shared to explicate the experiences of living with pain, and finally each participant's personal accounts of living with pain will be analysed.
CHAPTER TWO

DAVID, VINCE, VICKI, STEVE AND JOANNE TELL THEIR PAIN STORIES

2.0 INTRODUCTION

This chapter tells the pain stories of David, Vince, Vicki, Steve and Joanne. It highlights key aspects of their stories and points to events which the researcher believes to be turning point moments in their life trajectory. Turning point moments are termed *epiphanies* by Denzin (1989a, 1989b, 1989c); that is, events which when illuminated cause the individual to re-evaluate and then change their life course.

The researcher’s position, in light of the stories heard, is also discussed. The chapter concludes with argument related to the appropriateness of the chosen methodology to the research enterprise undertaken.

2.1 THE RESEARCHER’S POSITION

Pain is a sensation which is experienced by all. Reality is given meaning by language and in culture. Symbolic reality neither denotes the realm of natural events and biological processes, nor the personal subjectivity of the individual, rather it represents the mediating social and cultural world of ideas, values, sentiments, meaningful symbolic forms, social relations, and the like. It is this which constitutes the sphere of socially legitimated human reality in which most of us function most of the time. It is within a given society’s symbolic reality that medical systems exist and function that illness is shaped into a human experience, and that healing takes place (Kleinman, 1988). Hence, pain is provided with a legitimate and meaningful form and one learns how to feel, experience, and evaluate pain. Moreover, not only is pain
so shaped, but the attitudes towards and expectations of a particular form of medical care, and the way medical care is evaluated and health needs are established in a given society, are similarly constructed. Here, reality is effectively transferred from the outer socio-cultural milieu via enculturation to the inner world of the individual.

Language and other symbolic processes are clearly crucial in forming a symbolic pathway which links culture and biology, and which makes the medical domain a truly psychosomatic and socio-somatic one. Subsequently, it is important to recognise that health care systems are enmeshed within symbolic reality, and that, in turn, they give form to different kinds of realities within which pain may be viewed as illness, and healing occur. Pain utterances, like certain other forms of physical and emotional expression, achieve their significance, their factual status, by momentarily revealing the "natural" feelings and subjective experiences of the individual. Yet even at moments of severe physical or emotional suffering, the revelation of the pain experience is context-sensitive and socially organised. Thus, the health professional when confronted with people who are in pain inadvertently classify sufferers into two broad groups: those who experience real or acute pain and those with persistent or chronic pain, that is, pain which cannot be alleviated despite intervention. Experience has shown that the health professional is puzzled by the pain patient who presents in this way. The sufferer may have a correct story and there are historical clues suggesting that the pain suffered is real, but despite the continuance of diagnostic procedures and treatment the patient claims that the pain has not disappeared, although clinically it should have gone.
Notably, chronic pain sufferers are managed in the same way as acute sufferers, despite a recognition by care providers that their experience is quite different, separate from the initial nociceptive stimulus. It is believed that the persistence of pain in the sufferer, is largely dependent on behavioural changes which, in their turn, are induced, maintained and reinforced by environmental reward responses. Thus, this pain patient is characterised as one who has some interest in complaining about pain and/or whose coping strategies have failed. Moreover, Heath (1989:113) claims that “the interactional organisation of diagnostic work informs the expression of pain and constrains the ways in which medical practitioners are sensitive to and deal with the suffering of their patients”.

My gaze as a Registered Nurse was deeply influenced by the medical gaze (Foucault, 1972) in that things became visible to me, once seen. Here, pain, an object formulated as a discrete entity through diagnosis, could be observed and analysed. I believed, as others do, that pain is a symptom of disease. Unfortunately, this belief precluded an understanding that persistent pain is also a manifestation of illness and that many patients with persistent pain present no evidence of disease. Clearly, many of the pain patients under my care, as a Registered Nurse, represented a discontinuity between the presence of disease and complaints of pain. Thus, my interpretation of what I construed only as a symptom excluded many variables related to the experience. That is, as Hansen & Gerber (1990:24) state, the occurrence of specific environmental events, past experience with these sensations, and a variety of psychosocial and cultural factors.
It is as Vrancken (1989: 442) purports,

> pain makes us believe that we can cut ourself off from the body. Through rationalising pain (pain is constructed as) ‘I’, and my body. Thus pain can be depicted as the experience of psychophysical dualism. The antithesis of body and mind, body and soul, body and person becomes phenomenologically manifest in illness and suffering.

Accordingly, I and those in my position who are asked to care for the pain sufferer have been lulled into thinking in a dualistic Cartesian mode by the patient! We ask, do they really have pain? Do they look and behave as though they have pain? Are they acting in accordance with those who I believe to be in pain? Would I act like that if I was in pain? The non-consensual medical diagnosis further complicates the care of the persistent pain suffer because not only is their pain not relieved, but no sound medical opinion can explain their pain experience. These pain patients experience a sense of alienation from the realities which have constructed their experiences: their pain is not validated, and they enter into the world of ‘whinger’, malingerer and liar.

In retrospect, I entered this research as a sceptic, I listened to pain stories, and through the unfolding of each story learnt that pain is whatever the pain sufferer says it is. During the course of interviews, I developed a rapport with each participant and was amazed that each stated that they felt grateful for the opportunity to talk with me about an experience so personal and critical in their life. When given the opportunity to use a pseudonym, David, Steve, Vince, Vicki and Joanne were adamant that I use their real names. They wanted their stories told and they wanted to be listened to. I am privileged to share their stories with you, the reader.
2.2 ESTABLISHING INTIMACY WITH DAVID

I met David at a Pain Clinic in the first week of a Pain Management course he was undertaking. I arranged a time to interview him the following week. We met in an interview room, David appeared nervous and anxious to please. We discussed his time at the pain clinic and he stated that he missed his wife and his farm. We spoke about his wife and his grandchild and I told him about my children and my work at the university. This discussion took about thirty minutes and was well worth the time. David appeared more relaxed and when asked if he was comfortable stated that he was pleased to talk to someone who understood what pain was. He also stated that he did not know that pain could be ongoing; he thought it was something that could be fixed. He also suggested that in the country town in which he lived, people did not understand that pain was something that some people had to live with. He told me that he had spoken with his wife and that she felt it was a good idea to talk with me.

2.3 DAVID’S STORY

David is a 46 year old Shearer with a wife and two grown children. He has been married 24 years and was a keen horse rider and blacksmith. He has been the leader of a shearing team for over twenty years, owned his own property and believed that his life was fulfilling and that his future was bright. On the 30th April, 1992 he fell from a high rise shearing mill. He describes the event as follows:

I fell 5 foot, fell straight on the tail bar and I went to get up and I sort of couldn't get up, and my son was there he raced in and grabbed the sheep off me and I had to go and sit down on a drum, he ended up finishing shearing the sheep and that day I couldn't do any more I was just getting these awful pains down there, like switching the lights, like an electric shock and it was going down my both legs and ah I went back to the huts that night, we were camped out, and my daughter was cooking there in the shed and I had a shower, and I never even came out and had tea, I was just laying in bed and all night I just ....., and get my operation (David, Verbatim Transcript, September, 1995).
David continues to describe his life following his accident:

After the accident my wife made me go the doctor, it happened on the Thursday and I come home on the Friday couldn’t do any more, I just went to bed, you know, and lay down all weekend, and I just couldn’t move and my wife said you’d better go to the doctor, she rang up and made an appointment Monday morning and he said I’ll send you to have x-rays up at the hospital, bush hospital, and he said nothing showed up on them, so he looked at me x-rays and said take a month off work and come back and see him.

Then the months just went on and on and on he give me some pain killers and it was about it would have been about three weeks later I broke out in this bruise from my hip to my shoulder blade, it was just a big maroon sort of a bruise just come out overnight and I went in and showed him, he said Jesus and I think you’d better go and have, he sent me to a doctor in Sydney, St Vincent’s an orthopaedic surgeon, and he went, he said have you had a cat scan and I said no, and he sent me to have a cat scan and then me doctor sent me back to him and he said oh he said, I don’t want to touch anything like this that’s the words he said, but I’ll refer you to a neurosurgeon at St. Vincent’s and when he mentioned that I was a bit frightened I didn’t know much about it, you know, anyhow I come back home and I went and seen me doctor again about it.

I just laid around for months and that and putting up with the pain then I went and seen him and he said well your booked in to see a doctor, he said he rang me up and I said oh what does that mean, an operation, I’d never had an operation in me life and he said well you’d better go now and see him, I went down and seen him then he said he wanted to see a myelogram he knew what the trouble was he said I’ll take this bit of bone off there and this bit of that, I don’t know what the words he used now and he said I’ll book you in for a myelogram so anyhow they booked me in for a myelogram on 1st December, and 1st December was a Wednesday I had the myelogram on the Thursday, I don’t want another one of them either I was that crook [unwell] from it and um he come around on the Friday morning he said we’ve found your trouble he said I want to see you up in the clinic at St. Vincent’s there (David, Verbatim Transcript, September, 1995)

David describes his reactions to the news he needs surgery:

I went in there and he said now we’ve found your trouble, he said I can take the pain out of your legs, well he did tell me that and um, he said up here I won’t be able to do anything for you on my back. And ah I just said what would you do if you were me, he said. I wouldn’t hesitate, he said I’d have it.

I said Jeez I dunno, and um well I’m not, you’d better think about it anyhow before I walked out I said well if you think it will help I’ll take it and when I said to him you know what would you do he said well I wouldn’t hesitate
Well I thought well they know what they're talking about and ah I had the operation on the Monday on the 6th and... ah I'd have to come back I suppose and ah I went home and I was alright for about three months I wasn't too bad you know, still the pain in my legs had gone but they weren't gone completely and around the waist and into the pelvis and that and ah I was still getting pain, you know in the penis and ah it sort of eventually went a little bit and ah I went back and seen him and he said it takes, he said ah you look well those were his exact words, he said look real fit, well I was too, I used to try and used to do weights and not walking or anything just in the shed I was eating the right tucker [food] and that and he said it takes about 18 months to two years for everything to come together.

I thought Jeez you didn't tell me that you know and he said for all the nerves to get fluids and they swell and um now I come home and I just took that, and I come home and I started going to the pool every day just walking in the water, I was walking everywhere he told me to walk everywhere, and everywhere I went I walked, walked, walked and then it just started, and I thought well I'll get out and start mowing the lawn now and started mowing the lawn, and the minute I started doing anything the mongrel pains came back down me (David, Verbatim Transcript, September, 1995)

David describes the changes in his mood and persona:

Three months later and ah I just got that cranky in the end I started mowing the lawn mower around, my attitude changed, I've been married 25 years, I've a girl 24 and a boy 21 and I've never had a fight with my wife in my life and I'd just sort of bitching to one another, its my fault I'll admit she was A1, she couldn't get over the way I'd changed and everything and um, I thought, I just didn't know what to think any more, I then went back to me doctor, he wouldn't give me any strong drugs or anything like that he, this is Dr. L.

and um the person where I hurt meself, I'd worked for him for 15 years shearing you know I used to go and do his shearing every year he wouldn't even talk to me he just defied that I, cause I used his claim for, you know, and when I rang him up, when I first hurt meself I rang him up and said look Dr. L has put me off for a month can I get the, can you send me a form for worker's compensation, he said you'll be right just give it time, I said what am I going to live on, and he said just give it time you'll be right, and then I was in bed and the union organiser come around, cause some of the boys told him about it, he come round and seen me, and he said have you got the compo [compensation] going yet, I said no, no, this would have been about a month after that and ah he said what are you living on, I said just a bit of money I had put away he said, I said I rang him up and he wouldn't give me the papers wouldn't send me the forms, he said well you give me the phone number and everything and I'll go and see him, he did. He drove out the next day and seen him he wouldn't give them to him, but he told him that if he didn't send them within seven days he'd have in, something, they put some court order to send them and I got them in the mail, and from that day that blokes never ever spoken to me (David, Verbatim Transcript, September, 1995).
David explains his experiences with friends, workmates and his relationship with his boss:

After the accident he never ever spoke to me, and I'd worked for him for 15 years. And when we were flat out shearing at other peoples shed, he'd ring me up and say oh can you, get someone to take your place and come up here and help me do the crutching because the flies were eating them and that. Righto, I'll look around and get another bloke and I'll slip up there for a couple of days just to help him out, I done everything for him he turned dead set against me, never came to see me after I had the operation, never come near me, he just told all his neighbours what happened and they said it got to be settled you know, and all the other people I saw for after the operation I was walking down the street with me wife one day and this other bloke Billy Green, I said how are you going Bill and just looked at me and I shore for him for about 18 years too, he just looked at me and I could hear him saying he's only going for a back claim, you know.

I just, I don't go out anywhere I cant mix with people I just get too irritable and that, me wife she wants to go out, I just say, go on go for your life, she wants me to come you know and I'm just not up to it (David, Verbatim Transcript, September, 1995).

These events caused David to sell up and move from the town he had grown up in and re enter the workforce:

After that I just come home and I said that's it, I'm selling me house I'm getting out of here. I sold me house, put me house on the market, sold me house and bought a place at Bogavilla.

I've tried to go back to work. But no luck. I was on cement for two days, the first day wasn't too bad, the second day I had a job to get out of bed and I had to go and take pain killers, I was pumping them into me all day I don't know why i was taking pills because I hate it, so in the end I just said I cant handle it and that he went to pay me and that and I said don't worry about it, keep it for yourself (that was in May, 1995). Then I had a go at truck driving I only, it was too rough for me truck driving and tractor driving. I spent a night, two nights in hospital after I done a days truck driving, and ah I have just been doing nothing, I've been doing painting at home and when I get crook I just go and lay down (David, Verbatim Transcript, September, 1995).

David explains his experience of frustration at not being able to work, persistent pain and his thoughts of suicide:

and I supposed there was a time when I thought of just going down to my room and pulling a gun out and shooting meself, I wasn't game enough. I've felt like that half a dozen times, before I had the operation and after I had the operation.
When I felt like shooting myself the pain and just getting neglected by people I'd worked for so long and I had one of the best names around that area for a Shearer I was never ever beat, and I always shore over 200 a day and I was earning big money and now I'm only getting this you know. I was lucky when I hurt meself that I owned the house and car and everything and the money I got I just invested in this place.

I was too frightened to do anything. I thought if I got on and something happened you know I'd be back where I started. I still have me sheep dogs and that they are only pets now, they're the only things that I have been able to keep (David, Verbatim Transcript, September, 1995).

David describes his life with pain:

The time I've had the pain, its felt like a long time I know that, just thought, I honestly thought everything was just falling in a hole and I'd never get out of it, that's the way I feel. I started feeling like that six months after it happened cause I just thought it would go away, I honestly thought that. I'd never been to a doctor in me life until this lot come up and all that, I broke me leg once and that's about all, but I just, I honestly thought going to the doctor get in and out, get this and that and you'd be right, that's what I thought it was. But no. I just couldn't work it out, I said to him why can't you work out what's wrong, why cant you fix it. He started telling me about all the nerves and this and that, then he sent me to the orthopaedic fellow and he sent me, referred me to the neurosurgeon (David, Verbatim Transcript, September, 1995).

David describes himself and his life prior to the event of pain in his life:

Before the accident I was a happy go lucky bloke, got along with everyone, anyone can tell you that. I always liked a laugh and a joke, I used to go down the pub and have a bit of that on a Friday night not that I ever drank, I've never been a drinker I wouldn't have had a beer now for about 12 months, if its there I'll have it, if its not I won't. I went, I was always camp drafting I used to train race horses I was at the races every week, I've only just let me licence run out I shouldn't of but I'll re-apply for it again. and ah me and my wife went for a holiday every year and we haven't been for about three or four years now. Since the accident. Never missed, we always went away she's missing that too. We used to go up the Gold Coast, or down to Victoria or Sydney we used to go everywhere, up to Cairns one year, up to Longreach, took her around all through the Western Country Plain and all that. We enjoyed it, went away for two months just had a big year, and I just said right, I've been saving up for the years to do it had a caravan, I've still got the caravan, just hooked it up and away we went. On that trip that we went on I got a couple of jobs here and there shearing and the blokes couldn't get enough shearsers, I didn't want to do it, I'm on holidays but I ended up doing it for them, ever I was going to go again, but I can't do it now, but that's the way to go on a working holiday.

The time after my accident and the time of my myelogram was about 15 or 16 months, I used to be a sociable bloke, I used to always have race horses in Wagga, plus shearing, I'd get up early and do me horses and work, I used to be at the races nearly every weekend, it got confusing for me cause I had to turn the horses out I couldn't go on with it I couldn't even get out of bed,
I virtually was on the bed, in that 18 months I spent nearly 12 months in bed, just couldn’t move around. I started going all slobby [overweight] and jelly like, never went anywhere and I used to sit around I felt real bad, cause I was a bloke that was up early in the morning. At that time my wife and I we were just starting to argue, you know. We argued about anything, anything at all, I used to just go off me head, snap at the kids when they came home, me little grandson I wouldn’t hurt him for quids, he was a bit nervous of me, you know, cause I was always cranky you know, I’ve sort of learnt to control that.

On a good day, I’d hope my life would be to get out of shearing by the time I was 50, cause most blokes do because they’re pretty well wore out by 54, not many shearsers make it right through. I was one of the ones that could have gone a bit further, I never drank and knocked meself [lived an unhealthy lifestyle] about like some blokes did, and always had good tucker, some of the blokes would just drink all weekend and .... and I have never done that, I treated it as a business because I was contracting meself and um that’s all I had 11 months run of the year. I had 9 blokes working for me (David, Verbatim Transcript, September, 1995).

2.4 ESTABLISHING INTIMACY WITH VINCE

I met Vince and his wife at a People in Pain (PIP) support group meeting. As he sat in his chair he seemed very uncomfortable, moving from side to side and walking around the room. At the finish of the meeting I approached him and introduced myself; I had already been to previous meeting and support group members new me and the topic of my research. I explained my research to Vince and his wife, as it was the first time they had attended the meeting. Vince seemed eager to talk to someone about his pain, and later he joked about the fact that this was the first time anyone had appeared interested in letting him talk about his pain, it was something that he kept to himself. We arranged for the interview to be conducted in his home the following day.

On arrival at Vince’s home his wife, Lana, was present. I asked Vince if he wished the interview to be in private, that is between the two of us, but he declined stating that Lana experienced his pain with him and that he would not be here today if it were not for her. Lana was, thus, present at the interview. We sat at the dining table and
the three of us began to establish a relationship based on Dolby Stahl’s (1985) concept of intimacy. I talked about my family and children and most importantly about my interest in persistent pain, arising from my experiences as a Registered Nurse working with people in an orthopaedic/neurological ward. Vince and Lana listened intently and shared experiences of time spent in hospital, and what they described as the ineptitude of the nursing and medical fraternity when it came to understanding pain. Vince appeared at ease throughout the interview, which lasted approximately two and half hours.

2.5 VINCE’S STORY

Vince is 58 years old, married with two children. In 1976, at the age of 37 years he was a council worker and had a fall when crossing from one plank of wood to another. He landed on his ‘tail bone’. One month following the fall he returned to work, but continued to experience back pain. Between 1979 and 1981, his pain increased to the point where he was crying at work and taking pain killers to get through the day. He tells his story:

The accident was in 1976. I was working for the Council and I had a fall, I didn't fall any distance, say stepping from one plank to the other. I landed on my tail bone. That was 1976, well then for a month or so I was alright went back to work, then 1979 that is when the back started to pain then by 1981. I was crying when I went to work.

Before the laminectomy. I could actually live with the pain, it might have been aching things like that, but it still didn't interfere with, to me it didn't appear to interfere with life. But I was very cranky, very cranky indeed, I know it and there was nothing I could do about it.

I was still going to work, then in 1982 I went off on Compensation and had the laminectomy in 82. I can't remember exactly when now, about September 82, and he (the surgeon) said four months after the operation I'd be back at work,- but four months I couldn't even walk upstairs ah, 12 months after the operation they said, the specialist said it's something I've gotta live with, so um, where'd I go to from there, about in 1985 they pensioned me off from the council (Vince, Verbatim Transcript, October, 1995).
Vince goes on to describe his life leading up to the operation:

In 1981 I think before the operation I think I was off work, like, that's right I left the council then I started working for another building firm, doing schools, I think I was off work for two or three months and then I went back to work so then they give me a lighter job, fitting windows or something in the school so there was no heavy lifting involved, they give me a lighter job, well even then I think after a few weeks I couldn't stand it, so I went off again so then I think I was off on compo then until the operation, so I decided to do the operation the specialist made it sound so good (Vince, Verbatim Transcript, October, 1995).

Vince believes that the specialist was he was relieved when they said they had found something in the myelogram, cause he said four months after the operation you will be back at work. He states:

it gave me a lot of hope a lot of promise, but I think at that time I was only 40, I wanted to get back to work. I felt that the surgery would be a success. I really thought it was going to put me back on top. He never gave any indication that it wouldn't be. He said he had 92 or 94% success rate. So I said well that's pretty good odds for me.

I never had any benefit from that surgery, even in the first few days when I felt good when I was resting in bed. The only benefit they done with that surgery they reduced the length or the strength of pain in my right leg. Before the surgery I could get up the stairs, but after surgery I couldn't. But the doctor still maintains that the operation was a success because he eliminated a lot of pain out of the right leg, but then he put more into the back (Vince, Verbatim Transcript, October, 1995).

Vince explains his feeling and reaction after being told he was a failure because surgery did not alleviate his pain:

In the 4 months here, after the laminectomy I used to go to him, I think after about four months or so there he said you're just one of my failures he said that's (his pain) something you've just gotta live with. it knocked me for a six. That's when I couldn't accept it, that's when I started having these blackouts, these turns continued for the next couple of years, having all these fainting spells and things like that it was just tension built up inside me. I couldn't get rid of. I was probably cranky on everything and everybody. I'd say I was sour on the whole world. I was cranky and more short tempered with everyone I never had any benefit from that surgery, even in the first few days when I felt good when I was resting in bed. The only benefit they done with that surgery they reduced the length or the strength of pain in my right leg. Before the surgery I could get up the stairs, but after surgery I couldn't. But, the doctor still maintains that the
operation was a success because he eliminated a lot of pain out of the right leg, but then he put more into the back.

Between having the surgery and being told I had to live with the pain I think I was disappointed, I was very disappointed I never had any benefit from that surgery, even in the first few days when I felt good when I was resting in bed. The only benefit they done with that surgery they reduced the length or the strength of pain in my right leg. Before the surgery I could get up the stairs, but after surgery I couldn't. But, the doctor still maintains that the operation was a success because he eliminated a lot of pain out of the right leg, but then he put more into the back (Vince, Verbatim Transcript, October, 1995).

He describes his interactions with Lana, family and friends as follows:

Well I don't think I was worried about the family during the two years I didn't accept it, I mean I was more worried about myself, I didn't know about the family what they thought of the whole thing at that time. I think I was more concerned with number one. I was depressed, I'd say 99% of the time.

I lost em, I told em all where to go (friends). I didn't want them around, I did not want them anywhere near me. I don't confide in em or anything like that (Vince, Verbatim Transcript, October, 1995).

Vince summarises his feeling of frustration at the medical treatment he received and continues to receive below:

I need to talk with someone about what's going on. Yes, I think I want help but I didn't know where, cause I used to ask the doctors. I'd say I wanna see a psychiatrist I wanted help, and they said there's nothing wrong with your brain, you don't wanna see a psychiatrist, that's what they actually told me. I'm going to this bloke now at Chermside, I've had two visit's now but I think I'm just about ready to stop going to him, cause he's trying to treat me with medication too. I thought he could actually talk to me to get things out that way, not being able to deal with pain, but he's not, he's just trying to treat me with um medication, but I'm not sick at all, I've got no sickness at all. I am just in pain.

I didn't have anyone to talk to, only the doctors and they're not interested in listening, then the psychiatrist in Brisbane all he just keeps changing the medication every time I go there so. Now I refuse to take anything (Vince, Verbatim Transcript, October, 1995).
Vince describes his life prior to developing persistent pain:

When I was 37 before my accident I think we were on top of the world, we had nothing but we owned the house, we had the boat whatever we wanted to do we done, on top of the world. Mrn, I worked 12 hours a day, 13 hours a day, seven days a week.

They say that's the best part of your years is when your 40, and that was gone I've missed all that. Just give me a knife and I'll cut that 20 years, 15 years out of it. That's 15 years gone, I'd say the 15 best years of my life are gone.

Finally, things inside me said where am I going, I'm going nowhere. I said there's nothing left I said doctors cant help me, so I have to try and help myself. During this time I had all this built. Oh yes, I'd still be crying, I'd be crying and I'd still be working, I'd still be doing something around here even though I'd still be crying I'd still be working, I wouldn't go to bed and do nothing.

I asked why me? and no-one tells me, I don't get an answer, no-one tells me why (Vince, Verbatim Transcript, September, 1995).

Vince goes on to explain his inability to accept his pain as long term:

It took me two years to accept it. You know. Ah the way I was. Which was in pain, and that's its something I've gotta live with. Um, for every time I used to collapse I could be down the yard, I could be upstairs I used to collapse and they thought it was heart attacks and things like that and then they found out I was in the Gold Coast Hospital then, they sent me to the psychiatrist, they turned to me and they said if you accept the way you are the better you'd be, I couldn't accept it, so I used to have these tension build ups and I used to pass out, and they thought heart attacks for a while, but it was just tension.

So then when I basically accepted that I wasn't having these blackouts, so after that I had periodic flare up then with the pain, it was there all the time but periodically it just got worse and I'd just go onto these pain killers (Vince, Verbatim Transcript, October, 1995).

Vince explains his experiences with friends, workmates and family:

We used to do everything as a family, then when this started and even after the operation the boat sat on the grass for 12 months so then we decided to sell the boat, cause I can't use it could I.. couldn't stand the rocking in the boat, so we decided to sell that so our whole life changed completely. After that I did nothing. The whole family stopped doing things. Our whole lifestyle changed, we went on barbecue picnics or something like that but ah, we didn't go for any holidays, I think it was in 1980 we went away on a holiday, yeah, 1980 we went to Cairns, 1981 we went down to
Adelaide and Melbourne, before I had me operation but since then there's no holidays.

Before the laminectomy. I could actually live with it (the pain), it might have been aching things like that, but it still didn't interfere with, to me it didn't appear to interfere with life. But I was very cranky, very cranky indeed, I know it and there was nothing I could do about it. The kids wouldn't talk to me. And they still don't talk to me.

I didn't tell people I was in pain. Well they couldn't help me, I mean it's something you just keep to yourself. I think Lana new what was happening. Yeah, anybody could tell, I think they might even knew at work too but I didn't tell em (Vince, Verbatim Transcript, October, 1995).

In November 1994 Vince's pain flares again. Vince describes the event as follows and his desire to end his life:

I picked this water melon out of the fridge and your pain comes back. It was a bad pain worse than before. Lana, I think she knew, because I wouldn't be here if she took notice of what I done, I wouldn't be here. I insulted her to get her out of the house, really insulted her, and she wouldn't go and the lad was living here at the time and his rifle was in that bedroom. I insulted her to get out in the yard I would have used the rifle. She wouldn't, so she just rang up a doctor to see if I could make an appointment there, and I said I'll go around if I can get in, yeah, so I went to the doctors there he wasn't going to let me out of the surgery, you could see it, he wasn't going to let me out of the surgery and made me promise I wouldn't do anything so he let me go. It was close, yeah, I dunno, cause I didn't wanna go back to the way I was, yeah, but I think that's how my life's been every since.

In November when I hurt my back again I was feeling the lowest I've felt in a long time, I didn't see a future. I didn't that's why I wanted to use the rifle. Cause the amount of pain that I was in there, to me it felt like it was long term again, it wasn't the thing, to me the pain that I was in there, felt it wasn't going to heal itself in a week or 2 weeks something like that. I knew that cause the severity of the pain and the constancy of it I knew it was something that wasn't going to go.

I couldn't cope, I knew I couldn't cope Suicidal, it is suicidal isn't it. November. Last November that's when all the pain come back (Vince, Verbatim Transcript, October, 1995).

Vince describes his life with pain:

I had niggly pain all the time, but pain that you could actually live with or you just you could basically block it out and still work. I blocked it out by keeping my mind and brain occupied, working. I think it (the pain) gradually got worse year by year, till it got to 79 and that's when I couldn't block it out any longer (Vince, Verbatim Transcript, October, 1995).
Vince continues saying:

I just took it (the pain) as part of my way of life, I did not expect it to be, to get really bad, I just said oh yeah it's just a sore back, it will heal or settle so it didn't actually bother me then in 79 (Vince, Verbatim Transcript, October, 1995).

It took Vince almost two years to realise that the pain he was experiencing was effecting his life. He says:

I knew in 1981 that it wasn't going to heal when I was actually going to work and crying while I was at work, but then it got to the stage there I couldn't work, it was awful bad... I kept going to work even though I couldn't work. I was always an active person, I could never sit down doing nothing,

I'd wake up in the morning in pain, probably take some pain killers and get ready and go to work. I was sleeping through the night. I think that time, but I'd get up in the morning, still be in pain. I'd probably take a few pain killers with me to work, then when it got to a certain stage take some pain killers. I'd take pain killers at work when I couldn't stand the pain. And when I couldn't, then I'd be upset and crying at work. I suppose the pain killers worked for six hours, about lunchtime, yeah, like when the morning pain killers wear off. I didn't come home oh no, I stayed at work. I kept it to myself. The blokes at work they didn't know I was in pain, I kept it to myself (Vince, Verbatim Transcript, October, 1995).

2.6 ESTABLISHING INTIMACY WITH VICKI

When I first saw Vicki she was at a People in Pain support group meeting. She was sitting with her mother, husband and 18 month old toddler. She presented like any other young mother, but within minutes of the meeting commencing began shifting on her seat from side to side until finally she stood up and paced the room. She had an obvious limp, and leant to one side. At the conclusion of the meeting she approached me and voiced an interest in my research. We spoke for some time about her pain and I was impressed by her youth and in particular the supportive demeanour of her spouse. I spoke about my young children and the busyness of life when children occupy one's life. We seemed to easily establish a rapport, and arranged a time to
talk. I also took Vicki’s telephone number and promised to call on the morning of the interview to check her availability and pain level.

On the morning of the initial interview I called Vicki, who explained that she was experiencing more pain than usual, and the interview was postponed to the following day. I felt disappointed but called again the next day. Vicki seemed anxious to speak with me, so we confirmed a mutual time to meet.

When I arrived at Vicki’s home I was greeted and taken upstairs by her mother, who looks after her child when her husband is at work. Vicki was sitting at the dining table. We drank coffee while I explained the interview process, and I reiterated that if she needed to stop the interview or to move around room she should do so.

2.7  VICKI’S STORY

Vicki is a slim, attractive 29 year old mother, living with her partner, Bill, and they planned to marry in early 1996. At the commencement of her pain story she was single and a bar manager at a sporting complex in Brisbane. She also ran a somewhat successful business as a beautician/nail technician from home and planned a future as a make-up artist. On the 18th October 1992, while en route to work, Vicki was involved in an automobile accident. As we enter her story one is reminded that Vicki’s pain has been with her for only a short time (three years), compared to other participants in the study. Her story unfolds as follows:

What actually happened, um, I was changing lanes a guy in an orange car beeped his horn which made me swerve and as I swerved I collected the back passenger side of the car in the middle lane, in front of me, that hadn’t yet taken off, so he was stationary and I was doing 60km with my foot still on the accelerator and as I finished the swerve I went up alongside him and bounced on the passenger side two wheels and then back onto all four and I
landed about ten metres in front of the guy that I had actually hit up the backside. um.

I tried to open up the driver's door, it wouldn't open, so I got, I turned the ignition off, believe it or not, as soon as I stopped I went ok, no blood everything's ok and the engine was going whrrrrrrroo, so I turned the ignition off, because I thought the car was going to blow up at this stage, and I got out the passenger side and I hadn't even gotten to the nature strip and my legs were hurting and my back was hurting, and it got worse and worse and worse.

I don't know how long it was before the police arrived maybe ten minutes. I'm not sure. By that stage I could barely walk um, I could barely stand, I could barely sit, I was just in pain and just in shock, they didn't take my statement because I can remember him, some witnesses asked me who can I call for you and I got them to call a friend of mine who lived just around the corner from where the accident happened. And um, I can remember the policeman saying to him just take her home make sure she gets to a doctor. We can't take a statement from her at the moment because she's not making any sense. I can remember him saying that, yeah, from there Mark took me home, got me changed because I was in my work uniform and from there we headed to the Mater Hospital.

They came straight out put me on a bed, and gave me an injection straight away before they did anything. yeah, and um I can vaguely remember the x-rays, every time this man moved me I screamed and I remember screaming and he was saying I've got to move you around to get x-rays (Vicki, Verbatim Transcript, September, 1995).

Vicki describes her sense of frustration while hospitalised immediately following her accident:

I um, gave the doctor a mouthful as well as the red headed nurse who was in the room as well. I verbally abused them and told them what I thought of their method, like how dare you say she's got a sore back you don't know me, you know, you don't know what I've been through, you don't know how much pain I'm in. You stand there and say oh she's got a back, as though I was a real nothing. I was just taking up one of their beds. yeah.

No-one had bothered to come in and speak with me the doctor did, I apologise, for the first few mornings um, from what I can remember um, because I was still in so much pain and still face down him coming in and introduce himself, and they would, he would talk with nurse and say well we'll just continue with what we're doing with her at the moment, which was giving me injections every four hours, and I can remember, begging the nurse, she'd come in and they would even rays (Vicki, Verbatim Transcript, September, 1995).

Finally, Vicki discharged herself from hospital. She explains her desolation below:

I couldn't do anything. It was just devastating. I didn't know why I lost a lot of friends. I suppose because I had to rely on friends to do everything
for me so they got tired of me, so along the next three months after the accident I lost a lot of friends. In the end I just rang mum. Mum was living in Albury at the time and I just said mum I've got to come home I can't do anything here everyone hates me (Vicki, Verbatim Transcript, September, 1995).

Feeling all alone, Vicki leaves her home and returns to live with her mother:

On 10th January I boarded a plane to Sydney and then out to Albury where mum was waiting for me. She didn't know how bad I was until I got there. She was quite shocked at the state that I was in. From there we just sort of coped day by day and that's when the depression really started to set in (Vicki, Verbatim Transcript, September, 1995).

She explains her worsening mental state:

I would get these days where I'd cry you know for like 1/2 a day, and then I'd be fine for two weeks, and that went on for a few months, and then it went to a full day of crying, and then it went to two days, then it went to three days, as time went on the depression got worse and I didn't realise it was depression at the time (Vicki, Verbatim Transcript, September, 1995).

Vicki goes on to explicate her feelings at interrupting her mother’s life:

I've destroyed her life in the process, because her boyfriend at the time, and he and I just did not get on. He refused to have me under his roof, so mum had to move out from living with him and find herself another place so I could actually come home to her.

I felt really bad, because I'd just turned her life upside down and she didn't need a 26 year old daughter back on her doorstep saying hey mum, you know, I can't do a thing. You've even got to cook for me (Vicki, Verbatim Transcript, September, 1995).

While Vicki lived her pain, she was unable to comprehend her mood swings. She says:

I didn't know what the hell was happening to me and just used to bite down mum's throat all the time. I was just changing in every aspect of my personality and my moods and could never explain why. You know I just get these mood swings and had to just cope with them

I was just changing in every aspect of my personality and my moods and could never explain why. You know I just get these mood swings and had to just cope with them (Vicki, Verbatim Transcript, September, 1995).
By the middle of 1993, nine months after the accident, Vicki ceased to be a Worker’s Compensation case. She explains her reaction to this event and the paradox of pain which cannot be diagnosed:

They couldn’t find anything wrong that’s when I just, that when I was thinking I shouldn’t be sore, they can’t find anything that’s causing the pain I shouldn’t be sore I shouldn’t have this pain, so and denial was quite strong then to, as in I don’t have pain, I don’t have pain, I don’t have pain, oh god, I have pain, you know, I can’t have pain, you know, they can’t find anything they know what they’re doing, they’re the specialists they’re saying to me that there’s nothing in all these bone scans so I obviously am doing it to myself, you know, but as time went on, it just wasn’t right, you know, I’ve got pain, you know and they’re wrong, if they can’t find something that doesn’t mean I don’t have pain, you know, it took maybe 12 months for me to hit that point where I’ve got pain, you know, I don’t care what you say, I’ve got pain you know, and if you can’t find where it coming from then that’s not my fault that I’ve got pain (Vicki, Verbatim Transcript, September, 1995).

Vicki elaborates:

I was really upset, devastated, and, alone um. I felt pushed aside, disbeliefed, they made me feel like I was out for the money. I was wasting their time because all I wanted was the money from the compensation.

Doctors were saying I’m after the compensation money, not willing to help me, but willing to prescribe heavy drugs, like Valium (Vicki, Verbatim Transcript, September, 1995).

Vicki explains her confusion of living with pain and being told by the medical profession that her experiences were in ‘her head’.

I really did start believing it’s in my head, I’m obviously after the money, you know, and it was screwing me up even more thinking that way, because the pain was still there, you know, and like I’m trying to tell my brain, you know, you can make the pain go away because you’re making the pain there in the first place. So it really is, no-one’s believing me I’m making up the whole story. Well I was really blinded at that time to what was going on because, I’m still in denial now, but at that stage I was in total denial and I was trying to do things like a normal person would do and because I wasn’t coping, because of the pain, it was excruciating pain, I was yeah snapping and yelling and screaming at anything and everything (Vicki, Verbatim Transcript, September, 1995).

Vicki used the professional term denial to explicate her position:

Denial means to me that if people say that your mind can you know like, people that have cancer that they change their thoughts and they change their way of life and change their eating habits and the cancer goes in very
rare cases, and I thought my version of denial is that if I deny that I have the pain then I won't feel it, but that doesn't work. Because I don't want pain, I don't want it there so if I can deny it's there it will go away.

When I think back they were not helping at all, but at the time I thought they were because I was popping Valium-like it was going out of fashion and drugging myself out sleeping all the time and at that point I thought yes, pain relief, but now that I'm out of those doctors care and I'm back they weren't helping me at all (Vicki, Verbatim Transcript, September, 1995).

This confusion leads Vicki to thoughts of suicide: She explains:

Yeah, it wasn't working um, made me worse, I think that's at the point when I started to become suicidal, but I can't really pin-point the point where, I just sat down with mum this day and just said to her this is it mum, if I've still got it in six months time that's it, you know, and mum begged me not to do it and I tried to explain to her the pain relief behind doing it, the peacefulness behind suicide um there's no more fighting in my leg and the pain in my back just if I did it wasn't going to be there any more (Vicki, Verbatim Transcript, September, 1995).

Vicki continues to describe her experiences of the medical profession:

I met with Dr R. and he was disgusted that I did not make the effort to get up out of that bed um I had, he said, I had to do more for myself, I had to stop relying on my carers um and he also told me to sit properly in that chair and I said I'm sitting the best that I can. Um.

...and I have to do more,- and for someone that sulfur's pain when someone says do more that just says more pain, it's not the fact that to do more is going to make me more independent. At that point it's more pain you know, I don't care what anyone says,- it's more pain. You know you don't look at it as being more independent you just look at it as more pain (Vicki, Verbatim Transcript, September, 1995).

Vicki explains her fear at being denied analgesics:

Dr M. threatened me, he had me on Codral Forte which is what I've had since the accident, which is a totally wrong pain killer for me, it just never worked, I would have to take four to get the edge off the pain. Um and he was threatening me, I took, he gives me a lot of 20 tablets in a pack and I took those 20 tablets in 18 days and went back for some more and he threatened to take them off me, because I was taking too many, so he said to me you have, we give you 20 tablets they should last you six weeks, so every day I was fighting pain over and over and over again not only because he had threatened to take them away from me and they weren't working for me anyway but the fear of having nothing to even take that edge of the pain is frightening, it's so fearful that you put up with the pain so he doesn't take them off you (Vicki, Verbatim Transcript, September, 1995).
Vicki is willing to try any form of medication to alleviate her pain:

I am willing to try any sort of pain killer as long as the doctors or the psychiatrists are willing to work with me to get it right. As soon as I get to the right one I'll know and I'll let them know, but having doctors say things like that's just a too strong or you'll get addicted to that, so we're not even going to prescribe that for you is frustrating.

Because I'm living it, because I'm breathing it, it does make you do things like that, you know, it doesn't make sense to me how I can be this way, but I know why I am this way, but that doesn't help me, yeah, it does it makes things a lot clearer, but it doesn't make things any easier (Vicki, Verbatim Transcript, September, 1995).

Vicki describes her life prior to pain:

I loved music, very rarely watched telly, I could tell a joke, I was funny, I was happy, I was tactless that's a Scorpio I think. Sometimes rude when I had to be. I was loud, I was confident, I loved meeting people, I could talk under water, I could make quiet people feel comfortable, you know those quiet sorts of people that just sit there, I could really make them feel comfortable in a room. Um I was pretty and loved being the centre of attention. I was caring, helpful, strong willed, open minded, active, spontaneous, lively, very independent, I was a motivator in like my um my circle of friends, I was the one with all the noise, picnics out and ring around to make sure everyone could make it.

I was friendly, I was straight forward I was content, I was in touch with who I was, in touch with what I wanted, I was keen, I wouldn't really say ambitious, ambitious I look at people that would kick someone else in the back to get higher up in things. I was very keen, I was level headed, I loved being outside, optimistic, um a great attitude towards life, wasn't afraid of failure and loved trying new things. I was a good person to be around I liked the person (Vicki, Verbatim Transcript, September, 1995).

Vicki describes her future:

Um. At 35 I was going to run my own business, um, have my own house, have achieved the small little goals along the way where I wanted, um, like doing the nail course so I could set myself up eventually so I could work from home when I had a family, work my own hours to fit into my lifestyle, um I wanted to do a little bit of modelling, um learn the drums, you know just all these little things that I had planned to do along the way, but by the time I was 35 I was going to have achieved everything that I had planned, I had booked in to do a fantasy make-up course in February of 1993. Um it was going to cost me $1100 to do, and then I was going to harass Movie World to work voluntary on weekends so I can learn more, plus the people down there I'm quite sure would like their nails done, so my nail business would pick up as well. Just things that get back into squash, um, get back into netball, just little goals you know that I've wanted to do that I've set myself to do along the way. If I was still playing squash and netball when I was 35 that's great, you know, that's an added bonus. But, you know just doing things that I enjoyed doing, you know, its like people that have jobs and have been in that job for 10 years and they hate it, you know I always think why don't you change your job instead of coming home and bitching
and whingeing and moaning to everyone about your job, why don’t you just change your job, you know to one that you like, you know, I’d change jobs but that was with um like I’d go for interviews where they would promise promotions and grading from receptionist work to computer work, you know up the ladder to um credit department you know things like that just didn’t happen, you know, you got that job and that’s where you stayed and I would apply for whenever the jobs came up I would apply and I always got knocked back, you’re too good with job that your doing you know, so from then on my work with that company would deteriorate and I would go out and find another job where I could improve and get better and when I found that was never happening that’s when I thought well right I’ll go into business for myself (Vicki, Verbatim Transcript, September, 1995).

Vicki explains her *aloneness* and her desire to experience being with others like herself in the following statements:

People don’t believe that I suffer pain, specialists because I had the accident on my way to work, specialists seem to treat you like dirt. Um

My friends do not understand chronic pain and I’d go over to visit, and like I’d just cry, you know how you get those moments where you just cry for no reason. They don’t understand ..

I am alone in the sense of being in a room and feeling the same as someone else, I needed to be with someone else that suffered chronic pain that sort of alone, but support wise and talking to you know, I have mum and Bill but their understanding and the comprehension is, well I could sit down and I could say something and they say yep, I know exactly what you mean, rather than with mum and Bill I have to try and explain in a normal circumstance the way that I’m feeling, which is sometimes really hard to try and grasp how your feeling and then turn it around to a normal situation, so they can get some sort of idea of how I’m feeling. Whereas with another chronic pain person, you don’t have to do that you just say it and they know, and they go YES! I know what you mean.

Um, I am not normal, the same as someone else. I want to feel the same as someone else (Vicki, Verbatim Transcript, September, 1995).

Vicki describes being normal:

Normal to me and I should really smack my hand because I am normal, I am just someone that suffers chronic pain and I know that, but in short term normal is just a typical way of saying it, so I will slap my wrist again that’s not right, um, because I needed to feel like I wasn’t different, like I’ve always been my own person, don’t get me wrong, and being an individual prior to the accident was great, you know, but having chronic pain is a different, different if you know what I mean. yeah and I needed to feel the same as someone else.

Sue has given me that, Sue has given me that like if I sat in a room, I’ve always said that, if I sat in a room of people that don’t suffer chronic pain, I feel out of place, but if I sit in a room with other people that suffer chronic

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pain I feel the same and that's a really good feeling, just to be the same as someone else in that sense, but still be an individual which I'm still fighting to get back which is the person I used to be, yeah.

I've gotten hold of the right people that I've needed, I needed these people 3 years ago to help me through the chronic pain life and its only been recently that I have been able to grasp these people and not I am not letting them go (Vicki, Verbatim Transcript, September, 1995).

Today,

I am everything opposite to what I was, everything opposite to what I was, yeah and more. I am a very serious person now, I take everything seriously, things that used to be, you know how people say oh you fool, I'd take that to heart now. I am just a person that I don't like to be around and I can't escape being around me, the only escape I get is when I'm asleep, but I'm not awake to enjoy it, you know what I mean.

The person I am is still in pain. Who I really am is just blinded from me at the moment, so and that makes sense to me, so understanding that side, and that makes me feel better than feeling that I'm not the person I was. I am within me (Vicki, Verbatim Transcript, September, 1995).

Vicki relates her daily experience of living with pain:

Um. Well I don't really do much. It depends on the pain. It all seems to generate together during the day, as the day gets on the pain gets worse. I get it every day.

Coping depends on how I am mentally on that day if I'm having a good mental day I cope with it quite well. If I'm not, I don't cope with it. Yeah.

A good day is full of positives um, I can get through it, its doesn't drag me down, I feel I'm going to get my life back, um it's sort of like a game you play with the pain, you know, like ha ha you're not going to get me today you know, games and play and it gives you strength to keep going, yeah, like it revitalises you on your way to revitalises is not the right word, it rejuvenates you to keep going, yeah.

It all depends on the pain, yeah, depends on the pain, plus it depends on things that happen in my life (Vicki, Verbatim Transcript, September, 1995).

The desperation for a consensual medical diagnosis is significantly highlighted by Vicki in the following:

But yesterday I went to Brisbane to see a um Dr who it looks like he's actually found, he hasn't pin-pointed a diagnosis... and he's the first doctor I've actually found that saw it on the x-rays, you know, for three years

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people have been saying well nothings showing up on x-rays, bone scans and cat scans and you know so where is this pain coming from, but he saw it on the x-ray itself, which is great (Vicki, Verbatim Transcript, September, 1995).

Vicki wants to get better. She explains:

Better means getting control of and understanding what I'm going through and why I'm doing things I'm doing, and acknowledge what I'm doing when I'm doing it. Yeah, not so much physically but mentally (Vicki, Verbatim Transcript, September, 1995).

Vicki describes what it means to have pain in her life:

Pain means Um the lack of independence, with lack of independence comes invasion of privacy, um inability to do things, too scared to do things because pain might intervene um, I'm not the person I used to be and I believe the person that I used to be and hating the person I am now.

Independence at, yeah, that's not having to rely on anybody, confident in my own decisions, like I would make decisions that my friends didn't like or didn't agree with, but as long as I was happy in myself with my decisions with the things that I did I did them, and I would explain to them, you know, if you don't like it, you know it's not my problem. You know, but I'm going to do it anyway. you know um yeah just not having to rely on anyone for anything, financially or um I wouldn't say emotionally, because that what your friends are there for, for a hug here or there, or a joke, and but um just not having to rely yeah on people for things, like other than getting your car tuned you've got to take your car somewhere to get it tuned - things like that - you know you've got to rely on other people for things like that, but just everything in general you know in relation to your own life. I miss that (Vicki, Verbatim Transcript, September, 1995).

Vicki believes she is out of control:

I am out of control um, with all of my emotions, I would not be left alone with Callum, because, you know how sometimes you get irritating things that people, like if your watching telly and one of your children go bla, bla, and you go shshss, because it just, things like that my temper would go over the top, it would explode, so I was very scared and was never left alone with Callum. I would never hurt him, but I couldn't say I wouldn't hurt myself through the anger that would just explode erupt out of me as quick as that, from being calm, (snap of fingers) to erupting, as quick as that (Vicki, Verbatim Transcript, September, 1995).

Vicki explains the role of her partner in her life:

He's coping, he's great, he's terrific, he's one of the best normal people I've come across that handles me really well. because I don't know, I can't see my bitchiness and my snappy moods, um, and my short temper, whereas he can and he just says I need to go and lie down. You get to points where you're that frustrated and you get that aggravated you're full of that much hate that you just lash out at anybody there, anyone that's in reach you just scream at and you verbally abuse them for doing something that's stupid (Vicki, Verbatim Transcript, September, 1995).

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2.8 ESTABLISHING INTIMACY WITH STEVE

I met Steve at the Belmont Hospital Pain Clinic, a man in his mid thirties, tanned and casually dressed. He agreed to tell me his pain story and we met in a secluded, comfortable room at the hospital. He appeared at ease and launched into his story without prompting. Funnily, I had dressed casually for this interview and wore a leather jacket. Much of establishing a rapport, at the commencement of this interview, stemmed from Steve’s interest in my jacket and whether I had an interest in motorcycle riding, and this laid the basis for an intimate interview.

2.9 STEVE’S STORY

Steve is a young man in his thirties, divorced after eight years of marriage. He has one seven year old daughter from that marriage, and is currently living in a de-facto relationship with Danielle and her eight year old daughter. He had been a truck driver for 19 years prior to the development of persistent pain. He had just moved to the Gold Coast from Wollongong. Steve’s story differs from the stories told by David, Vince and Vicki, in that as a consequence of developing persistent pain, Steve is labelled a therapeutic morphine user. He tells his story:

It was about half past six at night I was at work ah, doing the same thing I did every night, night after night and um my suspension broke out from under the truck going around a right hand bend.

After the accident I got out of the truck they tried to cut me out I was pinned for five hours and they tried to cut me out and I could see daylight, not daylight but light through the right hand side of the truck and I had to turn myself around and pushing myself out of what was left of the steering wheel and the right hand seat and I pushed the right hand door out and I climbed out and walked out of the truck, my left leg was broken, I didn’t know that until two days later, but they said I just had cuts and abrasions and they said go home and have a good nights sleep and if you don’t feel any better in the morning go and see your doctor (Steve, Verbatim Transcript, October, 1995).
Steve describes his attitude of *she’ll be right* [sense of feeling things will turn out fine] despite feeling intense pain in his back:

I just said to me you'll be right. I went to the doctor the following morning and um he said I might send you up and have a few x-rays on your legs, and I said what about me back, they said. That's just your leg don't worry about it, he said you've been knocked around a fair bit and the bloke that did the x-rays said there's nothing to worry about, everything's ok go home, I went back and saw the GP and I said there's something wrong. Oh, no, no, you're right there's nothing coming up on the x-rays.

I said what are you going to do about me lower back I said its just, I said its just getting worse I said can't put up with it, so he wrote me out a script for Panadol Forte take these, if its no better in a couple of days come back and see me. I went home and laid up, nearly went around the bend with pain, and by that time from me knee to about the end of me thigh was black both sides of me leg. I went back and he looked at it and went ooh, ooh, better get you up and get some more x-rays done, I said even then I'm not that worried about me leg, its me back, I get tingling in me left hand and all down me left leg. He said oh that's your leg. That's your leg and um they said oh you've got a slight fracture in your leg its nothing to worry about it will heal, go home and rest, so I changed General Practitioner's (GP). The next GP said yeah, yeah, yeah and I told him what had happened and he wrote me out another script for more pain killers, and I said there's gotta be something wrong with my lower back, or me back, there's gotta be something outa wack [wrong], and I explained to him what happened to me in the truck how I was spun round and turned upside down and squashed and he said let it go for a few days and I said look, its letting go and letting go, and letting go and I said I'm getting in more and more pain, I said there's gotta be something wrong and he said well how much pain have you got, and I said a lot and he said well how much is a lot. I said I'd like to bash me head up against the wall I can't sleep of a night, so he wrote me out a script for sleeping tablets.

I said listen this is no good, I said you know, shouldn't I have an x-ray on me back, and he said oh yeah, we'll do that at the end of the week, so I went back at the end of the week, I went and had an x-ray and went and saw him at the end of the week, he said there's nothing there to worry about. Anyway it just gradually got worse and worse and by this time he, um two or three months went by and the doctor said we'll get you back to work and I said well, and by this time I was having trouble walking, like I'd wake up in the morning, or when I did sleep, I couldn't get out of bed I'd have to crawl on me hands and knees to the toilet get myself into the shower, and he said no, no, we'll get you back to work. You'll be right, you'll be right so I went back to work and I lasted two and a half hours I had to get in an ambulance and take me away. I went numb from the waist down I couldn't feel anything like I couldn't feel anything from the waist down, but from there up it was just like a red hot burning sensation in the lower part of me spine, and just gradually got worse and worse (Steve, Verbatim Transcript, October, 1995).
Steve explains his experiences with the medical fraternity:

I asked the specialist what he was going to do to me and he said you don't need to know that, I went away from there I was very upset and like he just wouldn't tell me anything like he was very arrogant.

I've been kicked around from the word go I have been, they treat you like a piece of shit they really do, they can't understand what you're going through.

GP's are arse holes. Well from why didn't um the doctor I'd first. I'd seen send me straight to a specialist. I went and seen two different GP's and all they wanted to do was prescribe drugs and keep you coming back so they get some money as far as I concerned. They don't, they don't know enough about pain, I don't know how to put it, its very hard. If you go and see your own GP, this is how I think it should work. He checks you out and says right, well I don't know anything about this, which they don't, they're just stabbing in the dark, as far as I'm concerned, they should say well look I can't help you, you better go and see this bloke over here, Joe Blow. I'll refer you to him, and see what he's got to say about you instead of leaving it, and leaving it, and leaving it, because the longer you leave it the worse it gets. I can guarantee it, cause you just freeze up and you just feel like you want to pull yourself into a little ball so you don't get hurt, you're in that much pain you don't want any more. I found, I've tried to hang washing out and do things like that on me own, it got beyond a joke, it really did I couldn't do anything in the end, it was more of me being scared. I was scared of hurting myself because me left leg kept going out from under me, and like I kept saying like is there any stretching exercises I can go and do, you know, should I go and get a massage, oh we don't know, they'd say.

I think they treat us like that because... I don't know, because they don't know. They're not educated properly they I dunno, they don't know what they're talking about and they tell you they do

The specialists are liars. They were lying to me. The specialist that operated on me, he told me lies after lies after lies. He said he'd fix me (Steve, Verbatim Transcript, October, 1995).

Steve lived for eight months with persistent pain. He describes his life during this time:

I was just a drone who couldn't talk to people cause I couldn't stand still, I couldn't stay in the one stop long enough and I was cranky irritable and then me wife wouldn't let me see me daughter cause she reckon I was too cranky but it was the only time I could get any relief when I was around her and I kept going back to the doctor saying listen you know, this is me GP, I said what's going on I said I'm in more pain than I've ever been

I knew it was a waste of time taking them because they're not doing anything he said you're gonna be in that much pain when you come off em
you're gonna kill someone or kill yourself (Steve, Verbatim Transcript, October, 1995).

He talks about what it is like to live with pain:

The pain's there but you sort of, try to take your mind of it, you're not worried so much like I can bend a lot better than what I could, because I'm not so paranoid before they'd told me I'd break in half, they told me ten more years and I would be in a wheelchair and then it was very confusing to start of with, cause I didn't know who to believe and I kept taking me gut feelings and saying these people have been so good and so quick off the mark to do something, and I kept thinking if I would have come here when this first happened maybe I could have gone back to work.

The pain has stopped me doing just about everything. Before August 1993 I worked six days a week, and actually I used to work, I used to start work on Monday night and finish on Saturday morning, I worked night shift permanent night shift, I'd get me daughter, we'd go swimming, we'd go to the beach, I used to water ski, ride motor bikes all the time, that's been me life from the word go riding bikes. I can't ride a bike any more, I just can't do it, I scream with pain and my whole side goes numb had to sell that, I used to ride a push-bike, like taking the kids out on push-bikes sorta thing, I can't do that, there's just no social life, you go out and you'd be miserable, you couldn't drink, if you did drink it would affect the medication you're on, and before you know it you're in that much pain and your sort of, and someone would bump me and you'd turn around and brrrr sort of thing, sort of burred up at everybody, always cranky, always, like not sleeping either, I've never been a person to sleep but just being in so much pain, violent headaches all the time, and it got that way that I got sick of people saying like you know what's wrong with you, what's wrong with you, I said I've got a crook back, and they'd say, oh yeah! Sure (Steve, Verbatim Transcript, October, 1995).

To Steve's delight in April 1994 lumbar disc degeneration is confirmed by CAT scan.

Steve willingly undergoes a spinal fusion and laminectomy. However, the surgery fails to alleviate his pain and Steve spends a further five months in hospital. He explains his feelings in regard to the continuance of his pain:

When the surgery did work I was very depressed, very depressed, I kept thinking to meself I get over it, they told me I'd never ever work again (Steve, Verbatim Transcript, October, 1995).

Analgesics become a part of Steve's life. He says:

They bought a Pain Management doctor in from North Sydney, and before I knew it I was on morphine. Injections to start off with and then they put me on tablets, Endone (narcotic analgesic), you name it I was on everything you could think of, and by that stage I was a raging junkie, but I
couldn't stop. I suppose it was also from the build up of everything and all
that on top of it.

Morphine, I was on morphine, pethidine (narcotic analgesics), morphine
you name it every couple of hours they were coming in and sticking tablets
into me, injections and I said to them, I said I don't like drugs, I said I hate
em, I said this is just, the pain is not going I've got constant pain all the
time, you'll be right, you'll be right, you'll get used to it, it'll come good, it'll
come good, so after spending like four or five months in the hospital, they
finally let me go home and I waited an extra week to see this doctor who
come in and seen me hoping like he would take me off all these heavy
drugs and put me onto something else to get me so I could go home, no
they sent me out of the hospital with a handful of all these drugs and letters
from the government to say that I'm allowed to use morphine (Steve,
Verbatim Transcript, October, 1995).

Steve describes his feelings of dealing with people who doubt the reality of his pain:

I was very pissed off, but I've done it meself, like you know I've had
blokes, you know you see blokes get out of trucks and they're all bent over
you know like I used to take everybody on meself you know like I worked
seven days a week when I had me own trucks, and carted produce and I
loaded bags of potatoes by hand. I've always been a person who worked
hard. I thought they were bludgers (Steve, Verbatim Transcript, October,
1995).

Steve talks about his relationships with friends and others:

I don't talk any more to people about how my back aches, but I used to.
Oh God yeah, me mother would ring up and I'd go ooooh christ me back's
aching, I can't walk, I've got a headache you know, the dog got run over,
the cat got stolen everything's going wrong, it sounds horrible doesn't it. It
didn't help me pain in the back, it makes it worse cause I'm thinking about
it more

Yep, yep as far as I was concerned they (friends) were not worth having,
cause they're not real friends I was a baby-sitting service, a cripple baby-
sitting service to these people who go out and get pissed cause I couldn't go
with em. I've still got good friends in Melbourne that have stuck by me and
that's from a different, that's when I was in Melbourne sorta thing. I wasn't
crippled, I'm not a cripple now, but um I cant go back to that live I lived
down there I cant ride bikes any more.

A couple of months ago I used to worry a bit about people believing I have
get pain and problems with my back but now I don't give a stuff, I know it
hurts. Me girlfriend made me stop worrying about others. She made me
see where I was going and what the hell was going on she used to say
you're giving me the shits, I said you bitch, she said I know it gets worse
and like she's giving me a hard time now all the time stop sitting there and
feeling sorry for yourself get up and walk round, and I used to get really
paranoid about getting up and walking around the room with people and
they'd be looking at you, why don't you sit down, and now I just say I've
got ants in me pants, I can't sit still I'm hyperactive, you know (Steve, Verbatim Transcript, October, 1995).

Steve believes that society and conservative pain management techniques require that the persistent pain sufferer denies their pain. He explains:

You are not allowed to talk about your back, like the way I put it now, if my back's aching I say my back's not aching or something. You can have a laugh about it, we all have a laugh about it, like I'd say that to her at home, she'll say how are you feeling Oh me back's not aching and she'll look at me and say yeah I know it's not, I'm fine, I'm perfect and I walk outside and crack and carry on like you know. I've seen the way you jump around your flexible like the way I used to be like. I'll get meself into a position and I'll crack and crunch and carry on like I'll get down on the floor and before I go and hide and no-one sees me doing it, but if I'm cracking I'll go into a different room and stand there and do it.

Steve experiences a sense of belonging in his relationship with Danielle because she too suffers pain:

Danielle and me got together earlier this year, I was with her before and then we got back together, she's been fantastic she's been more supportive to me than anyone has been and she is a chronic pain sufferer as well, and I'd say if it wasn't for her I wouldn't be here today really, cause like

We've been fairly happy at the moment, we could do a lot more but we can't, or cant I'm the one who's sort of very limited I can't do a lot of things. I get in a good position and I can't move and I've gotta be straightened out and moved around (sexual relationship) It takes the spontaneity out of it. If I get a good massage I'm right for 4 or 5 hours no worries, but then the next day I can't walk (Steve, Verbatim Transcript, October, 1995).

Finally, Steve finds a General Practitioner who listens to him:

I just couldn't believe it that sort of from being kicked in the guts from the word go in NSW and thrown from pillar to post and treated like a piece of garbage to be here two or three weeks find a GP. and he sent me straight to a specialist and when I've been to see this specialist he was just so, you could talk to him, he listened to me, I felt that he understood what I was going through and I thought this is so strange I couldn't believe it, I thought there might be hope for me yet, and um he said to me that he had a pain clinic here in Brisbane, and I shook me head. I said no mate I'm not taking pills again I said you can shove it up your arse, he said no, the idea is to get you off all the drugs and teach you how to cope with it.

I rubbed me hands together and thought you beauty, this is what I've been looking for because I kept saying to the other specialist, would it help if I start exercising, doing weights and building meself up, no, no, no, stay at home, rest you've gotta rest, you're not going to be able to do this, you're...
not going to be able to do that (Steve, Verbatim Transcript, October, 1995).

Today, Steve describes what he wants out of life:

I wanna get on with me life I know that. Go back to work. I hope I can go back. I don't know what I want to do that's my biggest problem, I'm not well educated. I think its too late to be educated I don't know what I can do, all the jobs I can do mean I've got to work long hours like of a night and stuff like that, I don't wanna do that, I wanna be like normal people, I just wanna go home at five o'clock at night, sit down with the kids and spend time with em and grow up with em instead of being this mess that sits on the lounge asleep all the time, that's what I've been like for years, and I just sit, I wanna be like a normal person and get on with me life you know, go to the beach, go on picnics, go for walks in the bush, push bike riding, fishing (Steve, Verbatim Transcript, October, 1995).

Steve envisages a future life with pain. He says:

I'll cope the same way I have now, there's still a light at the end of the tunnel. I'm still alive and like one thing I know after coming here is that I'm not gonna be in a wheelchair like I'm gonna deteriorate we all are, I mean you get old that's the thing. But I didn't expect it to happen so quick but I'm never gonna be out of pain I can live with that now, there's gonna be days when I feel like getting out with a ... and go and rip people's head off, but what do you do, do you sit there with a mournful look on your face, like I didn't realise until I come here how much boring people sound sitting there talking about how their backache (Steve, Verbatim Transcript, October, 1995).

Despite acknowledging the continued place of pain in his life Steve remains vigilant for the 'miracle cure':

Wouldn't worry me in the slightest, if I had $50,000 I'd go over and have the insurance company say we'll pay for your operation for you to be well and give you nothing, if it takes the pain away, I can go back and do what I want to do not a problem and I can run out of here and do what I wanna do, go back to work and I'd go, fair enough if I can go back and drive a truck for six to twelve months or something like that to get meself back on top which it wouldn't take long to do just go and work around the plot for six months and then come home, if I was out of the pain I'd pay for it wouldn't worry me, and that's sort of kept me going (Steve, Verbatim Transcript, October, 1995).

2.10 ESTABLISHING INTIMACY WITH JOANNE

I met Joanne in the fifth week of a pain management course at the Belmont Hospital.

She appeared tentative and tearful at the beginning of the interview and this continued throughout the interview, but we were the same age and that seemed to forge an
alliance between us to finish what we had started. She said she had a story and wanted to tell it, and she thought it was significant that I actually wanted to hear her story. I ensured that we were comfortable, with plenty of tissues and coffee. This interview was particularly difficult for me because many of the issues Joanne discussed seemed in some way relevant to me, as researcher, nurse, councillor as a human being and I suppose I chose to deal with her story later rather an earlier in order to reconcile personal thoughts and issues. On reflection, the interview with Vicki elicited similar thoughts and feelings.

2.11 JOANNE'S STORY

Joanne is 36 years old and married to Chris. They have no children, but hope to enter the IVF programme once Joanne is able to cope with her pain. Joanne has a supportive mother who keeps house and cooks. Joanne was retrenched as the State Accountant for the 'NatWest Bank', Queensland in 1991 and has been unable to work since. Her story begins with a fall from a horse in 1978 at the age of 18 years:

It was on a horse. The first time I have ever been on a horse and I was with a group of people who were experienced riders and um they had a piece of polythene pipe and they put it up the horse's backside while I was riding and the horse took off and, being my first time on it, I didn't know how to hang on very well, and the horse bolted I ducked to get away from a branch and just kept falling. I just fell flat on my back and um I was taken to the hospital. I was left there in pain for hours and hours and they finally came and cut my clothes off me and gave me a needle and took me to x-ray. But they x-rayed the top part of my spine and not the bottom part and they didn't pick up the breaks. They sent me home and um three weeks later I had my local GP out to the house as I wasn't getting better and he felt it, he said oh yeah come down for an x-ray. So I went down for an x-ray, I had broken three vertebrae. Fractured three of them. The GP he said oh yeah, there is nothing we can do, you will be right. The pain eventually got better so I could start walking and all this sort of thing but I had terrible back pain every day like.

Even back then I tried everybody. I tried chiropractors, acupuncturists, all this sort of thing because I have all this back pain down the bottom and um it was, I couldn't sit. That was the main thing and I had to sit to type or sit to do everything at work. It hurt so I was going to all these different doctors trying to get relief and um it was about 1984 I went to see the first
orthopaedic surgeon because I started limping (Joanne, Verbatim Transcript, September, 1995).

Joanne continues describing her life with pain between 1977 and 1984:

I was in severe pain and looking for alternative ways of dealing with it. It was the fact that my disk actually herniated, that is when I went to the first orthopaedic surgeon. I was just at work one day and um I just started to go like this, you know lean forward further and further and just couldn’t straighten and um within a couple of hours. I was right over and just couldn’t straighten (Joanne, Verbatim Transcript, September, 1995).

Joanne elaborates upon her pain experience and its effect on her life:

Before the operation I believe it (the pain) affected my self esteem. I wasn’t as outgoing and as fun loving and joking around. I became very withdrawn and very quiet and a lot of the time suffering the pain. I didn’t want to tell everybody about it so I more or less suffered in silence. Yeah it is hard, you don’t want to burden it on anybody and you feel as if it is better off for everybody if you don’t tell them. Family members knew what I was going through but it was very lonely, very lonely.

Hmmm the pain just took over my life. So not only did I have a life of pain at that stage was very, very lonely. I felt sorry for myself and my pain was bad so it was a pretty down time. I was very lonely. Being alone made my pain worse because I look at those years there they were very, very hard, especially just before that first operation.

Life, I would just go to work and come home. When I could go I would go to work and work as hard as I could and come home and just sit and watch TV. Great lonely life. I was mostly lonely because I chose to be. Yeah I didn’t want to go out, I didn’t want to mix. I found that I was such a bore when I went out anyway. I know I could have gone out but I took the easy way out (Joanne, Verbatim Transcript, September, 1995).

Joanne discusses life following initial surgical intervention:

After the first laminectomy I had about six weeks off work and the leg pain was a lot better. It didn’t actually go, it didn’t disappear but it was a lot better and my back was pretty good right until about 1989 and that’s when I started to get pain down the same leg.

I did have a couple of years that were pretty good, I couldn’t do everything. I still did have pain but I had a lot of relief, I really didn’t think I would be going in for another operation although I would have spasms here and there and be in bed a bit of the time but it wasn’t full on pain all the time. I don’t know why it came back (Joanne, Verbatim Transcript, September, 1995).

The following describes life on a good day in 1989:
A really good day would be going to work, I was on a good wage, had a nice car, enjoyed my work, come home and be with my partner. Lie down and watch TV. It was a happy time in 1989 and it was fine. A bad day would be waking up feeling the pain even when I go to get out of bed when I turn and struggling out of bed and trying to get into the shower. Trying to dress myself while all this is done in pain. Going to work when in pain then by ten o’clock I would be down at the physio and he would be working on me and strapping me up and get back to work. I would be a crippled mess and they would send me home by taxi and I would just go home and lie in bed and be in pain. Pain, pain, pain (Joanne, Verbatim Transcript, September, 1995).

Living with pain, and repeated failures by the medical establishment to fix Joanne’s pain pre-empts episodes of depression:

My pain. It’s um ... It was depressing, very depressing. Um made me feel very useless it was because I couldn’t do anything. I was in bed most of the time when my mother would come over and look after the house, and clean and wash and cook and everything for my husband and iron I was just in bed. So it got to the stage where I think I more or less just gave up and thought well this is how I am going to be. I really went bad.

The specialist was good but I just had a feeling that he really didn’t know what pain I was going through. I just didn’t feel that he knew how much pain I was going through and how debilitating it was and I just couldn’t do anything. It was more or less stalemate I was saying I can’t but he was saying but you have got to (Joanne, Verbatim Transcript, September, 1995).

Joanne explains her sense of satisfaction when tests confirmed a medical reason for her pain:

I felt pleased when all of a sudden this x-ray result said I have pain because I finally felt as if I had proved something. I was sick and that I was in this terrible pain and I wasn’t putting it on and I just wanted something done about it. It felt good because I knew people close to me believed me. I believed it myself, but it felt good when I could actually prove it. That I wasn’t putting any of it on, and it was all really genuine and to just get out of the suffering and the misery that was really good. I was just in such much pain and to get out of that misery. The thought of it was good after the operation there was a hell of a lot of pain anyway so I thought I would be pain free as soon as I had the operation which took a while to comprehend. Just actually the thought of having the operation and having all this relief, pain relief, the pain was just out of this world (Joanne, Verbatim Transcript, September, 1995).

Joanne recapitulates upon her sense of self after her second attempts at surgery does not alleviate her pain:
I was disappointed because I thought the pain would go but it was just as bad in my back before the laminectomy and then suffering all the pain of having the operation. That in itself was just painful enough (Joanne, Verbatim Transcript, September, 1995).

She elaborates upon her surgeon’s comments to her in 1990:

He said you will eventually get back to normal soon, and he kept saying well the operation was a success but you know you have got to get out and exercise and lose weight and I just couldn’t do it by myself. I told him so. He would them prescribe me Codel Forte. I was taking all these painkillers because he was saying to me if you take the painkillers, but I found that even the painkillers were not even relieving the pain so I just found that I wasn’t able to do anything, but I would take the pain relievers anyway.

The last time I saw him he said oh well you are just going to have to live with it and he gave me the prescription for painkillers. So it was more or less just keep going and eventually you will be painless but try and exercise as much as you can but it didn’t. I tried to exercise and it was just full of pain so I mean I was in so much pain that anything that caused more pain I just wouldn’t do it (Joanne, Verbatim Transcript, September, 1995).

In 1991, Joanne was retrenched from work. She explains:

They just said, they believed for my own sake I should have time off to try and get my back better, but I just had no where to go to get it better. I just didn’t know what to do. I have had two operations, and still in all this pain. I just didn’t know what to do, where to go I just lived as much as I could.

I was retrenched because of my back I was only making it to work two, maybe two - three days a week and always going home sick in pain. So it got to the stage where I just couldn’t handle work and they retrenched me. I wasn’t happy at the time to be retrenched, but looking back, it was the only thing because I wasn’t functioning.

It was upsetting up I was very upset about being retrenched because I had been there for eight years or something and I was really upset that I was retrenched but deep down I knew it was the only way because I really wasn’t pulling my weight. I knew it was the right thing, it was just upsetting for it to happen. I suppose I was just thinking that I could go on the way I had been going on, I didn’t think it was going to change (Joanne, Verbatim Transcript, September, 1995).
Joanne explains how she coped during this time:

I was coping during that time, but I wasn’t happy. All the time I would break into tears. I really went inside, in myself I became quiet. I don’t know I just withdrew and just coped by myself because my husband would be at work all day and all that sort of thing, so I just coped by myself by staying at home and lounged around and did nothing (Joanne, Verbatim Transcript, September, 1995).

Joanne tells of her thought of ending her life:

Um Some times I just didn’t want to live. It just didn’t seem worth living because I had no life (crying).

When I was at a low I was cranky, depressed, upset and crying, bad tempered, didn’t laugh, even up to now (Joanne, Verbatim Transcript, September, 1995).

She continues:

One time I was so low that I had sleeping tablets and I wasn’t me and I just wanted to be pain free. I just took a handful of them. There was about ten or twelve or something. It only worked for an hour (laughing) and I was awake again. It didn’t work for very long. I didn’t really want to do anything that would really hurt. I just wanted to get away, just be by myself just sleep and feel no pain. To a place where you don’t feel pain and I have a problem I would forget. Where I can be a normal person, I suppose a normal person isn’t an exact description is it. Normal is different for different people. Get back to having a life and even just being able to I mean I got to the stage where I couldn’t do housework. No one wants to do housework but I wanted to just to prove myself that I could do it. I couldn’t do anything, not a dam thing, so normal to me was functioning as a wife and I wasn’t able to do that and I wasn’t able to look after my husband or myself. Oh yeah just to function as a partner (Joanne, Verbatim Transcript, September, 1995).

[In February 1995] I was admitted for ten days for the back pain. I had a couple of specialists see me then because I was after an answer for what was happening and the same sort of answer from them was “oh well you know its just your old trouble”, you will just have to learn to live with it. So um I went home and I tried to live with it and it is just getting worse and worse. I went back to my specialist again and he said exactly the same thing (Joanne, Verbatim Transcript, September, 1995).

During the period July to August, 1995 Joanne describes her life as being:

At the lowest point because I went to the doctor again and he just said oh you have just got to live with it. It is just scarring tissue that left from the other operation and no more can be done, surgery wise so it will um what did he say, just the nerves would just shut down and then I would stop
feeling pain. I was really upset about that. It was not the answer I was looking for.

Well I am certainly not a centre of attention um I just like if I go to parties or something like that I would be one of the background people. I wasn’t always like that. I used to be very bright and bubbly but um just sort of something within me died (crying). It was my will. A will to go on really. Everything just seemed so hard. You know it is easier to give up (Joanne, Verbatim Transcript, September, 1995).

Joanne continues:

When I went home I felt Depressed and useless...Umm I felt I wasn’t any good to anyone, myself as well. The pain was just so intense that I just wouldn’t do anything. I couldn’t walk without immense pain, I just didn’t go out. My husband and I have sort of been hermits for the past couple of years, because we just don’t bother going out. It got to the stage where I couldn’t even sit in chairs any more, so we just stopped going out. We just stayed at home, boring life. It is upsetting. I was very upset.

I saw it as I had no future and I didn’t know where I was going and so did my husband. We have just sort of been talking about it lately and his thought is exactly the same, but he said he would always stand by me. He said he would never leave me. W we weren’t looking at a very happy future. He said he could see me by the age of forty in a wheelchair. That was upsetting, sort of thinking that he was thinking that as well as I am and there just didn’t seem any hope and um the pain was very depressing. I just cried all the time, just unhappy thoughts, crying (Joanne, Verbatim Transcript, September, 1995).

Family and friends are also effected by Joanne’s pain. She explains:

Oh boy, it has greatly affected the lives of people around me. Um it affects my husband’s business because I am supposed to do all the bookwork down there and there has just been months where I just haven’t been able to do it and I know financially that we would be in a better position if all that sort of work was up to date.

My husband has got children two children himself and they come over every fortnight, and um when my pain is bad, we would just sit around. We used to go out to the markets and take the kids down to Sea World, and just all sorts of activities like that, but the last few years, the last couple of years, it has just been, we would just stay home. I just couldn’t go anywhere.

The fact that my mum, she has been worried sick about me. I reckon I must have taken ten years off her life worrying about me and um my family, everyone just constantly worries about me, my friends.

I didn’t realise that I had that many people that cared about me when I was out there in all that pain. People would always ring up and say how are you
going and I didn’t want to tell them, like I would say oh yeah I am alright but I didn’t feel like opening up and telling them that the pain was killing me and all this sort of thing (Joanne, Verbatim Transcript, September, 1995).

Joanne continues:

I didn’t talk about it a lot. They would ring up and ask how I am and this sort of thing and I would say oh yeah it’s alright, bit sore but I would try not to talk about my back. I just didn’t want to talk about it because I didn’t want to layer a load on them, they were concerned about me, but they really didn’t want to hear about it. I mean I wouldn’t want to hear about it if I was, the situation was turned. No, I didn’t talk about it much. I felt it was ok to not tell them the truth because I thought I was protecting them. It was something they didn’t really want to hear anyway so, it would be upsetting, quite often yeah I would break down yeah after they hung up (Joanne, Verbatim Transcript, September, 1995).

Joanne explains her sense of belonging when she meets others in her predicament:

It really makes the difference when you have got a group of people who are in the same situation, like we form a strong bond more or less. We all know we have been through the mill and you come to a place like this, and we don’t, most of us don’t talk about what we have all been through. We all know that we have had a problem, but we encourage eachother. You know you have a bad day, an off day, and they seem to know what you are going through and you just keep each other company. Just the support you get from each others. I think they are fantastic, you get so much support from them to I know that they know you are hurting and they don’t let you give up and that’s what I reckon I needed back in 1991. After I had had the second operation I just couldn’t recover from it. If I had had known other like myself back then I don’t think I would have gone to any of the lows that I have been at (Joanne, Verbatim Transcript, September, 1995).

Joanne concludes her story by saying:

My spirit...um it was broken. It was, you know, I didn’t have the will, I didn’t have spirit I didn’t have, it was just existing. Let’s see, just inside of me, I just felt flat and it just, I didn’t want to do things. I didn’t want to talk to people. I didn’t, there were lots of things I just didn’t want to do and that started before the first laminectomy. It started to um, it was the fact that the pain just went on for so many years and um I guess all my other friends that I met at work and that sort of thing, they were young and they would go out dancing, and partying and having a good time. I knew I couldn’t do it because of the pain because I tried to go out a couple of times and I just used to have to go, go home. So it got to the stage where I just thought, no I can’t be bothered. So I would, I just couldn’t even go to these parties, to discos, all that sort of thing. I just used to go home and it just made me worse because I wasn’t getting out, I wasn’t mixing. I felt defeated, I would just go home and be by myself (Joanne, Verbatim Transcript, September, 1995).
2.12 CONCLUSION

The pain stories told by David, Vince, Vicki, Steve and Joanne emphasise the significance of lives which are consumed by pain. Their anguish and sense of alone-ness is aptly captured in their descriptions of repeated failed attempts to find pain relief. All continue to experience pain, and any attempt to understand the advent of persistent pain necessitates the development of a discriminating sense of the sufferers attempts to be healed in terms of their lived experience of pain, their fear, their loss of control, the disruption to personal and social aspects of their lives, the loss of an envisioned future, and in some cases the wish for death. These experiences weaken the bond between the cultural dialectic which defines what is to have, and be in pain. The persistent pain experience removes the persistent pain suffer from the social sphere, which creates the context of their experience. Not only does pain pose a very real threat to the suffering individual, but it does the same for his or her social nexus. Moreover, the very values and sense of order inherent to society may be called into question by the advent of persistent pain, as may be the forms of social stability and control. The attempts of Western medical discourse to treat all pain in a traditional manner, may be interpreted as an attempt to restructure the socio-cultural dialectic of pain, in order to make sense of the experience as it unfolds, operating at both poles, to strengthen and support the bonds linking the individual and social experiences of pain.

Herzfeld (1986:113) asserts that

... the cure of sickness also serve as acts of moral commentary. As such, they (medical discourse) define(s) or reconstitute(s) the sufferer's relationship with society by translating a set of symptoms, that is, privately experienced signs of disorder, into a pattern that the patient recognises as belonging to a highly conventional and therefore public discourse. The significance of bodily sickness (pain) must, therefore, be read (in a way) where curing generally represents a form of symbolic...
closure. In a successful cure, the end of the incantation is also the end of discomfort; and thus, where the illness corresponds to an awareness of social discord or disadvantage, the cure also signifies a restoration of balance, an end to the kind of situation that, as we might say, makes us “sick” or “uneasy”.

Unfortunately, the persistent pain sufferer does not return to a sense of balance, and remains “sick” and “uneasy” throughout their life course. Thus, the quest to find meaning in their pained lives exhausts personal and familial resources, and pain must then be interpreted within the framework of individual existence.

The following chapter will examine literature pertinent to formulating an understanding of living with persistent pain. This review acknowledges the importance of empirical methods of research into persistent pain, but focuses upon modes of thought which have as their epicentre the lived experience of spending each day with pain which will not abate.
CHAPTER THREE

LITERATURE REVIEW

3.0 INTRODUCTION

Research relating to the topic of pain is extensive and has been based mainly in philosophical views which have represented pain in two significant ways. The first view has attempted to understand the ontological substance and significance of pain as it is experienced by the individual (Carson & Mitchell, 1998; Bendelow, 1995; Cassell, 1991). The second, views pain as an empirical indicator for impending danger which must be acted upon and relieved through interpretation and management (Menges, 1984; Melzack, 1973). De Moulin (1974) suggests that the interpretation and management of pain in Western society reflects a preoccupation with the need to objectify the nature and intensity of the pain experience with the consequent valuing of the experts or professional voice in preference to the lay voice of the pain sufferer. The dynamics between the voice of the expert and the lay voice provides the fabric through which the pain event is experienced and contextualised in the persistent pain sufferer's life.

The review of literature to follow provides an overview of the historical development of the construct of pain and identifies the salient themes recurrent in the literature relating to persistent pain. Themes include the effects of the biomedical model on pain understanding, finding meaning in pain experience; the need to suffer pain; and the language of pain. The review concludes with a discussion of the pain event within the context of the life of the persistent pain sufferer and the subsequent need to formulate an understanding of pain from this standpoint.

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3.1 HISTORICAL INFLUENCES ON THE PAIN CONSTRUCT

The pre-Christian, Christian and post-Christian periods have each shaped the construct of pain in contemporary Western society. Their influences have extended from the natural and the superstitious to an existential understanding of the place of pain in one's life.

The pre-Christian period deemed pain natural if it was suffered as a result of injury, magical and supernatural, or of spiritual significance, if associated with disease. The emphasis on magical, supernatural or spiritual ideation developed in response to the invisible nature of pain and the belief that such pain was cast upon the individual as punishment for sin. Likewise, then, to suffer pain was to better oneself in the eyes of God for wrong-doing (Procacci & Maresca, 1984; Tu, 1980). Significantly, the word pain is derived from the Latin poena, meaning penalty or punishment (Szasz, 1975:2). Christianity reinforced the view of pain as punishment for sin, be the cause obvious or not, and suffering as a redemptive pastime to be endured and esteemed. Moreover, the words pain and suffering became linked in the literature and provided the basis for commonplace understandings of the pain experience in Western society. This metaphysical construction of pain underwent substantial revision during the post-Christian period due to the evolution of court life and the subsequent need to maintain order, a phenomenon coined 'the civilising process' by Norbert Elias (1939, cited in Mennell, 1989), together with the rise of Cartesian dualism in the eighteenth centuries.

Norbert Elias' theory of the civilising process (Mennell, 1989; Shilling, 1993) postulates that the rise of court society in Europe mitigated the imposition of social
control on innate, biological functions. It suggests that with the increase in the significance of court life and the consequent use of institutionalised codes for body management, the civilising of individuals and society reduced the arousal level of the individual allowing for introspection. It may be hypothesised that with diminished arousal and increased introspection, individuals developed sensitivity to the pain experience. Mitchell (1886, cited in De Moulin, 1974) postulated that increased sensitivity to pain has developed since the 1700s, a period coinciding with the advent of the civilising process.

Paradoxically, increasing awareness of embodiment and, thus, the pain experience occurred at the time individuals were required to develop a repertoire of sophisticated behaviours which restrained their innate qualities. Thus, pain was experienced and “it hurt”, but the model citizen was expected to endure quietly. This issue has been addressed in the literature by De Moulin’s (1974) description of Madame de Bonnac’s (1751) calm and composed demeanour during breast amputation and the bravery of Louis XIV who maintained public appearances and duties despite suffering from severe physical ailments. The depiction of these scenarios are significant because they imply that the individual was able to exert substantial control over the biological processes of pain sensation. That is, pain as a bodily process rather than pain as an extension of the soul. This alteration in thinking occurred not only as a result of increased awareness of biological function and restraint, as emphasised by the civilising process, but accompanied the rise of Cartesian Dualism.

The prolific influence of Cartesian dualism and scientific reductionism on the development and consequent management of pain in Western society can be traced to
the post-Christian period. This period signified scholarly dissatisfaction with the teaching of the Church and the deity. Thus, the move to understanding the body as independent from the prerogative of God initiated the study into the micro-workings of the body, in particular the role of sensations. Thus pain, a natural phenomena, was also conceived as a neurological sensation which resulted from an increased sensitivity of every sense, especially touch (Procacci & Maresca, 1984:3; Procacci, 1980). Further, the notion of the opposition of pain to pleasure became evident, in that sensations were seen as pleasurable when their sensible extremes were held in proportion, whilst in excess they become painful and destructive. It was believed that this opposition of senses was 'linked in the head' (Procacci & Maresca, 1984:3), instigating the contemporary belief that pain is anything which is not pleasurable. However, despite clear evidence of the significance of the central nervous system and the brain to sensation and thus pain (Procacci, 1980; Procacci & Maresca, 1984) the view of pain developed by Aristotle, as a passion of the soul, prevailed for the next 23 centuries stifling any attempt by scholars and philosophers to shatter the stronghold of the deity on the body and society.

The discord between scientists, reporting pain as a sensory phenomena, and most philosophers, expounding the traditional Aristotelian view of pain, was exacerbated by the rise in scientific study in the nineteenth century and the subsequent modern study of pain as known today. This discord culminated with the domination of Western medicine by a philosophy which may be traced to the 17th Century philosopher Descartes, who conceptualised the human being as compromising mind and body, permitting the study of the body, leaving the mind, now believed to house the soul, to the dominion of the church (Ng, 1980). Interestingly, it may be argued
that early scholars purposefully misrepresented the work of Descartes, who actually
admitted that the mind and the body were interactive, to gain a mandate to govern the
body and suppress the power of the Deity. Thus, under the mantle of Cartesian
dualism medicine replaced the priest or shaman as the mediator between the physical
and spiritual world.

To sum up, it has been suggested that the separation between the Pre-Christian,
Christian and Post-Christian periods on the construction of pain is arbitrary. Pain in
the first instance was aligned to the metaphysical and later emerged as a sensation
which was understood in relation to bodily experiences. The effects of this alteration
in thinking were linked to the effects of the civilising process and the rise in Cartesian
dualism and reductive science. Cartesian dualism simplified pain to a neurological
sensation occurring in a part of the body alerting the individual to an underlying
pathology. Scientific reductionism reduced the body to a set of parts which, when in
need of repair, produced the sensation of pain. Hence, the significance of pain as a
sensation was separated from pain as an experience. Moreover, the effects of
Cartesian dualism and scientific reductionism have provided the contemporary
framework for biomedicine and the biomedical model of disease, and thus the
construction of pain in Western society. Through historical and social connections,
biomedicine embraced the art of interpretation and explanation of bodily events
(Morris, 1991:33; Procacci & Maresca, 1984), and it is to the effects of the biomedical
model on the construct of pain, that the review now turns.
3.2 THE EFFECTS OF THE BIOMEDICAL MODEL ON PAIN

The biomedical model of disease, a consequence of Cartesian dualism and scientific reductionism, has had a threefold effect on the body. First, traditional Western medicine came to view the body as a machine with disease as the effect of a mechanical breakdown, or as the result of a defective part. Second, the focus of the mind-body split is on the identification of the causal mechanisms of disease, and thus molecular biology. Third, disease or breakdown is viewed in a detached, temporal and impersonal way as an episodic event (Ng, 1980). Needless to say, these developments have had consequences for the construct of pain, in that pain has now been reduced to an indication of abnormal body functioning. In order to deal with pain, the cause of pain needs to be established, generally within the body, and eradicated in a detached, temporal way. Accordingly, it is apparent that the biomedical model does not discern the psychological or social outcomes which result from the pain experience, the disability which ensues or the effects of living with a possible handicap. Turk (1979:129) states that persistent pain represents an assault on multiple areas of functioning, not just the body. Thus, patients may face separation from family, friends and other sources of gratification; the loss of key personal roles; disruption to plans for the future; disruption to their self-images and self esteem and the uncertainty and unpredictability in their futures and emotions. Kleinman (1988) and Snelling (1994) maintain that contemporary health care priorities and approaches to pain management remain entrenched in the materialist pursuit of biological mechanisms of disease, preventing a questioning of the conditions of the life worlds of the individual suffering pain. Value is misplaced on the technical pursuit for the control of disease, rather than on an understanding of the psychosocial concerns of the
patient. Anderson (1981:427) suggests that Western medicine is over concerned with pathological processes and therapeutic regimes that produce cure.

3.3 FINDING MEANING IN THE PAIN EXPERIENCE

Meaning through validation

In contemporary Western society the meaning of pain is obtained by seeking medical attention or help. As long as a reason can be attributed to the presence of pain, the meaning of pain is inconsequential because the end of this scenario is an acceptable known. That is, a treatment is prescribed by the medical officer to advance a cure. Melzack & Wall (1988:34) and Morris, (1991:35) state that the help seeking actions of patients follow a distinctive process. That is, the person acknowledges the occasion when pain becomes a different and significant event moving from absolute meaninglessness to full meaning, prompting the need for help.

The medical diagnosis constitutes an interpretation of this request by making sense of the individual's pain through identification of its cause. Thus, pain interviews and assessment are concerned with establishing the quality, location, duration, and severity of a presenting individual's pain in order to establish diagnosis and treatment. The assessment is based on a set of preconceived observable behaviours, which reflect the influences of Cartesian dualism on biomedicine, and the individual's subjective experience of pain, albeit Field's (1987:189) contention that verbal descriptions of pain, as simply an observable behaviour, ignore the fact that the description of pain is quite distinct from the pain sensation or perception.
This issue is compounded by the doctor's ability and statutory authority to diagnose, and hence validate an individual's condition as an illness, to change behaviour by diagnosis and treatment, and to add a social state by assigning the meaning of pain to a disease process (Brody, 1987). Thus, the patient's subjective account of their pain experience is not accorded credence until it is quantified and rendered 'objective' (Kleinman, 1988).

**Discounting of subjective experience of pain**

Biomedicine’s quest to render the meaning of pain to the disease process alone is underpinned by the assumption that all pain behaviours are instigated by the desire to obtain relief and cure. It may be suggested that in any exchange, the individual in pain uses persuasive language to legitimise their need for assistance from the health professional who, in turn, has a bias in relation to the results of the exchange and in the interpretation of the language used by the individual. This creates a dilemma for the persistent pain patient who always has to prove that they are in pain. Interestingly, when a biomedical diagnosis is not possible to the exclusion of all else, as is the case for individuals in this study, the sufferer is forced into a search for a meaning for their pain, because the diagnosis of pain acts as a legitimising sanction for their experience.

Fagerhaugh & Strauss (1977:5) assert that the management of pain, whether diagnostic or symptomatic is contingent upon medical ideology and its powerful organisational expressions. Medicine's reliance upon the biomedical model is widespread, and significantly the reason for poor health care provision in relation to persistent pain which cannot be traced to a cause. Despite this ideological predicament the medical fraternity has been reluctant to completely relinquish control
of this pain typology to other fraternities within health care discourse. This typology of pain remains a distinct medical problem in its own right which requires attention and treatment (Melzack & Wall, 1988:36). That is, the cause of the pain although not empirically verifiable within the biomedical paradigm is girdled in the need to be related to deep tissue, peripheral nerves, or sensory nerve root damage.

Psychogenic pain

Eventually, pain which is unexplainable in medical discourse is termed psychogenic, and believed to manifest, as a dream, hallucination or memory, because the individual is experiencing some pivotal psychological disturbance (Fields, 1987; Merskey, 1980). This underwrites the coupling of pain and psychiatry, in which there are three main classifications systems categorising psychological and psychiatric problems relating to persistent pain: The International Association for the Study of Pain (IASP) Taxonomy; The International Classification of Disease Index, Ninth edition (ICD-9) under the category Psychalgia (307.8), where pain is discussed in relation to mental origin; and the Diagnostic and Statistical Manual, Third edition, (DSM III) under the category of chronic pain.

In the DSM III ratings pain is again categorised into first, somatoform disorders (307.80), including psychogenic pain, and more particularly pain which after considerable evaluation uncovers no organic or pathophysiologic mechanism to account for pain. Second, hypochondriasis (300.70) which is an exaggerated belief concerning, and preoccupation with physical ailments. Third, somatisation disorder (300.81) when physical evaluation does not support the diagnosis of any physical disorder which can account for the intensity or duration of the pain experienced, but
the individual continues to believe in the severity of their illness (Tyer, 1992:17-20). Hence, the significance of placing the experience of pain without organic cause under the gaze of psychiatry was seen as appropriate by health professionals who tended to refer to these patients as "medical heretics" because their pain experience did not conform to the accepted views of pain treatment and management (Szasz, 1975). Blumer & Heilbronn (1982), Smith & Duerkson (1980, cited in Melzack, 1988) and Merskey (1980) support this view, reporting that individuals experiencing undiagnosed pain tend to suffer higher incidences of depression and insomnia, albeit that in most instances the longevity of their pain experience and concern for their lack of a definite medical diagnosis preceded their depressive state (Kleinman, 1988; Cassell, 1991; Bendelow, 1993).

Interestingly, despite the creation of this pain typology within biomedicine, the effects of the biomedical model on the pain experience precipitate the patient's dissatisfaction and unwillingness to accept meaning for their pain in psychosocial explanations: as this explanation, by societal mores, denies that their pain is founded in sound biological anomalies worthy of somatic treatments and a legitimate medical sick role (Kleinman, 1988:59). Furthermore, from this perspective, for the individual experiencing pain there is no such thing as psychogenic pain because their referents for pain in Western society are shaped by biomedical discourse (Szasz, 1975). Fagerhaugh & Strauss (1977) suggest that those experiencing persistent pain resist a psychogenic diagnosis for their pain as it implies that their pain is not real. Unfortunately, this results in the individual being left with less and less social context to give meaning to their pain experience.
Feelings of betrayal

The lack of social context to support the individual experiencing persistent pain without a definitive medical diagnosis may be attributable to the repercussions of the civilising process and the tenets of the postmodern world in which pain is silenced through a ‘fix’ mentality. Pain technologies and practices in such a society are shaped and regulated by medical discourse that silence the individual experiencing pain. This silencing occurs as a consequence of denial of pain, a denial made possible through identification of cause and cure. Furthermore, the effects of the civilising process have potentiated the need to deny and silence the pain event. This is illustrated by the pain sufferer’s eagerness to downgrade their experience into a list of complaints which may be collected to represent its cause. Thus, when a cause for pain is not forthcoming, the sufferer is not prepared to perceive the questions and consequent meaning that pain may present when it cannot be denied.

The resultant effect of society’s silencing and denial of the pain event is twofold for the persistent pain sufferer, for whom there is no definitive medical diagnosis. First, from a Foucauldian perspective (1972), their failure to silence, and thus deny, pain may be viewed as aberrant or deviant behaviour. Second, the denial of meaning for pain, and its subsequent labelling as psychogenic in medical discourse maintains and perpetuates the individual’s suffering as punishment. This view represents the influence of Christianity on the development of pain, for classifying deviant behaviour. Thus, human suffering is claimed and controlled by the medical profession (Illich, 1976).
Herein lies the frustration and sense of betrayal felt by the individual suffering persistent pain which can not be halted or managed within the accepted paradigm. Simply, no easy 'fix' or medical solution exists for their pain. These pain sufferers have been lulled into the hegemonic beliefs and practices of the curative ideologies, and thus the conviction that health care staff are obliged to relieve their pain. Their inability to do so represents the failure of the hegemonic practices of the health care system, and the ideologies it represents (Fagerhaugh & Strauss, 1977). Consequently, as individuals experience the failure of treatment, after treatment persistent pain becomes an experience about which there is increasingly nothing to say, nothing to hope, nothing to do. It casts the sufferer into a featureless landscape (Morris, 1991:77-8), and the "lived body" becomes one simply existing and acting in the world. In persistent pain, the body becomes the "object body", a rebellious body which thwarts our will (Gadow, 1980). Pain, is truly an ontological assault affecting the very being of the sufferer and not simply their life activities (Brody, 1987). Morris (1991:34) asserts that when

cures repeatedly fail, however, or when the explanations patently fall flat, we [sic] must confront again - with renewed seriousness, even desperation - the ever-implicit question of meaning. Moreover, pain, despite the myriad of implications it not only suggests always demands interpretation, like an insult, it seems to require an explanation.

If explanation cannot be found in biomedicine, the hermeneutics of pain concerns itself with the art and science of interpretation (Morris, 1991:33) whereby to be in pain may not only indicate underlying pathology, but also punishment for wrong doing by the gods, or suffering which must be endured to and for a greater end (Tu, 1980).

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Illich (1976) argues that the transition of pain as a traditional experience which implies the unique human performance called suffering to the medicalization of pain as a technical matter deprives the individual of the inherent personal meaning of pain experiences. Tu (1980) & Schrag (1982) discuss the many layers of meaning attached to the technical usage of the word pain by experts, which relegate the traditional understanding of pain to the background. This is an understanding which heralds pain as a challenge to the integrity of the individual; pain as an inevitable part of the subjective reality of one’s own body; pain as universal, constantly transforming in response to the individual’s reactions to it. Thus, this perspective demands a discussion of the need to suffer pain.

Suffering pain

The present perspective of pain and suffering intimates that pain may constitute suffering when it is overwhelming, uncontrolled, unexplained, or in some other way associated with a dire meaning which calls into question the continued, integrated existence of the personal self (personhood) (Brody, 1987:30). Cassell (1991) elaborates by advising that because modern medicine focuses exclusively on bodily pain, it ignores the multidimensional aspects of personhood and personal meaning, inadvertently increasing the suffering of patients while seeking to relieve it. This rests in the antiquated obligation of the doctor to relieve suffering (Szasz, 1975), although the issue of suffering receives little attention in medical discourse. It is also noted by Cassell (1991:31) that the sources of suffering encompass a number of issues. First, that suffering is not confined to the physical; second, that the individual suffers not only from the presenting issue, but the attempt to treat or remedy it; and third, that one
cannot anticipate the source or intensity of the suffering. Notably, Schrag (1982) asserts persistent pain sufferers experience suffering in all its forms.

For those caught in a life of chronic suffering, Pinder (1988) provides valuable insight into the experience of becoming "off-balance". That is, the attempt of individuals with persistent pain to deal with the resultant disequilibrium, caused by their pain on their life, by bargaining tangentially with themselves and with others. The relationship between the persistent pain sufferer and the balancing process signifies an inability to predicate their lives on the notion of an orderly, predictable and stable trajectory. This occurs because the suffering of persistent pain is always an event visualised in the possibilities for the future. Suffering becomes a state of severe distress associated with events that threaten the intactness of the person (Cassell, 1991). The inability to anticipate the future can create a world which is intolerably anarchic (Pinder, 1988:69). There is no taken for granted world! What becomes certain is that the health status and experience of the sufferer will change and readjust over time through negotiation and re-negotiation with the pain experience, roles, relationships and expectations as the pain suffer reconstructs everyday life in order to avoid, minimise, or otherwise manage their pain. However, the perceived threatened destruction of the person continues until the personal integrity of the individual is restored. This restoration extends to altering the experience of suffering and reviving the disrupted connectedness of the sufferer with themselves and with significant others (Cassell, 1991). From this it is evident that the person experiencing persistent pain without definitive diagnosis suffers most, because their pain represents a constant and recurrent attack on their personal integrity. Their fear involves their future: they must ground themselves in the present of coming to terms with the mundaneness of

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daily living. Hence, it may be suggested that the persistent pain sufferer's life is in a state of crisis, with their pain representing the opening of a huge vault or fissure precipitating the need to know what pain means and how to describe it.

The ability to describe pain is dependent upon the individual’s capacity to use language. Thus, attempts to understand the pain experience depend upon establishing a language which reflects not only a universal understanding for a singularly experienced phenomena, but an understanding which contextualises, and validates, the pain event of those who suffer it. Pain is subjectively and culturally derived, with divergent ideologies about pain, and health and illness affecting the embodied pain experience (Melzack & Wall, 1988:15; Fagerhaugh & Strauss, 1977).

The language of pain

Within any culture there is variability in the distribution and hierarchy of discourse. Thus, depending upon who makes a statement, that statement will be viewed as truth within that discourse (MacDonnell, 1986:2). Certain discourses have been structured such that the concepts of “truth” and “knowledge” are used to secure the power and prestige of that particular discourse, and this has been the case with medical discourse. Medical discourse has been able to maintain its place within society as representative of the only profession with indisputable authority to determine the significance of the pain experience. Foucault suggests that discourse is constituted through “discursive formations” which are underpinned by rules. These rules are derived from the social norms embedded in a discourse, and serve to give homogeneity to the discourse (Gutting, 1989:231). The speakers of statements unwittingly conform to these rules,
thereby promoting the perpetuation of the dominant discourse by ministering to the interests of those in power (Holmes, 1992).

In language, the words used, and their meanings alter from one discourse to another (MacDonell, 1986), so that meanings are embodied in technical processes, in institutions, and in patterns for general behaviour (MacDonell, 1986). Foucault’s analysis of discourse and language is invaluable when discussing the language of pain. Clearly, cultural mores are established and maintained through the discursive practices of the dominant discourse, whereby shared understanding of the 'locally shared cultural idiom' make sense of the pain experience (Kleinman, 1988:4) and standardise indisputable truths for the local cultural system, or discourse.

Pain, because it is an internal experience is always described in language. Language is a complex, learned and culturally determined behaviour which reflects and reifies the dominant discourse. Language as a powerful discursive tool has perpetuated the difference between mind and body processes. Shrag (1982) suggests that the opposing perspective on the epistemology of pain reflects modern philosophy's rational and empirical biases in relation to theories of knowledge. Thus, the vocabulary of pain is suspended between the objective and subjective sides of the phenomenon in such a manner that the language of pain displays an intrinsic ambiguity (Schrag, 1982). Furthermore, it is asserted that the biomedical model has created the construct of pain, trading on a distinction between pain experience, usually construed as a sensation, and pain behaviour (Merskey, 1990). Schrag (1982) terms this the linguistic-conceptual crisis of the vocabulary of pain. It is a crisis grounded in an epistemological inquiry relating to how someone know that someone is in pain and

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whether pain is a sensation, a behaviour, or both! If it is both, then which arises first needs explication in order to understand the implication of for accounts of pain. Moreover, the issue here is the lack of understanding of pain relative to its axiological and epistemological status. That is, no one will understand another’s pain unless they themselves have experienced it (Illich, 1976:141). Experience confirms that one is never more alone than when in pain: the sufferer is alienated from the discourse which shaped the pain experience. C.S Lewis (1962, cited Morris, 1991:51) succinctly states that no-one can experience pain as a collective sum no matter how much pain we witness, or imagine, we can feel only our own singular pain, much as a single glass can hold only one glassful.

Tu (1980) elaborates this position, claiming that as long as society seeks to place a universal perspective on the subjective nature of pain the meaning of pain will remain inexplicable. The dilemma for one researching pain originates in the constructed dichotomy of working with the separateness of sensation and behaviour and the purported disparity between the singular and the universal. Until pain is studied by a process which connects the personal and the cultural, that is the singular with the universal, a composite picture of the role of pain in the context of the life of an individual will remain elusive.

In summary, pain sensation and the language used to describe it is shaped by culture. Within cultures there exists a hierarchy of discourse, and in Western society the discourse of biomedicine, and thus its language, is valued above all else. This valuing of one discourse over another is maintained through discursive formations and normalised practices which validate the way in which individual’s cope with and

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ascribe meaning to their pain. Thus, it is clear that the language used to articulate the pain experience requires investigation in order to advance an understanding of pain experiences which cannot be reduced to the biomedical gaze, which has been constrained by historical precedence paradoxical for the pain sufferer.

3.4 SUMMARY OF LITERATURE

The review of the pain literature delineates the influences upon the pain construct, deriving from Pre-Christian, Christian and Post Christian periods. These influences include the ideation of pain as a natural phenomena, when the causative agent is visible; and pain as a manifestation of the magical, supernatural and spiritual in cases relating to the invisibility of the causative agent. These influences are reflected in the notion of the mind-body split. Coupled with the effects of the civilising process, they have shaped the construct of postmodern pain, that is pain is an experience which must be controlled, silenced and denied through medical diagnosis and cure.

However, it has also been suggested that the contemporary construct of pain does not present a clear cause and effect relationship. Personal experiences of the individual either enhance or detract from the ability to withstand pain. Pain is a function of the whole individual, not just minds and bodies, but real entities who exist in the world. They have present and past thoughts, perceptions, personal histories and hopes and dreams for the future. The advent of persistent pain in their life is something which needs to be contextualised and understood within the fabric of their being. Morris (1991:34) suggests that pain can only be understood and given meaning within the parameters of the eclectic social and personal systems of explanation.
For the persistent pain sufferer without the benefit of a consensual medical diagnosis pain is more than the sum of particular events which occur as a part of their pain career. Rather, their pain becomes immersed in a reciprocal relationship with their life. Thus, the trajectory of their pain assimilates with their being, becoming inseparable from their life course. Kleinman (1988:29) asserts that biography is an appropriate research method to study pain within the context of the persistent pain sufferer's life. This method allows the creation of knowledge relating to the personal world of the persistent pain sufferer, through unveiling the meaning of living with pain and an understanding of the complex inner language of hurt, and the desperation of living with illness.

The following chapter introduces and discusses the Interpretive Biographical method and its suitability for the study of pain as it is conceptualised in the life of the persistent pain sufferer, without a consensual medical diagnosis. The method, its variations and situatedness in relation to Dolby Stahl's Literary Folkloristic Methodology will be revealed.
CHAPTER FOUR

METHODOLOGY

4.0 INTRODUCTION

An understanding of pain, and the life stories of pain sufferers, presupposes that the sufferer is able to use a language which is shared and understood by all. Pain, an inner sensation and a perception, is always described in the language of experience. Language is a complex, learned and culturally determined behaviour which reflects the dominant discourse, and therefore articulates an understanding of pain which is shaped by the distinction between pain as a sensation and as a behaviour; sensation which may only be authenticated through, and by the use of language. Pain sufferers use language as a tool to convey their pain. That is, the form of language used by the pain sufferer translates their personal meanings of pain into a textual medium of, first the signified (voice), and then the social text or narrative. This text is again translated by the reader and the listener. Language as a social medium is established within the discursive elements of the dominant culture, and therefore by creating its understanding, legitimates pain as a cultural and personal experience which is encountered alone, but which also encompasses ubiquitous meaning.

Morris (1991) contends that the health care delivery to, and for, patients whose pain does not readily conform to diagnosis is fraught with innuendos of mental illness and deception, with patients knowingly being labelled, and made to feel like ‘whingers’, ‘bludgers’ or ‘neurotics’. Despite their verbal complaints of pain, the lack of medical diagnosis does not sanction and give legitimacy to their pain stories. This unwillingness to accept the patient’s story is embedded in medicine’s history and the

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culture in which it has been shaped. Historical, and consequently Western cultural influences insist that the amount and quality of pain experienced by a person is dependent upon detectable physical and physiological antecedents despite recent claims that the pain one feels is the consequence of personal experiences and the ability to contextualise pain in and on one's life. This is particularly significant in the case of persistent pain when one adopts pain as a career which entails abandoning a previous life plan and formulating a new one with persistent pain as the centrepiece (Brody, 1987:82). This abandoning of one's previous life marks a turning point in the life path of the pain sufferer as it is an acknowledgment of the importance of their pain when considering future prospects, highlighting the individual's experience of living with persistent pain, and it effects their independence, status, and relationships with others.

Pinder (1988) and McLean (1986) assert that the handling of encounters with others is clearly an interpretive process. The researcher defines the utterances of the pain sufferer and actively responds on the basis of these interpretations. There is an acknowledgment that all people have a past, with life experiences - illness, pain, relations with others, misery and pleasures which form the backdrop for their lives. Hence, the personal experience and meaning of pain, and its treatment arise from the past as well as the present.

Blumer (1962) expands this notion by suggesting an individual's behaviour is not simply the result of such things as environmental pressures, stimuli, motives, attitudes and ideas, but the interpretation and resulting actions. Hence, pain is not encountered as a timeless or universal phenomenon, but rather as anchored in specific times and
places which brings meaning to it (Morris, 1991). Moreover, it is not one simple,
single entity; its meaning is changeable in context and over time and therefore must be
interpreted and understood within the historical timeframe - theological, social,
economic, scientific, and psychological - in which it is being shaped. This
interpretation and subsequent action forms the fabric of the pain sufferer’s life and the
telling of the story, that is the narrative of their life. Hence, an event, which at one
time is dismissed as insignificant in the course of daily life, becomes subject to
reinterpretation. Through retrospection, the event may drop its original air of
meaninglessness, and at last exposes the origin of an unseen chain of events with
insignificant pain finally turning scandalous and terrifying, forcing some unwanted
transformation in the life of the sufferer.

It may be seen from the above discussion that an understanding of the role played by
pain in the life of the persistent pain sufferer would best be known through a
methodology which highlights the essence of the pain experience and the significance
of this experience to the life trajectory of the sufferer. The interpretive process and
more significantly ‘interpretive biography’, as described by Denzin (1989a, 1989b,
1989c), are such methodologies. The interpretive biography illuminates an
understanding of pain as a personal and cultural phenomena. The following chapter
will provide an overview of the biographical method and the chosen biographical
strategy used to provide a contextualised narrative of the life experiences of the
persistent pain sufferer.
4.1 THE BIOGRAPHICAL METHOD

The biographical method of research originated in the 1920s and 1930s in the School of Sociology, University of Chicago, and despite being foreshadowed by the methods based in the empirical sciences since, there has seen a resurgence in its methods in the 1980s and 1990s. A resurgence cementing with the establishment of the Biography and Society Group in 1986 (Denzin, 1989a; Plummer, 1983). Central to this resurgence was the view that expressions of human experience can be read as social texts (Denzin, 1989b). This view represents a historicist perspective in that meaning is seen as an historical event determined by the context in which it occurred and also by the historical situation. Similarly, it acknowledges that explanation is communicated via public language, while understanding is an intimate, experiential act, allowing for a multiplicity of meanings within the text.

The biographical method presents the experiences and definitions held by one person, one group, or one organisation as this person, group or organisation interprets those experiences. Biographical materials include any record or document which illuminates the subjective behaviour of individuals. A thorough transcription of an interview is one form of biography. This study will use the interpretive biographical method to contextualise and represent the life of the pain sufferer whose pain does not conform to the existing discursive view of pain.

The interpretive biographical method entails the collection and analysis of personal-life documents, stories, accounts or narratives which illustrate turning point moments in an individual's life, and are set in the lives of ordinary people. These turning point moments may occur within the broader historical, institutional and cultural arenas.
which encompass an individual's life (Denzin, 1989c). The experiencing of a turning point moment, its definition and its implications for the life fabric of individuals provides the focus of interpretive research (Denzin, 1989a, 1989b, 1989c). Simply, biographical methods are conventionalised, narrative expressions of life experiences. Summarily, these conventions relate to notions of the existence of 'other' and Elbaz (1987, cited in Denzin, 1989b:18) contends that the presence of 'other' in writing biographical texts means that they are written in a double perspective - that of the teller and that of the writer, with the perspective of the 'other' directing the pen of the writer. Moreover, the biographer makes sense of the teller's life bearing in mind that biographical texts are ideological statements which reflect or defend the position of the writer. Further, the biographer uses family beginnings and objective life markers to commence the biography, since the family represents the 'zero point' of origins in the teller's life and objective life markers reflect key critical points in the life of the teller which may become turning point experiences. In this research the biographer uses the recognition of the pain experience by the sufferer to mark the 'zero point' of origin of the pain experience. Simply, biographical method incorporates the exposition and understanding by which the "real" appearances of "real" people are created. Moreover, it is a literary technique for inscribing a body of experiences connected to the life of a given individual (Denzin, 1989a; Plummer, 1983). A life infers the biographical experience of a named person created and named in culture, and biographies are built around the core experiences of this person. Core experiences are those which have a significant and permanent effect on the life of a person, bringing about a resultant transformation or change in perception and or behaviour. Denzin (1989c:40) terms this the epiphany of a life. Epiphanies form the basis of personal experience stories. They occur in problematic situations, such as the
developing of persistent unrelieved pain, which need reconstruction and interpretation in order to glean understanding of the personal nature of culturally determined experiences. Hence, a focus on the epiphany attempts to unravel the complexities between the universal and the personal, because no individual is singular, rather they are representative of universal social experiences and social processes grounded in the historical moment which surrounds the person's life experiences. These experiences and their attributable meanings form the stories of an individual's life in a reflexive, interactive and dynamic way. They represent the ability of the human being “to endure, to prevail, and to triumph over the forces that threaten at any moment to annihilate all of us” (Denzin, 1989a:83).

The subject matter of the biographical method is thus the life experiences of a person. Smith (1994) suggests that when written in the first person, it is called an autobiography, life story or life history; when written in the second it is called a biography. This method relies on the verbal and written expressions of meaning, with these expressions providing the window into the inner life of the person (Denzin, 1989a:14). Derrida (1972:249), however, cautions that in biographical language, as in all language, there is “no clear window into the inner life of the person, for any window is filtered with the gaze of language, signs, and the processes of signification”. Thus, language is only a tool or device for creating texts, and so there never can be a clear, unambiguous statement of anything, including an intention or meaning. This issue is of particular significance to this study because in research relating to pain the researcher is only able to interpret and understand the pain of the sufferer in relation to personal referents and a standpoint shaped by the discursive practices of dominant ideologies.

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4.2 THE INTERPRETIVE PROCESS

The fundamental assumption which underpins this process rests on the significance of interpretation and understanding as key determinants in social life. Social life is comprised through individuals making interpretations and judgements about personal and other's behaviours and experiences. Thus, the subjective nature of interpretation and judgement often results in misinterpretation of behaviour and therefore erroneous understanding, or more confusingly behaviour which does not conform to accepted judgements of interpretation when another's experience is not your own, or your own is not another's experience. Hence, processes set in place to facilitate a particular understanding of one's experience are not appropriate when attempting to deal with the individual undergoing the experience. The interpretive process seeks to uncover each individual’s experience of their life and to bring understanding of their life experience as a result. Understanding has to do with the experience of other individuals and their minds and relies on the meaningfulness of all forms of expression in which experience is couched. This meaningfulness is bestowed on expression by interpretation (Maclean, 1986). Moreover, understanding is not an autonomous, ahistorical, human activity but a medium through which the world is interpreted, providing a basis from which one is able to characterise their being in relation to self and others. Bendelow (1993) suggests that there is a need to extend the construct of pain from the Cartesian proposition which inevitably acts to divorce mental from physical states and tends to attribute single reasons or causes for the pain experience to the notion that pain is an everyday experience linking the subjective sense of self to the perceived ‘objective’ reality of the world and other people, thereby allowing the discussion of feelings and emotions. Here, the world is a shared world, created and sustained by a shared understanding in the form of language. Thus,
understanding becomes linguistic, historical and ontological. Interpretation is now not an activity so much as a disclosure: in interpreting pain the researcher and the pain sufferer do not, so to speak, throw a ‘signification’ over some naked thing which is present-at-hand, rather when pain is encountered as something with-in-the-world, the experience already has an involvement which is disclosed in our understanding of the world.

The pain sufferer’s and the researcher’s understanding of the world is best described by the concept of the hermeneutical circle. This circle implies that in order for the experience of pain to be understood those concerned with experiencing the phenomena must have as pre-understanding of the concept in order to understand the concept. Odman (1988) explains this understanding as history. Pre-understanding functions as a structure through which understanding is re-experienced and re-examined. At the moment of understanding, pre-understanding and understanding are a dialectical entity, in which both parts and dependant upon each other. Interpretation, therefore, is never a presupposition, or an apprehending of something presented to us, but is founded on what we already know and our experiences of it (Maclean, 1986). Heidegger (1977) contends that interpretation places in the open what is already understood. Thus, the communal folklore of pain works in a dialectical relation with the private folklore of pain as one informs the other and vice versa. Melzack & Wall (1988) elaborate on this idea, asserting that pain is not only a highly personal experience, dependent on cultural learning, the meaning of the situation and other factors which are unique to the individual, but it is a communicative process seeped in the problem of semantics in which wide variation in interpretation and meaning and scientific verification misrepresent the experience as it is suffered. Jefferson (1986)
declares that there is no escaping the historical situatedness of understanding because understanding is the ontological ground of our being-in-the-world. Thus, meaning through understanding is not determined by the subjective intentions or utterances of the persistent pain sufferer, rather the linguistic system as a whole imparts meaning of the experience. Notably, McCaffery (1983) defines pain as whatever the experiencing person says it is, existing whenever she or he says it does.

4.3 VARIATIONS IN BIOGRAPHICAL METHOD

There are many variations of the biographical method. The life history is the generic form of the biographical method and all variations derive from it. The life history is an attempt to discover what happened and how something happened in the life of a person, a group or organisation. Contrastingly, a life story focuses on a life, or on a significant segment of life, as reported by the individual in question. It is therefore a personal narrative, a story of personal experience. The intent of the life story is to gain in a single sweep the objective and subjective experiences of one person’s life. It deals with fictions, and on this count differs from the self story (Plummer, 1983; Denzin, 1989a, 1989b). That is, standards of truth in biographies relate to facts, facticities and fiction: facts relate to events that are believed to have occurred or will occur, facticities describe how those facts are lived and experienced by interacting individuals, and fiction is a story which deals with real or imagined facts or facticities (Denzin, 1989a:23). Truth then is relational to the facts and facticities within acceptable ways of understanding the life world. Here, it may be assumed that a true fiction is in accord with dominant discursive practices, therefore it creates for the reader believable experiences (Denzin, 1989a:23). Thus, the truth of the story told is dependent upon the reader’s ability to identify with the story told.
Self stories are told by an individual in the context of a specific set of experiences. Self stories position the teller centrally to the narrative that is given. They are literal stories of an event or an experience. Self stories build on the notion that each individual is a storyteller of their own experience, an oral historian of their own life. Self stories, however, are also oral histories because oral histories are concerned with factual accuracy focusing on events, processes, causes and effects rather than on the individual, whose recollections furnish oral history with its raw data. Thus to collect self stories is to collect oral histories of the self. These self stories become personal narratives and take the form of what Dolby Stahl (1985) and Denzin (1989a) call “personal experience narratives”. Personal experience narratives are stories which people tell about their experiences and may be related to the traditional folklore of a group. Personal histories are the reconstructions of life based on interviews and conversations.

4.4 SELF STORY

A self story is a narrative which creates and interprets a structure of experience as it is being told, and they may be single or multiepisodic. Denzin (1989b:186) states that a self story is told by an individual in the context of a specific set of experiences. They are structured and simultaneously deal with the past, the present, and the future, unfolding in the telling, as the teller explains her or himself and the events of the story. The narrative draws on everyday experiences and identifies core, shared values of the narrator and the listener, which are then placed among broader cultural and ideological themes (Dolby Stahl, 1985:49). It uniquely creates an intimacy between the teller and the listener. Dolby Stahl (1985:51) contends that the teller and the

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listener connect selves in a context of shared and sharable experience. The story of
the persistent pain sufferer is a story which shares a sequence of events that are
significant for the narrator; it has a plot and makes sense to the narrator having a
temporal, causal sequence of events (Denzin, 1989c). The content of the story exists
independently of its telling.

This study uses the self story or personal experience narrative as outlined by Denzin
(1989a) and Dolby Stahl (1985) to develop an appreciation of the contextual
understanding of pain in the life of the persistent pain sufferer. The life trajectory of
the persistent pain sufferer from the point of developing pain to the date participants
attended the second interview with the researcher provide the scope of the personal
experience narrative captured for analysis. That is, the development of pain in the
sufferer, the recognition of pain as detrimental to daily life, and their subsequent and
ongoing attempt to find meaning for this pain; to final realisation that their pain is
persistent and unable to be located within diagnostic reasoning; and finally, to the
acknowledgment that their pain is their life. This causal sequence represents the
turning point moments in the pain sufferer’s life, which are termed cumulative
epiphanies because they result of a series of events that have built up in the sufferer’s
life (Denzin, 1989c). Thus, the self story is told within and about the experiences of
the persistent pain sufferer as it unfolds. The named person in this instance is the
persistent pain sufferer, whose persistent pain becomes the biographically meaningful
event, with experience occurring at the surface level and at a deep level. Deep level
experiences effect the person to the inner core leaving lasting marks upon them. The
experience, definition and intricacy of these deep level experiences in the life of the
individual is the focus of this research. Interpretive research attempts to synergise the
ongoing interaction of the pain sufferer, with the stories that come from their experience (Denzin, 1989c:42).

4.5 BIOGRAPHICAL ANALYSIS

There are several interpretive approaches to biographical analysis. This study will use Dolby-Stahl’s (1985) literary folkloristic methodology for a microcultural analysis and interpretation of interview transcripts of the persistent pain sufferer, and Denzin’s interpretive strategies (1989a:56) will provide a macro-cultural analysis of their stories. Thompson (1978) suggests that no self story will contain all the stories that can, or could be told about a single life. Thus a cross-multiple narrative drawn from the self stories of individuals located at different points in the process ensures that history, structure, and individual’s receive fair and thorough consideration in the research. That is, a single personal experience narrative may be presented and connected to a life story of a given individual. Second, a collection of self and personal experience stories may be collected and grouped to a common theme. Last, the researcher may attend to the process under study rather than the person whose life is enmeshed in the process.

4.6 TRUTH AND VALIDITY

The use of narrative to glean an understanding of the experience of living with persistent pain has connected the history of pain science and literature to the everyday life experiences of the sufferer to emulate the reflexivity which characterises contemporary inquiry, and furthers the postmodern deconstruction of tenuous boundaries among meanings which are embedded in Western medical discourse (Sandelowski, 1991). The conception of human beings as tellers of their own stories, and the producers of their own texts, signifies a chasm in which the analytical
problems of attempting to understand life events, epiphanies so to speak, may elude the conventions of objectivity and validity. Sandelowski (1991:161) deems these problems as ones relevant to the ambiguous nature of truth, the metaphoric nature of language in communicating putatively objective reality, the temporality and liminality of human beings' interpretation of their lives, the historical and social constraints against which individuals labour to impart information about themselves to other individuals, who in turn, labour to listen, and most significantly, the inherently contradictory project of making something scientific out of everything biographical. Narrative approaches to the study of lives reveal the extent to which these problems have been conditioned by empirical rather than narrative or biographical standards of truth and by a preoccupation with obtaining information at the expense of understanding expression (experience).

In the biographical context, the concept of truth (like the concept of cause) is reclaimed from the pure sciences. Biographical truth is distinguished from other kinds of pure science truths by its emphasis on a life-like, intelligible and plausible story. Denzin (1989a, 1989b) observes that a life story is a fictional, often literary, production, contrived from experience. Biographical truth is defined as an agreement within a community of minds with events believed to have occurred, facts, and with how these events were experienced by interacting individuals. Here, fictions are not meant to be truths in the narrative context, but rather they are truths within the stories which contain them. Narratives are truthful fictions, but fiction is itself linked to interpretation in that all interpretation involves human fabrication; that is the making out of what happened and the making up of what something means (Sandelowski, 1991). Moreover, the subjectivity of life histories is both a weakness and a strength. The weakness is often in creating a unreliable record of external facts; the strength is in illuminating an encounter between self, life course and society. Similarly, life histories or documents of life are not waiting to be taken: they have to be composed. Like snapshots, they are not panoramas but partial views; each story is constrained by
the purpose for which it is composed and, therefore, despite the immense histories of individuals only those pertinent to the crucial purpose of the narrative are included (Bellaby, 1991).

This research, in keeping with Bellaby’s (1991) perspective, is concerned with the display of ideas, beliefs and values inherent in the participants’ pain stories through shared language and systems of representation. The emphasis is on the social construction of issues which shape the context and experience of enduring persistent pain, without a definitive or consensual medical diagnosis, and thus link stories to the relative social positions of those who construct them, those to whom they apply, and the audience to which they are addressed. Self stories, as a part of life histories, meld the personal with the ubiquitous in order to illuminate apparently idiosyncratic features contained in personal stories to latent structure which are both cultural and social (Bellaby, 1991).

Storytellers in a remembering moment strive to achieve the most internally consistent interpretation of the past-in-the-present, the experienced present and the anticipated-in-the-present future. Located within the hermeneutic circle of interpretation and re-interpretation, stories with common elements may be expected to change with each telling, making the idea of empirically validating them for consistency completely alien to the concept of narrative truth (Sandelowski, 1991). Bruner (1986) contends that the preoccupation of the storyteller and the researcher is not how to know the truth, but rather how experience is endowed with meaning. Further, the interpretation of the teller’s text forces the researcher to first attend to what is placed immediately before them - the sufferer’s story of pain - before transforming them into descriptions

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and theories of the lives they represent. Riessman (1990) points out that narratives are always edited versions of reality, not objective and impartial descriptions of it, and interviewees always make choices about what to divulge. The narrative informs us, however, of what was paramount to the construction of the persistent pain experience in the research interview, and how sense is made of these experiences (Anderson, 1991).

Dolby Stahl's (1985) literary folkloristic methodology provides a framework in which the readings of pain stories account for meaning whether it be inherent in the text, or transmitted from the persistent pain sufferer to the researcher. This method is not preoccupied with the need to find and validate meaning, as an absolute truth, rather the existence of meaning and the coherence of the story told, in a historically determined setting, is paramount in uncovering first, the epiphanies contained within the story and second, the significance of identified epiphanies to the life trajectory of the persistent pain sufferer, without a definitive or consensual medical diagnosis.

4.7 LITERARY FOLKLORISTIC METHODOLOGY

Dolby Stahl (1985) contends that those using folkloristic methodology must comply with the following prerequisites. First, that the document to be analysed must be part of a life story or a personal experience narrative. The method must involve the researcher in its entirety. Second, the researcher undertakes the responsibility for hearing, listening to and interpreting the document. Third, the researcher must share the narrator's point of view. To see the world and its problems as they are seen by the individual living inside them. Fourth, the researcher must be knowledgeable in literary theory and critique in order to situate and deconstruct the story being told.
Last, the researcher must take full responsibility for the document which is interpreted.

4.8 CONCLUSION

In summary, interpretive biography provides an umbrella for understanding the experience of living with persistent pain. It is well suited to studying the presentation of self in everyday life, for storifying experience in a naturalistic form. This method does not fragment the text into discrete content categories for coding purposes but, instead, identifies longer stretches of talk that take the form of narrative, a discourse organised around time and consequential events in a ‘world’ recreated by the teller (Riessman, 1990). Moreover, interpretive biography, using literary folkloristic methods, has much to contribute to the study of persistent pain, focussing on naturally occurring texts of identity which emerge in the course of interviews. Telling stories is significant in that individuals, during the telling of their stories, make sense of disruptive events in their lives. Furthermore, beyond making meaning, examining the story told, and the story listened to, can illuminate the performance aspects of language.

The following chapter describes the use of Dolby Stahl’s literary folkloristic methodology as it is applied to this study. The steps of the methodology include:

1. locating of the subject within a given social category;
2. the identifying of salient themes and experiences in the participant’s life;
3. the connecting of the subject’s life history and life story to larger social meanings, including communal and private folklore;
4. understanding that the subject’s life story reflects a set of meaningful experiences which, when told create an emotional bond between the teller and the listener;

5. realising that the private, inner meanings of these experiences to the subject can never be fully illuminated;

6. interpreting the materials by sharing in the world of the experience of the subject;

7. bringing the interpretive approaches of literary theory and criticism to bear on the life story materials; and,

8. acknowledging that the researcher creates the document that is interpreted.
CHAPTER FIVE

METHOD

5.0 INTRODUCTION

This chapter discusses the framework for analysis of David, Steve, Joanne, Vince and Vicki's persistent pain stories. Analysis will entail two steps. First, each story will be analysed using Dolby Stahl's (1985, 1989) literary folkloristic methods. Second, a thematic analysis of all stories will be undertaken using Denzin's (1989a, 1989b, 1989c) interpretive strategies.

5.1 LITERARY FOLKLORISTIC METHODOLOGY

As I noted earlier Dolby Stahl (1985) contends that those using folkloristic methodology must comply with the following prerequisites. First, that the document to be analysed must be part of a life story or a personal experience narrative and that the researcher accept the responsibility of interpreting the text within its aesthetic

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context thereby involving the researcher in its entirety. Second, the researcher undertakes the responsibility for hearing, listening to and interpreting the pain stories told. Third, the researcher must share the narrator's point of view; that is, to see the world and its problems as they are seen by the individual living inside them. Fourth, the researcher must be knowledgeable in literary theory and critique in order to situate and deconstruct the story being told. Last, the researcher must take full responsibility for the document which is interpreted. In order to fulfil the requirements of Dolby Stahl's (1985) methodology the following steps need to be undertaken:

<table>
<thead>
<tr>
<th>Step One:</th>
<th>The location of the subject within a given social category.</th>
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<td>Step Two:</td>
<td>The identification of the salient themes and experiences in the participant's life.</td>
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<tr>
<td>Step Three:</td>
<td>Connecting the subjects life history and life story to larger social meanings, including communal and private folklore.</td>
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<td>Step Four:</td>
<td>Understanding that the subjects life story reflects a set of meaningful experiences which, when told create an emotional bond between the teller and the listener.</td>
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<td>Step Five:</td>
<td>Realising that the private, inner meanings of these experiences to the subject can never fully be illuminated.</td>
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<td>Step Six:</td>
<td>Interpreting the materials by sharing in the world of the experience of the subject.</td>
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<td>Step Seven:</td>
<td>Bring the interpretive approaches literary theory and criticism to bear on the life story materials.</td>
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<td>Step Eight:</td>
<td>The researcher creates the document that is interpreted.</td>
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The following discussion provides an overview of the steps to be undertaken in biographical analysis and interpretation pertinent to this research.

5.2 THE LOCATION OF THE SUBJECT WITHIN A GIVEN SOCIAL CATEGORY

This step entailed the identification of individuals suffering persistent pain without a consensual medical diagnosis, and gaining access to them.

Gaining Access

Participants were individuals who voluntarily wished to participate in the research. They were accessed from Pain Clinics attached to Belmont Hospital, Brisbane and centres dealing with pain management in the South Coast Health Authority region of Queensland, particularly from the People in Pain Group which met under the auspices of Queensland Community Mental Health, Environmental Health Services, Miami.

Participants’ names were gained from listings provided by clinic and support group enrolment. Initially, participants were approached by centre staff in order to ascertain interest in the research enterprise, and then personally by the researcher who explained the process and research requirements, addressed questions, gained consent and arranged subsequent interviews.

5.3 PARTICIPANTS

All participants were English speaking adults, three males and two females, between the ages of 20 and 45 years of age, and each had a history of chronic/persistent pain. That is, they experienced ongoing pain despite treatment or medical interventions, for a period of longer than six months, the accepted conventional time frame for terming
pain chronic/persistent. All participants had sought medical solutions for their pain, a response which continued to be implied by their visits to pain clinics and support agencies.

The delineating of participants as described in Chapter Two ensured that the researcher had identified and conformed to the categories and meanings used to define the research cohort.

Ethical Considerations

Ethical clearance was obtained from the University of Western Sydney’s Ethic’s Committee, Belmont Hospital and the South Coast Health Authority.

Informed Written Consent of Participants

The researcher contacted organising staff of the People in Pain (PIP) Group and Belmont Hospital in order to discuss the research to be undertaken, and staff were asked to initiate contact with the pain sufferer, in relation to participation in the research. The researcher visited each facility and discussed the research with each participant.

Each participant was given a full verbal explanation of the research by the researcher, including complete details of the duration of the research, time required from the participants, and the nature and aims of the research and the processes involved. This explanation was accompanied by a written Plain Language Statement (See Appendix One) and incorporated an opportunity for participants to ask questions of the researcher. Prior to commencement of the research each participant was given a three days ‘cooling off’ period in order to
reflect upon their involvement in and commitment to the research. Following this time, potential participants again met with the researcher and further opportunity provided to clarify issues. At the end of this session those who were willing to participate in the research were requested to sign a Consent Form (See Appendix Two).

This research safeguarded the human rights of all participants by adopting a number of strategies:

- Participants were clearly made aware that they were able to voice concerns, make comments or to withdraw consent at any time during the research without fear of penalty.
- Participants were made aware of their right to read transcripts of their interviews.
- During interview sessions participants retained the right to either cease the interview or to turn off the recorder.

The researcher provided privacy and comfortable surroundings during each interview. The offer of anonymity, via the use of a pseudonym was declined by each participant as each participant wished to be known by name. Confidentiality of each participant was protected by adopting the following:

- Audiotaped conversations were transcribed by someone external to the research. The external individual transcribing the tapes of interviews did not know any of the participants individually.
• The signed consent forms, transcribed interviews and all recorded data, will be held by the researcher for a period of five years following the completion of the research. This information is stored in a locked place to which only the researcher has access.

• No information about the participants will be revealed to people unless written authorisation is gained from participants.

• Participants in the research maintained the right not to be harmed during the course of the research. It was acknowledged by the researcher at the commencement of each interview that reflection upon personal experiences and treatments may cause the participant some distress, particularly when participants may feel that nothing is being done, or has been done in relation to their pain. Similarly, it was also acknowledged to participants that the opportunity of telling their pain story may be an uplifting experience. All participants stated that the interview, while physically a taxing experience, was uplifting because finally someone was interested in hearing their story. The researcher, however, was prepared for either response from participants and attempted to mediate and channel feelings in a positive way. Strategies for maintaining the safety of participants included:
  • the free access to research transcripts and the right to clarify and address issues transcribed.
• an acknowledgment by the researcher of subjective bias and an undertaking to be non-judgemental, open, empathetic and responsive to the needs of participants, without providing a false sense of security for participants in relation to acting as mediator with medical personnel or as therapeutic counsellor.

• the well being of participants was upmost to the research imperative

• interviews were prolonged, or curtailed in cases of pain exacerbation. Participants were provided with the opportunity for referral to appropriate supportive personnel, if deemed necessary or requested.

The steps taken to ensure the confidentiality and anonymity of participants complied with the ethical guidelines outlined by the National Health &Medical Research Council and the regulatory bodies of the University of Western Sydney, Belmont Hospital and the South Coast Health Authority in Queensland.

5.4 THE IDENTIFICATION OF THE SALIENT THEMES AND EXPERIENCES IN THE PARTICIPANT'S LIFE

This step entailed a process whereby participants’ stories of suffering persistent pain were listened to and recorded for interpretation in a mutually conducive atmosphere.

Data collection methods

Semi-structured interviews provided biographical data for analysis and interpretation.

Participants were required to participate in two interviews.
Interviewing

Semi-structured interviewing with open-ended questions were used to record the accounts of personal experience and self stories of participants as it was assumed that meanings, understandings, and interpretation of pain in one’s life cannot be standardised. Further, the style of interviewing, in keeping with the parameters set by Denzin (1989a, 1989b, 1989c) and Dolby Stahl (1985), took the form fashioned by Douglas (1985:15) and termed 'creative interviewing', whereby the storyteller and the researcher, in an egalitarian, trusting way creatively and openly shared experiences with each other in order to potentiate greater self understanding.

Interviews occurred at the discretion of the participant. For participants derived from the People in Pain (PIP) support group the interview occurred in their homes, with a one week interlude between interview one and two. For those participants derived from the Pain Clinic at Belmont Hospital the initial interview occurred in week two and the second interview occurred in week five of the programme. Interviews approximated two hours duration depending on the psycho-biological condition of the participant.

Initially, participants were requested to give their story, recounting a set of life experiences relating to the recognition of the search for meaning for their pain, and their consequent life trajectory. This self story, then provided the focus for the second interview, with the researcher asking the participant to expand on particular sections of the story, which had been identified by the researcher as turning point moments or epiphanies, a term employed by Denzin (1985) which will be expanded upon below.
Interviewing entailed the use of a tape recorder. Participants were informed of the same and consent was negotiated, and verbally recorded prior to each interview. Similarly, participants were informed that they would be required for a second interview and that both interviews would last approximately two hours.

The initial interview

At the commencement of the first interview participants were given a pictorial summary of the Chronic Pain Cycle (1992) and asked to locate themselves in relation to the pictures and captions shown (See Appendix Three). This picture was used as an icebreaker and to establish rapport with the participants. Next the participants were shown a depiction of a chronological life trajectory with the date of the initial interview marked on the right side. Participants were asked to identify a day/date when they began a search for the meaning of their pain. That is, a day/date which heralded a personal realisation that pain was not going to abate. These dates represented the beginning and end point of their pain stories. The progression of the interview revealed to the researcher significant dates and events pertinent to the participant’s pain story. These dates and events were then cross checked against the telling of the story in the transcribed text, remembering, as Sandelowski (1991) contends, that stories include a temporal ordering of events and an effort to make something out of those events, to render, or to signify, the experiences of persons-in-flux in a personally, culturally coherent and plausible manner.

Interview Questions

- *Are you experiencing pain at the moment*

- *Can you describe your pain for me?*

- *What were you doing? How did you feel about the pain?*

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• What did you do about the pain?

• How did you feel about the about the things (other) that were happening to you?

• Try and recall the period in your life when you first experienced/ noticed that you had pain.

• What is your understanding of the words chronic pain?

• Do you think that there is anything that can be done for your pain?

• How do you feel about the idea that they may not be able to do anything about your pain?

• How important is it for you that they find a reason for your pain?

• Can you recall how you explained your pain to the doctor on your first and subsequent visits?

• How do health professionals make you feel in relation to the pain you are experiencing?

• How do you cope with your pain?

• Can you tell me about your life since you developed pain?

• What triggers your pain?

• Can you recall times in your life when your pain was worse?

• What was happening in your life when your pain became worse?

• Do you think that your pain has had an effect in your life.
• Do you think your pain experience has had an effect on the lives of the people you live with?
• What are your hopes for the future?
• Can you describe your future for me?

The Second Interview

This interview followed transcription of audio tapes and an identification, by the researcher, of turning point moments or ephiphanies for the participant. The researcher returned to the interview to seek further clarification of the participant’s story. Each participant, prior to the commencement of the interview was given the opportunity to read their transcribed text and to make comment upon or alter stories if they felt that the transcribed text did not adequately reflect their position. Interestingly, all participants did not avail themselves of this opportunity.

Questioning

In keeping with Denzin’s (1989a, 1989b, 1989c) approach, the researcher commenced interviews using broad based questions relating to the participants’ demography, description of pain and the development of a chronology of each individual’s pain story. The beginning or recognition of the pain event as troublesome provides the zero point of origin of the context of the pain experience in the life of the sufferer. Because the chronicity of pain is non-ending, the end point of the story is set at the day of the second interview.

Each participant was asked to pinpoint significant dates between the dates provided. Askham (1982) asserts that interviewers rarely ask directly for a story, rather it is more appropriate for the interviewer to move backwards and forwards around an
event which is deemed significant by the participant. Thus, questions are phrased to refer to a specific time period (ie the two months prior to the development of pain; the day of your accident; the month after you noticed the development of your pain episode) and the participant is asked to fill in the events occurring during the specified time (Minichiello, Aroni, Timewell, & Alexander, 1990:118). Askham (1982:561) states that this process “artificially forces (sic) a story by setting its beginning and its end, and requesting the recounting of more than one event within these limits”.

Reflective Journal

The researcher maintained a reflective journal of personal impressions of pain, pain experiences and the shared understandings arrived at as a result of the dialogue between the storyteller and the interpreter. This journal facilitated the creation of an intimate relationship between the storyteller and the researcher, in fulfilment of prerequisites set by Dolby Stahl (1985). The assumption that intimacy is only possible between two people when a commonality of emotional and communicative development exists underpins literary folkloristic methodology. Dolby Stahl (1985; 1989) contends that personal experience narratives or self stories promulgate the intimacy whereby the storyteller is more able to express their “inner life” and share with the researcher some of the private folklore in their persistent pain experience.

5.5 CONNECTING THE PARTICIPANT’S LIFE HISTORY AND LIFE STORY TO LARGER SOCIAL MEANINGS, INCLUDING COMMUNAL AND PRIVATE FOLKLORE

No self story or personal experience narrative occurs in a vacuum. Stories are derived from larger group, cultural, ideological and historical contexts (Denzin, 1989a:73). The persistent pain sufferer’s story exists in the cultural texts of biomedicine and in
the shared histories with others who experience pain generally, and more particularly with those who are like the persistent pain sufferers, themselves. Denzin (1989a:72) asserts that to understand the events contained in a life, and thus its ephiphanies and subsequent self stories, one must penetrate and understand the larger structures, as they provide the fabric from which the story is shaped and told.

Comprehension of the persistent pain sufferer’s story entails the belief that language is a means of understanding what it is to be (Birch, 1989) and that understanding of the pain story is not simply a matter of the end-stopped, closed-off classification of a dichotomy between object and subject. Rather, in the attempt to connect the persistent pain sufferer’s story to larger social meanings, including that of the communal and private folklore of pain the researcher sets out to understand the whole of the story, or text, from its detail, and the detail of a text from its whole - the hermeneutic circle.

In order to do this the text must be read and re-read, with a final reading of the text being unachievable. From an interpretive perspective understanding is a dynamic activity, an interaction or dialogue which is never fully completed, never finished, never closed off. Understanding, therefore, is not an activity which people can perform; it is not something that is done, it is a part of being, of existence, of language. Gelven (1982:315) asserts language shows rather than tells. *Telling* concentrates on the idea of language as referential, *showing* concentrates on the idea of language as manifestation (Birch, 1989:7). Subsequently, the connection of the pain sufferer’s story to larger social meaning involves the viewing of text as a means by which teller/participant and listeners/reader/researcher share an effect not described
in language, but shown by a language. Thus, an idealised language is presented between two voices, each perpetually in search of, but unable to find or overcome, the other (Birch, 1989:8). This highlights the interaction, the struggle where meaning is not fixed, meaning is decentred and reality becomes a play of languages, where neither the voice of the participant or the researcher is ever determined as correct or incorrect. Viewing the text in this way recognises language to be social and institutional, acknowledging meaning as “a continual flickering, spilling and defusing of meaning” (Eagleton, 1983:134).

Lifeworld as backdrop

The concept of lifeworld, introduced by Habermas (1981a; 1981b), is succinctly defined by Holmes (1992:148) as a set of practices, skills, habits and stances that provide a set of enabling conditions for the operation of intentional states. These attributes as said to form

the backdrop of understandings against which actors and speakers, persistent pain sufferers, conduct their affairs, enabling and constraining performance, and reproduced through the medium of communicative action. It is the resource for interpretive and intersubjective tasks...a shared stock of interpretive patterns, and taken for granted certainties.. a pre-understood context that makes understanding possible (Holmes, 1992:148).

The backdrop may be said to equate with the idea of social system or more expansively with the notion of culture. Bascom (1965) asserts that the essential purpose of folklore, as backdrop, is to validate culture, educate and maintain conformity. Hence, the world, or the backdrop of the persistent pain sufferer forms a micro system, or private folklore of pain, within the subsisted of chronic pain which is given meaning and validated within the system of pain discourse, or the communal folklore of pain. The communal folklore of pain, in turn, is framed within the social
system of Western medical discourse. Holmes (1992) contends that the lifeworld, or social system gradually distances itself from subsystems as the focus of particular subsystems differentiate and evolve.

Diagram representing the interplay between lifeworld and subsystems of pain.

Western medical discourse

Communal folklore of pain (acute)

Chronic pain

Persistent pain without diagnosis

Private folklore

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In each instance, communication norms and behaviours are undermined and diminished. From this standpoint the private folklore of the persistent pain sufferer, by societal standards is acultural, because in culture and in language, pain is conceived as transient and curable. Thus, the inability to normalise the persistent pain experience within communal folklore, particularly by those who do not have a consensual medical diagnosis, consigns the pain sufferer to the solitary experience of attempting to account for their pain within the confines of a discourse which abnegates their experience. This attempt leads to repeated failure, and further alienation from society which has constructed pain in language and behaviours. Further, the referents for pain do not augment sufficiently to ease the dilemma for the individual who is unable to find relief for their circumstance. Similarly, sanctions which normally apply in pain folklore are premised by the notion that pain is acute and treatable.

Persistent pain is not a series of *acute pain episodes* and it is impermissible to moan persistently. Thus, the sub-culture of the persistent pain sufferer, and consequently the development of private folklore relating to this experience, is used to bond such individuals, and exclude non-sufferers. This sub-culture comes to exist as a consequence of the acultural dimensions of persistent pain in Western society. Moreover, a home is provided for persistent pain, without consensual medical diagnosis, in culture and an appreciation that the persistent pain experience fundamentally alters the entire experience of living, and the sufferer's conception of their affliction and their *self*.
Williams (1988) describes the complexity of culture as the dynamic interrelation between processes termed the residual, dominant, and emergent. The Western Medical System is a significant generalising description which exerts influence on culture as a whole. The residual is, by definition, effectively formed in the past, but is still active in the cultural process, not only and often not at all as an element of the past, but as an effective element of the present. Hence, certain experiences, meanings, and values which cannot be expressed or substantially verified in terms of the dominant culture or social system, are nevertheless lived and practised on the basis of the residual, cultural as well as social elements, of some previous social and cultural institution or formation. A residual cultural element is usually placed at some distance from the effective dominant culture, but some part of it, which is useful to the dominant culture, is incorporated for the dominant culture to make sense. However, the dominant culture cannot permit too much residual experience and practice outside itself without risk. Thus, meaning and values which are created in actual situations in the past, and which seem to have significance because they represent areas of human experience, aspiration, and achievement of the dominant culture may be neglected, undervalued, opposed, repressed, or not even recognised. Similarly, meaning and values may incorporate the actively residual by reinterpretation, dilution, projection, discriminating inclusion and exclusion enabling the work of a selective tradition to be especially evident (Williams, 1988). This notion is elaborated by Hilbert (1984) who suggests that contemporary pain folklore is underpinned by the belief that pain will eventually dissipate. When pain fails to respond to treatment, sufferers must assemble resources extrinsic to accepted pain folklore in order to organise, understand and bring meaning to their pain experience, and most significantly to define the role of pain in their life. Hence, the social meaning of residual is always easier to understand given

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that meaning is largely ascribed to social formations and phrases of the cultural process in which certain real meanings and values are generated.

Text and discourse

Michel Foucault (1972) asserts that a text is produced as the result of discursive formations which are intrinsic to the ideological system of a society. Discourse is a social process; its subjects are ‘interdiscourses’ determined by an array of discursive practices which are determined ideologically and politically. Thus, a text is only considered to be understandable in terms of the larger discourse. Accordingly, the discourse of pain is indicated by formations which extend beyond individual pain stories. Hence, literary analysis through deconstructive enterprises is a political activity because this analysis is involved in power, and power is immanent in discourse.

5.6 UNDERSTANDING THAT THE SUBJECTS LIFE STORY REFLECTS A SET OF MEANINGFUL EXPERIENCES WHICH, WHEN TOLD CREATE AN EMOTIONAL BOND BETWEEN THE TELLER AND THE LISTENER.

Dolby Stahl (1989:1) states that

Literary folkloristics is an integrative criticism which identifies the many private or collective traditions that function as meaningful allusions in the reader or listeners interpretation of a literary text. Exploring the relationship between these traditions and the listener/reader’s (researcher) interpretations of the text is the objective of this kind of criticism. Its aim is to demonstrate how specific textual interpretations evolve, given interpreters of a literary text.

It is the listener who identifies the traditions, and it is the experience of hearing the text that is translated into an interpretation (Dolby Stahl:1985, 1989). Hearing of the text is twofold: first, the researcher hears the story as it is told; second, the researcher hears the story through aural recording. However, accurate interpretations of the text
are only possible if, in the telling and hearing of the story, the researcher is able to create an emotional bond with the participant. This emotional bond is created prior to and during the interview and Dolby Stahl (1985, 1989) calls this the establishing of intimacy, that is, a desire for familiarity, a desire to know someone else and to be known in return.

In the establishing of intimacy the researcher clarifies the participant’s motivation for involvement. It is claimed by Denzin (1989a, 1989b), Dolby Stahl (1985, 1989) and Riessman (1990) that it is during the interview process, as in the rest of social life, that language as the major cultural resource draws on shared experiences and constructed meanings to create reality. Thus, a particular self is constituted and portrayed in the relationship developed through intimacy.

Simply, it is acknowledged that pain stories were told because persistent pain sufferers wanted to be listened to. In the telling of their pain stories they offered the researcher an invitation to intimacy. Dolby Stahl (1989:28) contends that this offer for intimacy is particularly real for people who grow up in our lonely culture. The intimacy developed between researcher and participant is notable in that the telling and listening to each participant’s pain story provides one way in which participants enjoy intimacy without recourse to the rights that are assumed to come with family or group membership. Not surprisingly, the participants in this researcher were eager to share their pain stories, articulating that in most cases it was the first time anyone had voiced an interest in their pain. Dolby Stahl (1985:15) concurs stating “the problem is that the people who most need and want to tell their stories often feel that no one

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wants to listen”. Further, it is contended “it requires a certain boldness to tell such stories; it requires human affection to listen”.

To sum up, it is the interplay of shared culture and experience and the unique events, within the pain story that allows intimacy to grow. At the instant the persistent pain sufferer begins a story, the interaction with the researcher is strategically significant because this discourse form draws the researcher most fully into the immediacy of the teller’s world, and into their point of view. Hence, the interview uncovers quintessential moments, and depicts events which are critical to the teller’s sense of him or herself.

The development of intimacy ensures that the teller does not experience the perception of being devalued by the researcher because this is representative of their lived experiences (Hilbert, 1984; Bendelow, 1992). Past experiences of feeling devalued frame a life where the sufferer has not been ‘taken seriously’, not been ‘treated as a credible person’, and not been listened to (Anderson, 1991:48). Thus, the emotional bond created in the telling of the story must induce a feeling of worth and acceptance on part of the researcher as this will have bearing on how the story is told and, thus, how the life of the teller is restructured.

5.7 REALISING THAT THE PRIVATE, INNER MEANINGS OF THESE EXPERIENCES TO THE SUBJECT CAN NEVER FULLY BE ILLUMINATED

Interpretive biography, and subsequently literary folklorisitic methodology, more than any other form of discourse, effectively pulls the listener into the teller’s point of
view. The persistent pain sufferer's story portrays a slice of life, often by dramatising and re-enacting a particular interaction; that is, the advent of pain in their life and the circumstances which represent turning point moments in their life trajectory, thereby providing 'proof' of how it is to live with pain. Through the process of intimacy, the listener/researcher is drawn so deeply into the teller's experience that often a kind of intersubjective agreement about 'how it was and is', is reached. Dolby Stahl (1989:10) contends that literary folkloristics assumes that the hearing of a text is a creative act in which the researcher/listener's own large store of cultural and personal resources is used to produce a unified resonance of meaning.

Barthes (1972) asserts that a text is not written in a vacuum, rather the text is an expression of the cultural and literary experiences of the reader, which either subvert or endorse the cultural of literary norms of reading. Thus, it is contended that the literary text, or transcribed interviews, be regarded as expressions of the psychology of an individual, which, in turn, are an expression of the milieu and period in which the individual lives. Hence, the text will be likened to any other social institution and viewed as changing in character and function, in step with the society that produces it. Further, assumptions which underlie not only the naturalistic paradigm for conducting research, but literary folkloristic methods are grounded in the belief that individuals live within the dynamic of multiple realities which are constructed, interactive and inseparable. Therefore, statements made by persistent pain sufferers are time and context-bound (Lincoln & Guba, 1985:47). However, within this methodology the quest to discover the author's (participants) true intention is not central to providing an authentic interpretation of the text. Maclean (1986:122) asserts that
a preoccupation (to) find and validate meaning necessitates a dualism between that which is correct and therefore justifiable as a text or the actuality of meaning and coherence in a historically determined setting devoid of absolute values and truth
Barthes (1977:160) succinctly describes this as “the death of the author and the birth of the reader”.

The act of reading is an interactive process between the text and the researcher where intersubjective meaning is constructed between the sender of the linguistic message and the receiver of the message. Within literary theory the transcription of interview tapes is regarded as communication. The participant sends a message to the researcher which has been converted to the medium of literary text. The message text is about something, vis a vis content and reality. Further, the literary text is designed to be a specifically motivated form of discourse: that is, it has something to say (the interview tapes have been transcribed because the participant is telling a story that the researcher wants to hear) and is the medium for this communication. Simply, the author/participant sends a literary text about reality to the researcher/reader in language. Importantly, Barthes (1972) contends that the reading of a text consists in actively constructing a meaning for the text and not in passively deciphering the meaning. The plurality of meaning in a text is the logical consequence of the absence of any authorial intention in literature. Thus, the researcher’s intention is to produce an interpretation which realises just one of the possibilities contained within the plurality of the text. Accordingly, it must be acknowledged that the inner meanings of experiences for the persistent pain suffer can never be fully illuminated and that any reading of a text requires the researcher/reader’s active cooperation in its production (Jefferson, 1986). In consequence, any attempt at interpretation by the reader must confront the paradox of a permanent, ahistorical framework of rationality, knowledge, truth, reality, right or wrong, good or bad and the contrasting view that there is no such framework which provides for absolutes. This premise is referred to as the
objective/subject debate, with the former arguing that there is only one correct meaning and the latter accepting a plurality of meaning. This latter view represents a historicist perspective in that meaning is viewed as an historical event determined by the context in which the event occurred (Maclean, 1986). Similarly, the objective/subjective dilemma effects the process of understanding. That is, from an objective standpoint understanding is the result of clearly demarcated causal explanations. But, significantly, explanation is communicated via public language, while understanding is an intimate, experiential act. This problem is exacerbated by the issue of universal, public descriptions of the unique and the private. This is a problem for the persistent pain sufferer. Notably, the legitimation of interpretation is tantamount to the vexing issue of legitimising the persistent pain experience.

A deconstructive reading of participants’ pain stories attempts to illuminate the logic of the text’s language as opposed to the logic of the author’s claims. It teases out the texts implied presuppositions and explicates the inevitable contradictions in them (Jefferson, 1986). Thus, a deconstructive reading will take the logocentric oppositions at work in the text, revere them, and then question them in such a way as to neutralise them. Subsequently, the aim of deconstructive criticism to give voice to the silences inherent in the text, that is to make problematic taken for granted understandings through the posing and answering of questions in a number of different ways.

Deconstruction

Deconstruction is a powerful expression used to describe a critical practice which rejects traditional ideas which assume that literary texts, transcribed interview documents, are structures of determinate meaning accessible to objective critical
procedures (Raval, 1986). Derrida (1972) asserts that the status of a text cannot be determined by its boundaries, as no text is ever finished; meanings are never completed either by the authorial completion of the text, or by the determination of the author's intent to fix a final or single meaning. Birch (1989) elaborates, commenting that language is a means of understanding what it is to be (Birch, 1989:5). Understanding is not simply a matter of end-stopped, closed-off classification of a dichotomy between object and subject. Analysis sets out to understand the whole of text from its detail, and the detail of a text from its whole - the hermeneutic circle. In order to do this the text must be read and re-read with a finite reading of the text being unachievable. From an interpretive perspective understanding is a dynamic activity, an interaction or dialogue between the text and the reader which is never fully completed, never finished, never closed off. As noted earlier, understanding, therefore, is not an activity which people can perform; it is not something that is done, it is a part of being, of existence, of language. Gelven (1982) asserts language shows rather than tells. Telling concentrates on the idea of language as referential, showing concentrates on the idea of language as manifestation (Birch, 1989:6). Accordingly, questions about the text demand other questions, resulting in a movement of effacing and forgetting. The significance of forgetting is crucial, because this phenomena sets up a dialectic, between a state of knowing and a state of not-knowing, an indeterminacy about meanings and knowledge which is crucial to the theory of deconstruction (de Man, 1975).

The deconstructivist enterprise, rather than relying on the inflexibility of signification, sets up what appears to be firm readings of text by emphasising the silent voice contained within the text. Derrida (1972) offers the notion of intertextuality, whereby
one text reads another without the final resolution of finding true meaning in a particular said text. Deconstruction from this perspective, is aligned not only with specific literary or philosophical texts, but also the deconstruction of philosophies and institutions (Birch, 1989). Here, the deconstructive approach allows the researcher to interrogate “the linguistic means by which a text, or discourse comes to exercise its power” (Norris, 1980:282). Thus, the idea of interrogation is important to the deconstructive approach because central to this enterprise is a questioning of the underlying assumptions of a text. The reading of a text is a powerful political activity because an interrogation of the text illuminates not simply the linguistic structure of the text, but the ideological, philosophical, economic, and historical practices of the text (Birch, 1989). Michel Foucault (1972) asserts that a text is the result of discursive formations which are intricate in the ideological system of a society. Thus, a text is only considered to be understandable in terms of the larger discourse. Here discourse indicates formations which operate beyond individual language texts (the discourse of pain). This discourse can be read as text. Birch (1989) contends that an analysis of discourse, and of the discursive practices which originate text is, thus, an analysis of history, because history may be constructed as a series of discursive practices, each with its particular ideologies and ways of controlling power. Hence, there is nothing outside the text because the text is inclusive of not only words, but the signifying practices and structures of representation beyond the text (Derrida, 1972). This emphasis on political activity flags the deconstructive approach as significant to the development of “showing” the text of Western medical discourse which, it may be said has represented a distorted and stereotypical picture of ideas, treatments and management of pain.
Through a deconstruction of pain stories the researcher interrogates the text to show their distortion. Said (1978:5) contends that "the process of deconstruction demythologises the text by using the tools of Western scholarship against itself" by questioning the assumptions at the base of the text in order to question the ideology behind the text. Thus, the life world of the persistent pain sufferer is illuminated.

Analysis is the viewing of text as a means by which writer/participant and reader/researcher share an effect not described in language, but shown by a language. Thus, an idealised language is presented between two voices, each perpetually in search of, but unable to find or overcome, the other (Birch, 1989:7). This highlights the interaction, the struggle where meaning is not fixed, the subject meaning is decentred and reality becomes a play of languages, where neither voice can ever be determined as correct or incorrect. The effect of textual analysis is to recognise language as social and institutional, not only the individualistic internalisation of meaning, and to acknowledge meaning as ever-changing and contextual (Eagleton, 1983).

5.8 INTERPRETING THE MATERIALS BY SHARING IN THE WORLD OF THE EXPERIENCE OF THE SUBJECT

Dolby Stahl's (1989) steps four to six incorporate the analysis and interpretation of pain stories. Dolby Stahl's (1985) and Denzin's (1989c) method of biographical analysis presuppose that the researcher is an "informed reader". The informed reader is one who knows the language being used in the story; knows the biography of the storyteller, albeit partially; is able to take the teller's perspective in the story; is willing to take full responsibility for their interpretation of the story; has to some extent
experience of the experiences contained within the story; is conversant with a range of Interpretive theories which will have significance for the story being told; and, knows that meaning is created by the reader and that there is not one true meaning for the story. Denzin (1989a:52) aptly summarises that premise stating that the story told is never the one heard!

5.9 BRING THE INTERPRETIVE APPROACHES OF LITERARY THEORY AND CRITICISM TO BEAR ON THE LIFE STORY MATERIALS.

Dolby-Stahl (1985) asserts that the biographical method must use strategies for literary interpretation and critique. The biographical method necessitates that the contexts and frames of reference of the storyteller are considered in the reading of the text. This research uses an understanding of hermeneutical inquiry, Marxist literary analysis, the feminist’s use of the concept of resistance, and Foucault’s description of power to enable a sharing in the experiences of pain participants, thereby creating an interpretation which is both grounded in the personal and the cultural. The following provides an overview of literary theory analysis and the applicability of the theories used to interpret persistent pain stories.

5.10 LITERARY THEORY

Jefferson & Robey (1986) assert that the purpose of literary theory is to illuminate and call into question the relationships between critical and scholarly practices in order to challenge the established forms of those practices. Accordingly, literary theory may view the text from a range of perspectives and that in most circumstances theories will concentrate on some elements of the text to the exclusion of others. They, therefore, suggest that it would be appropriate to define a set to questions to be asked of any theory of literature. These questions may include: What is the relation between text
and author? What is the role of the reader? How does the theory view the text and reality, and what status does it give to the medium of the text language?

For the purpose of this study literary theory encompasses the sentiments of both criticism and scholarship, focusing on the experience of reading the transcribed texts of participants. Thus, the life experienced by persistent pain sufferers will be seen to consist of the feelings, images, sentiments, desires, thoughts and meanings known to the person whose life it is, a life as told is a narrative, influenced by the cultural conventions of telling, by the audience, and by the social context. The reading of texts allows one to undertake reading of the text for specific purposes. Thus, this study is concerned with describing, interpreting and evaluating the meaning of living with pain as the story is heard and read. It makes problematic, taken-for-granted understandings of pain and the menagerie of experiences which accompany its development through the posing and answering of questions in a number of different ways.

5.11 MARXIST LITERARY THEORY

Marxist criticism is broad in scope and more focussed than other forms of literary criticism because it endeavours to combine textual analysis with the study of social and historical contexts. Today, Marxist analysis is concerned with the ideological function of literary forms and the prevalent interconnection between textual specificity and supposedly extra-textual matters such as the reproduction of social power (Macherey 1978; Eagleton, 1990).

Marxist theories differ from other theories of literature in the following ways. First, social reality is not viewed as an indistinct background from which literature emerges
or blends. Reality is considered to have a definite shape which is formed as a consequence of its interface with history, rampant with series of struggles between antagonistic classes and the modes of production in which they engage (Forgacs, 1986). Moreover, reality is not static, it is the result of a determinate interplay or dialectic between particular class relationships and particular political, cultural and social institutions as they are related to the system of economic production. Seldon (1989) asserts that culture is inseparable from the historical conditions in which humans create their material lives; the relations of dominance and subordination (exploitation) which govern the social and economic order of a particular phase in human history and which in some way will determine, not cause, the whole cultural life of society. Hence, culture is a field of struggle in which the meaning of the social world is at stake. Cultural signs are transversed by conflicting interests in an attempt to control them for their own ends.

Second, Marxist literary theory is underpinned by the assumption of base and superstructure. Forgacs (1986:167) purports that one of the major distinguishing features of Marxist thinking is the emphasis placed on the socio-economic element in any society as an ultimate determinant of that society’s character. Here, ‘socio-economic’ refers to the social relations created by the means of production in a particular society. In a capitalist society, this is the relationship between the employer and the employee, which is believed to be embedded in exploitation, and therefore a source for potential or actual conflict (Forgacs, 1986:168). Thus, the basic economic structure (base) creates a number of social institutions and beliefs which act to regulate or dissipate the imminent conflict and keep the mode of production intact. Western capitalist economies have a number of structures in place to support the
mode of production. These institutions and values uphold the mode of production and form the superstructures of a particular society. Superstructures interact with, and are influenced by historical change.

Contemporary Marxist thinking suggests that changes and forces within the superstructure influence the dynamics of the base. From this standpoint the positioning and dynamic of the superstructure is significant given that literature is placed within the superstructure of society (Forgacs, 1986; Williams, 1988). Thus, a recognition of the contradictions which exist within society and the dialectical nature of ideology on base and superstructure must be considered in relation to the historical and social interpretation of literary texts (Newton, 1988:85). Moreover, it is contended by Macherey (1978:133) that contradictions within the text may also be exposed by silences within the text because societal ideology makes it impossible to speak. These textual absences are symptoms of ideological repressions of the text’s own unconscious. Here, the aim of Marxist criticism in relation to pain stories is to make these silences ‘speak’ and to reveal the texts inherent ideological flaws, stresses and incoherence.

Third, the concept of ideology and its dialectical relation within the literary text is significant in Marxist literary analysis. The term ideology conveys a sense of collective representation of ideas and experience as opposed to the material reality on which experience is based in order to establish consensus in society. Abrams (1993) asserts that ideology, to those who live in and with it, seems natural and an inevitable way of seeing, explaining, and dealing with the environing world. Althusser (cited in
Seldon, 1989:40) contends that ideology is “a representation of the imaginary relations of individuals to their real conditions of existence”. It is suggested that ideology is normally lived as if it were totally natural, as if its imaginary and fluid discourse gives a perfect and unified explanation of reality. (and that) once it (ideology) is worked into a text, all its contradictions and gaps are exposed (Seldon, 1989:40).

Significantly, Althusser asserts that ideologies alter in relation to the form and practices of each mode of state apparatus (institutions which maintain the dominant ideology within the superstructure) which operate through the means of interpellation which requires the individual to acquire pre-established subject positions which, in all cases, serve the interests of the ruling class (Abrams, 1993:244).

Eagleton (1988:247) contends that the literary text is a product of ideology, whereby the relation between text and production is a relation or labour in which the instruments of reading and writing transform the text into a specific product which reveals the text’s ideological relations to the world in which it is produced. History is present within the text as ideology. It operates upon the text by an ideological determination which, within the text itself, privileges ideology as a dominant structure determining its own imaginary relations to the real within the text. Forgacs (1986:169) postulates that if ideology is a representation, so too is literature. Eagleton (1988:249) elaborates this view stating that the text is a tissue of meanings, perceptions and responses which inhere in the first place in that imaginary production of the real which is ideology. The textual ‘real’ is related to the historical real, not as an imaginary transposition of it, but as a product of certain signifying practices whose source and referents is, history itself.

Thus, it is purported that although ideology pre-exists the text, the ideology of the text is produced in two ways: first, objectively, between the text and ideological
influences. Second, by the relation as subjectively flaunted, concealed, intimated or mystified by the text itself. Furthermore, Eagleton (1990:72) asserts that literature is the most revealing mode of experiential access to ideology because it appropriates the real as it is given in ideological forms, but does so as an illusion of the real, such that it dissolves the modes of production into the 'concrete life' which is their product. Thus, the literary text appears as a natural object, denying the determinants of its productive process. Thus, the truth of the text is not an essence but a practice - the practice of its relation to ideology, within a particular social and historical context. Williams (1988:241) asserts that the aesthetic of the truthful depiction of reality is central to Marxist literary analysis, whereby an accurate account of reality is a contribution - whatever the subjective intention - to the Marxist critique of capitalism.

Herein lies the importance of Marxist literary analysis in understanding the character of the dominant ideology. That is, no mode of production and, therefore, no dominant social order and, therefore, no dominant culture ever in reality includes or exhausts all human practice, energy and intentions (Williams, 1988:245-6). The development of the concept of social formations significantly enhances Marxist literary theory because it makes possible the view of a decentred literary text. Social formation are structures in which various aspects of structure exist in complex relations of inner contradiction and mutual conflict. Consequently, the economy is viewed dialectically as the circulation of commodities, whereby circulation is only an ideological representation of relations between people - workers and bosses; health care providers and persistent pain sufferers - where surplus value is extricated from the interaction between both. This relation between individuals exists on the premise of commodification, a process in which individuals have labour power to sell, but lack everything necessary for the

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realisation of this attribute. Bottomore & Rubel (1973:26) assert that this relation has no natural basis, but is the result of historical developments, the product of many economic revolutions and from the discontinuance of older forms of social production. Forgacs (1986:169) elaborates this view postulating that representations are ideologically based, and therefore prevent individuals from perceiving the contradictions between classes, or discourses, in which they are subjectively formed. Subsequently, the world of objects displaces the individual and value is reduced to commodity value and the domination of the human world by a world of objects. A concern for, and the autonomy of, the individual is lost in the massive and monolithic market-system leaving the individual alienated from the world if they are unable to identify with the mode of production, as valued by the dominant discourse. Moreover, the modes of domination actively exclude a wide range of human practices and experiences by effectively defining that which is acceptable in the social and cultural.

Accordingly, a Marxist analysis is mandatory to the understanding of pain stories because this perspective analyses the reach of dominant ideological practices into the social order and the reflection of the order on cultural and social processes. Thus, within this perspective the process of production forms a singular social act, and the product is only valued in so far as it is of use to the society with produces it. In this society, therefore, the individual is only valued in relation to fulfilling role obligations within the means of production. Thus, the individual must be seen to have direct and verifiable impact on the life of the culture/group in which he or she resides (Williams, 1984:91-3).
To sum up, this research uses a broadbrush approach to Marxist literary criticism. It melds the concept of the interrelationship of culture and cultural products with the role played by ideology in determining an understanding of the literary text (Newton, 1988; Eagleton, 1990). Marxist theories of literature have a simple premise in common; that literature can only be understood within the larger framework of social reality (Forgacs, 1986) and any attempt to divorce literature from the society and history in which it is formed will render the same deficient. The literary critic attends to the text’s unconscious - to what is unspoken and inevitably suppressed.

This perspective is significant to the reader of the persistent pain sufferer’s story because it develops an understanding of the private folklore of the persistent pain sufferer, whose pain by societal standards is inexplicable.

5.12 MARXIST CONCEPTS RELEVANT TO SELF STORIES

In order to establish the relevance of particular Marxist concepts for understanding pain stories a discussion of the interplay between key concepts needs development. Fundamentally, Marxism suggests that there is a relationship between the forces of production and the relations of production, and that this relationship is fraught with conflict and contradictions owing to the disparities in power relations inherent in the relations of production. The relations of production exist in a dialectic with the superstructures of society, which in turn influence and are influenced by the base structure. Thus, the place of individuals in society necessitates exploitation and oppression by those who own the means of production of those who are defined in relation to the labour they have to sell. This situation is compounded by the pervasive effects of ideological representations which further alienate the individual from the
means of production and a consciousness which permits maximisation of human potential.

To sum up, within Western society an individual must effectively function and cooperate within the social relations of production. This is done by the individual actively selling personal labour in return for a monetary recompense. In the case of individuals who are unable to perform this function, due to incapacity, there is an expectation that following a period of time and the individual’s motivation to be well, the individual will return to work. If the incapacity persists, society deems that the individual will seek professional help in order to return to work. This may be achieved through cure of an ailment or adaptation to the problem. If the individual is unable to return to work they are labelled bludger or malinger. In the case of the persistent pain sufferer, without a consensual medical diagnosis this is intensified because in most cases the suffer is unable to return to work or find reason or cure for their pain. In a society which defines one’s worth by the work one does this precipitates feelings of despair, hopelessness, poor self esteem and ultimate alienation from the society which defines not only who one is, but the pain experience. Thus, people find fewer resources in their environment and culture which can assist them in coming to terms with their suffering. They are, therefore, forced into further dependence on medical expertise and specialisation. It becomes a case of: I’ll help--I can’t--help Yourself!
5.13 IDEOLOGY (FOLKLORE)

Human consciousness is constituted by ideology. Ideology describes the beliefs, attitudes, and habits of feeling and behaviour that a society inculcates in order to generate an automatic reproduction of its structuring premises (Waitzkin, 1991; Shilling, 1993). Ideology, is that which preserves social power through culture in the absence of direct coercion. Marxist ideology maintains that it is through a covert alliance with the legitimising position, power, and economic interests of the ruling class that a particular ruling class is maintained (Hahn & Kleinman, 1983; Eagleton, 1988; 1990). Here, literature as an ideological tool, which promotes the imaginary relation to one’s material condition of existence, consists of strategies of containment which seek to prevent a full understanding of social totality. However, despite an attempt to appear self-evident, literature will always illuminate the fissures and contradictions within that which it tries to conceal, because it cannot refrain from describing the problems it attempts to resolve (Abrams, 1993).

This research will examine the dialectic nature of ideology and pain folklore. It is the contention of the researcher that a rhetorical understanding which anchors itself in the reflexivity between participants, ideology and the acknowledgment of the indeterminacy of subjective meaning best begets an understanding of the impasse of pain experience and context.

5.14 CONFLICTS AND CONTRADICTIONS

Contemporary Marxist (Eagleton, 1988; Forgacs, 1986) thinking suggests that changes and forces within the superstructure influence the dynamics of the base. From this standpoint the positioning and dynamic of the superstructure is significant
given that literature is placed within the superstructure of society ( Forgacs, 1986; Williams, 1988). Thus, a recognition of the contradictions which exist within society and the dialectical nature of ideology on base and superstructure must be considered in relation to historical and social interpretations of literary texts (Newton, 1988). For Marxist criticism, the unravelling of the text's logic is a process of ideological relevance because the literary text, like all ideological practices, seeks an imaginary reconciliation of real contradictions. Paradoxically, however, in an attempt to reconcile and represent the 'totality' of literary text, limitations, shortfalls or dissension between interests are made apparent. Thus, the determinant form of ideology unwittingly reveals that ideology's absences and silences. Macherey (1978:160) concurs stating contradictions within text may also be exposed by silences within the text because ideology makes certain things impossible to say. All ideologies are constituted by certain definite exclusions and such textual absences are symptoms of ideological repressions of the text's own unconscious. Herein the significance of Marxist criticism to analysing pain stories is explicit. That is, the absences and silences, objectified in literary text, are made visible to reveal the text's inherent ideological flaws, stresses and incoherence. The text finds itself twisting into the incoherence of self contradiction, struggling unsuccessfully to unify its conflicting elements (Fowler, 1991).

The intent of this type of analysis is to not provide the reader with a neatly unified product to be unproblematically consumed, but to reflect in its own conflicting irregular forms something of the contradictory character of social reality itself, thereby, compelling the reader to question the text in order to elucidate the conflict and contradictions contained within the text and to acknowledge these.

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5.15 ALIENATION

Marxism attests that work provides the most important and vital means by which individuals fulfil their basic needs, their individuality and their humanity. Thus, if an individual is unable to fulfil this need they become dissatisfied and estranged from their real selves. Marx coined the term alienation to denote a worker's sense of removal from the production of goods and services (Haralambos & Holborn, 1991:136). This term, however, has evolved to encompass the general emotions of an individual who experiences powerless, despair, a sense of non-belonging, exclusion and loneliness (Hawthorn, 1994) within a given society. The use of this literary concept is particularly useful for contextualising the event of persistent pain in Western discourse because of Western society's inability to normalise the persistent pain experience within its ideological practices or communal folklore, particularly for those who do not have a consensual medical diagnose. Within this ideological formation the pain sufferer is sacrificed to the solitary experience of attempting to account for their pain within the confines of a discourse which abnegates their experience. This attempt leads to repeated failure and further isolation and alienation from the society which has constructed pain in its own language and behaviours. The isolation and alienation from society renders the persistent pain sufferer as passive and powerless. Foucault's discussion of power, however, represents the struggle between issues relating to the structure and agency debate. Its deconstructive capacity provides another valuable tool from which to view the plight of the persistent pain sufferer.

5.16 FOUCALUT AND DISCOURSE

The concept of discourse is key to many of Foucault's ideas. Foucault (1972) describes discourses as ways of identifying truth and knowledge at historically
specific moments, which together provide a set of rules which define particular realities. This is especially pertinent to scientific discourses, and therefore the discourse of Western medicine, which is legitimated by the rationality paradigm. Discourses contain power because they establish particular truths and knowledges, and their power is exercised through the creation and sustenance of social norms, practices and institutions. Discourses exist in related groups of controlling practices, or in discursive fields.

Foucault (1972) characterises a discursive field as a body of anonymous, historical rules, always determined in the space and time that have defined a given period, and for a given social, economic, geographical, or linguistic area. Moreover, the conditions of operation of discursive formations are underpinned by a number of rules. Holmes (1992) elaborates by proposing that a discourse is a pattern of thought and action which includes compatible and contradictory elements. The unstable constructions which are given homogeneity and viability by the rules under which they are convened. Thus, the speakers of statements unwittingly conform to these rules, thereby promoting the perpetuation of the dominant discourse by ministering to the interests of those in power. These rules are constituted as follows: the first rule relates to the formation of objects of which the statements are about. Gutting (1989:234) suggests that social norms become the object of concern from society. Objects are similarly associated with those whom a society gives the authority of deciding what objects belong in a given discursive formation. The next rule, the enunciative modality, refers to the kinds of cognitive status and authority statements have. In terms of the persistent pain sufferer, this modality determines the right of the sufferer to use a given mode of speech to articulate their experience. Last, the formation of concepts in terms of the articulated discourse,
and the theoretical viewpoints asserted by that discourse are substantiated is considered.

In language the words used, and their meanings, alter from one discourse to another. Subsequently, meanings are embodied in technical processes, in institutions, and in the patterns for general behaviour. Moreover, Silverman & Torode (1980:135) assert that in language ‘two voices’ constantly interrupt in search of, but unable to find or overcome the other. Birch (1986:7) states that this is significant about this way of thinking in that:

it foregrounds not the individual subject, but an interaction, a struggle, a play, where understanding and meanings can never be fixed... The [voice] is therefore decentred, and reality becomes a play of language, where neither voice can ever be determined as correct or incorrect.

Pecheux (1975) asserts that a connection exists between discourses and ideological practices and, significantly, with the language which is supposedly shared by all. Foucault (1978) and MacDonell (1986:43) submit that all discourses are generated from clashes with one another. That is, in order for one to know that one is in pain, one needs to know others are not in pain. When the persistent pain sufferer positions themself as the narrator of their story, they select and arrange their story in order to participate, by means of implicit reflection, in the information and events being described. Reissman (1991: 45) asserts this view stating “a narrative is a politically motivated production of a certain way of perceiving the world which privileges certain interests over other”. Thus, the narrator or storyteller is automatically endowed with power, with control over the material presented: a power which flows to her or him through the position as organiser of the story. Thus, the position of organiser of the story is a political one; but one that non-the-less supports dominant views on pain.

Frow (1983:74) asserts “texts and [pain] theories are the result of the discursive formations, which are intricated in the ideological system of a society”. Birth (1986:16) however believes that the power to organise and reflect upon experience
need not depend at all upon knowledge, expertise and benevolent facilitation of the health care provider, as knowledge is relative to a particular discursive practice which may change at a given time and in a given space. This means that we allow a plurality of knowledges and meanings around illness and disease. The living voice is a means through which direct access to the self or to subjectivity is gained. The voice is pure, single and independent. When one calls a writing a voice then one, is attributing power to the individual or group concerned. King (1995: 227-8) states that the term voice tends to carry with it, unconsciously, the assumption that the group (or individual) has a natural authenticity, is identical to itself, uncontaminated by the language and values of others. Derrida (1979.ix) however, cautions that the meanings given by the living voice depend upon a process of differentiation between signs. Language, and hence voice cannot be a transparent medium of subjective experience because no voice is uncontaminated by the terms, values and concepts of others. Voice, is thus intricately connected to complicated contestations and valorizing of meanings. Subsequently, the politics of pain discourse may be seen to be rampant with words and phrases with connote a particular political dimension (MacDonell, 1986). Thus, the researcher contends, if the voice of the persistent pain sufferer demands to be heard, if story is an inevitable vehicle for the knowledge and experiences which arise out of the life-world of the pain sufferer, the researcher needs to understand this. Thus, it may be argued that to give the persistent pain sufferer voice means to acknowledge the distinct epistemology of a social and political group. Although, Walker (1994:48) warns that “language and its representation is a two edged sword. It enables us as human agents to share a world of understanding but in doing so, it severely compromises how we might form and reach those very understandings in the very act of representing”.

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Within this experience, medicine occupies a legally created position which entails a monopoly over a set of services and accessories which results in the exclusive right of doctors to determine the parameters of bodily/pain experience. Foucault (1973) illustrates how, around the time of the French Revolution, disease, a discrete phenomenon, became to be located in the body. The conceptualisation of disease which was found to be in the anatomy was the product of what Foucault (1973) referred to as *le regard* which was translated as ‘the gaze’. In the medical gaze, the body is objectified into a discrete entity to be observed, analysed and treated. This necessitates the need for diagnosis and or surgical and medical intervention which acts to relieve the presenting symptom. Within this discursive formation the embodied person must be motivated to get well and is regarded as *cured* when the objective signs of disease or illness abate (Peerson, 1995).

5.17 TRUTH AND KNOWLEDGE

The dominant rationality discourse which encompasses society’s knowledge demands, exists in the struggle with other processes for gleaning knowledge. This is particularly evident with the emergence of knowledge gleaned from different epistemological paradigms (MacDonnell, 1986). From Foucault's perspective, the acceptance and use of multiple paradigms for research and theory development are outcomes necessitated by the productive aspects of power/knowledge (Dzurec, 1989). Accordingly, certain discourses have been structured such that the concepts of "truth" and "knowledge" are used to secure the power and prestige of that particular discourse. Hence, knowledge is not neutral or free: it is a by-product of the dominant ideology. Through a process of socialisation knowledge is manipulated to sustain the status quo of a particular
discourse. Significantly, pain discourse or the communal folklore of pain is maintained by the persistence of beliefs held by health professionals and the social milieu that pain is merely the symptom of disease. This premise is constructed by the dominant discourse to maintain not only the dutiful position of the sufferer, but the position of medicine. Nettleton (1989:1184) discusses this point in relation to dentistry. She states

we are concerned here with the exercise of dental power and the formulation of different 'truths' that have existed about pain and fear. This is because within the discourse of dentistry they are both objects and effects of the professions techniques of observation and analysis. The meaning of these two concepts is derived from their spatial location

The understanding of the conceptualisation of pain serves as an illustration of the way in which the medical gaze has occupied differential spaces and how this gaze deflects from the experience of having pain to a specific part of the anatomy, and finally to a social space which surrounds and transcends the lived experience of pain.

5.18 FOUCAULT AND POWER

The conventional understanding of power dictates that it occurs from the above down, diffusing to the lowest level of social stratification (Racevskis, 1983:81). Individuals are constituted by power relations, power being the ultimate principle of social reality (Sarup, 1988:81). Here, power is not discernible as a commodity. It is a name given to a complex strategic relation in a given society with all social relations being power relations.

In Foucauldian analysis, power is not monopolised by any one subject through its control of a predominant discourse; the discursive field comprises multiple subjects who manipulate various discourses to some extent. Foucault (1987, 26-27) states

power exercise over the body is conceived not as a property, but as a strategy...[it] is exercised rather than possessed; it is not the privilege

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acquired or preserved, of the dominant class, but the overall effect of its strategic positions - an effect that is manifested and sometimes extended by the position of those who are dominated... this power is not simply an obligation or a prohibition on those who 'do not have it', it invests them and is transmitted by them and through them; it exerts pressure upon them just as they themselves in their struggle against it resist the grip it has on them.

Sarup (1988:71) contends that if reality was constructed by our discourse rather than reflected by it, how could we ever know reality itself, rather than merely knowing our discourse. According to this dogma we can never know anything at all; we are prisoners of our discourse. Lather (1991:200) concurs, asserting

we are inscribed in that which we struggle against, how can I intervene in the production of knowledge... when each attempt at understanding is not so much description as inscription, marking with words that impress investments of privilege and struggle

Further, Foucault (cited in Dreyfus & Rabinow, 1982:187) suggests that power is imbued with calculation in all social relationships. Power relations have specific purposes, and through certain rules or laws the dominant discourse is maintained. It is, further, asserted that via individual ignorance of the operations of power and knowledge that power is maintained. Thus, individuals are constituted by power relations, power being the ultimate principle of social reality and, therefore, an empowering concept. Moreover, each discourse provides discrete techniques of discipline and control to sustain discursive power.

5.19 DISCIPLINE AND NORMALISING STRATEGIES.

Discipline may be identified neither with an institution nor with an apparatus; it is a type of power, a modality for its exercise, comprises a whole set of instruments, techniques, procedures, levels of application, and targets. It is a 'physics' or an 'anatomy' of power, a technology and it may be taken over either by 'specialised' institutions, or by institutions that use it as an essential instrument for a particular end

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(schools, hospitals), or by pre-existing authorities that find in it a means of reinforcing or reorganising their internal mechanisms of power, or finally by state apparatuses whose major, if not exclusive function, is to ensure that discipline reigns over society as whole to ensure the continuance of that society (Foucault 1979:137).

The normalisation of disciplinary power facilitates the construction of a norm, which encompasses every aspect of modern existence. The disciplinary techniques of modern society employ the normalising hegemony of rationality to construct docile and useful subjects. Further, the judges of normality are present everywhere. Disciplinary society orders human multiplicities such that power relations are exercised at minimum cost with maximum intensity, linking their effects to increased productivity, utility and the emergence of specialised, empirical systems of knowledge. In *The History of Sexuality, Volume One*, Foucault (1978, 92-94) provides the following description

> power must be understood as the multiplicity of force relations immanent in the sphere in which they operate and which constitute their own organisation; as the process which, through ceaseless struggles and confrontations, transforms, strengthens, or reverses them; as the support which these force relations find in one another, thus forming a chain or a system...; and lastly as the strategies in which they take effect, whose general design or institutional crystallisation is embodied in the state apparatus, in the formulation of the law, in various social hegemonies. Power is everywhere because it comes from everywhere power is not an institution, and not a structure; it is the name that one attributes to a complex strategical situation in a particular society. Power is not something that is acquired, seized, or shared relations of power have a directly productive role ...the manifold relationships of force are the basis for wide-ranging effects of cleavage that run through the social body as a whole. Power relations are both intentional and non-subjective.

According to this view, therefore, power is circulatory and dispersed through a decentralised network of social institutions, and is only later employed by macrostructures such as state or class. The differentiated nature of modern society and the dispassionate and sovereign mechanisms of power function beyond conscious
subjects, so that individuals are simultaneously the source of power mechanisms and their expression (Best & Kellner, 1991). Subsequently, these heteromorphic power mechanisms affect the individual’s pain experience by constraining the body within discourses of pain, which operate under the premise of rational-scientific knowledge to produce a “restrained, mute, and hypocritical” self (Foucault 1978:3).

Foucault’s (1978) critique may shed light on the knowledge-pain complex by uncovering the regime of power which creates and sustains the discourse of the body as the site of control. The purpose of this complex is to account for the fact that the persistent pain experience is spoken about, to discover who does the speaking, the positions and viewpoints from which they speak, and the institutions which prompt people to speak about it, and which store and distribute the things that are said. Significantly, this complex also determines what is not spoken about. What is at issue, briefly, is the over-all “discursive fact”, the way in which pain is “put into discourse”. Thus, power does not operate through the repression of the pain experience, but through the discursive creation of pain and pained beings. This is described as “bio-power” (Foucault 1978:140), a process of politicisation and disciplining which encompasses both human anatomy and larger society (Best & Kellner, 1991:50-1).

5.20 DISCIPLINE AND THE BODY

From a Foucauldian perspective, the body was invested with local power relations geared towards the economical and efficient generation of “productive” and “subjected” bodies. The process of domination began when rituals that centred on the body as the site of repression were replaced with techniques of supervision, training
and correction. In schools, hospitals, factories, army barracks and prisons, the smallest detail of life was precisely inspected, regulated and encoded. Disciplinary systems operate through body systems, which minutely divide the body into functioning segments; manoeuvres that regulate and economise each gesture for efficiency; and examinations that hierarchise and reward conformity. The disciplinary institutions apply utilitarian and anonymous power effects to produce homogenised normality. The disciplinary system enhances individualisation by singling out differences in the population (Kurzweil 1983).

Disciplinary punishment applies to any deviation from the norm and incorporates a range of techniques. Punishment is "corrective" in nature with a "double juridico-natural reference" (Foucault 1979:179). That is, it punishes lacks or gaps through correction and training. For example, the body is monitored for incorrect attitudes, irregular gestures, lack of cleanliness, continued pain. At the same time, by way of punishment, a whole series of subtle procedures are used, from light physical punishment to minor deprivations and petty humiliations. It is a question both of making the slightest departures from correct behaviour subject to punishment, and of giving a punitive function to the apparently indifferent elements of the disciplinary apparatus so that, if necessary, everything might serve to punish the slightest thing; each subject finds themself caught in a punishable, punishing universality (Foucault 1979:180-2).
5.21 DISPARITY OF POWER IN THE HEALTH PROFESSIONAL AND THE PERSISTENT PAIN SUFFERER'S RELATIONSHIP

Historical developments have rendered the doctor and the persistent pain sufferer unequal in matters of power, and thus authority. It is this inequality which shapes and informs their professional association: an association permeated in ritualistic-social discourse embracing body kinesics, proxemics and non-verbal cues. Both are institutional and interpersonal and facilitate the validation of a code of behaviour as significant as the spoken word (Tellis Nayak & Tellis Nayak, 1984). Comparatively, through the use of formal language, the individual's ability to innovate or deviate from the dominant discourse is severely restricted by conventional, physical and institutional arrangements. Further, communication is asymmetrical and one of its real functions is to express and consolidate unequal power and authority. Norms for communication become so ingrained that speakers unwittingly perpetuate the unequal order from which they stem. Pappas (1990) asserts that within these encounters ideological communication takes much of its force from the symbolic impact of medical science and the asymmetry of the doctor-patient relationship. Nettleton (1989) describes this as a framework of participation in which those acted upon can choose how to act; to comply or, indeed, to defy. Foucault says that a power relationship involves the actions upon the actions of others and provides a field of possibilities; an arena for interaction.

Significantly, Foucault's (1965) discussion of insanity provides a means for understanding the management of the persistent pain sufferer without a consensual medical diagnosis. That is, insanity is seen as socially threatening and morally repugnant because the insane refuse to engage in productive labour, which is both a
social obligation and the key to moral salvation. In the classical age, for the first time, madness was perceived through a condemnation of idleness and in a social immanence guaranteed by the community of labour. This community acquired the ethical power to segregate, permitting the ejection, as into another world, all forms of social uselessness. It was in this other world, encircled by the sacred powers of labour, that madness became what we know it to be today. The quality of insanity was demonstrated by the relationship of its discourse to rationality. In this sense, insanity was nothing more than a deviation from reason, that is, truth - it was the manifestation of nothingness. Confinement was the rational response to the social elimination of these individuals, who signified nothing and were non-beings, in the sense of being productive members of society. Also, the insane could not be accounted for within the rationality of the dominant discourse and presented a challenge to the very social nexus of a given society. Thus, in classical discourse insanity was constructed as the great unified experience of unreason affecting body, soul and mind. Rationality alone, with its monopoly on truth, located and treated the sickness that affected the entire human organism; and classical therapeutics attempted a physiological, psychological and moral cure thus entirely enclosing insanity in a pathology. A transformation which later periods received as a positive acquisition, because at least it would make the recognition of truth possible. That is, the reduction of the classical experience of unreason to a strictly moral perception of madness would secretly serve as a nucleus for all the concepts that the nineteenth century would subsequently vindicate as scientific, positive, and experimental (Foucault 1965:196-197).
Likewise, it may be postulated that the persistent pain sufferer, without a medical diagnosis has endured a similar fate. This experience, has been organized through a process of internalisation of social norms and a rational conscience which dictates, via the use of discursive formations, a realm of observation, diagnosis, and therapeutics. If one continues to speak of having pain, a moral space is created in which one is accused, judged, and condemned, and from which one is never released except by the disappearance of the experience, which represents the vindication of the rationality discourse (Foucault, 1965:167). In *Madness and Civilisation* (1965), Foucault argues that modern psychology developed as a product of rational discourse, which constructed insanity as the pathological departure from its established moral and social norms. The power mechanisms of the classical age are refined and developed into technologies of disempowerment and isolation in the modern age: the scientific discourse of modern psychology isolates insanity in guilt and, hence, is atomising and dehumanising. Thus, in Foucault's analysis, the modern asylum symbolised the triumph of rationality as does the development of pain management clinics where persistent pain sufferers are required to deny their experiences and return to the accepted modalities of life. Similarly, persistent pain without a consensual medical diagnosis has been rigorously excluded from Western discourse through the development of chronic pain syndromes and the *DSM-IV* classification system (Morrison, 1995) which rids traditional medical discourse of those who fail to comply by reclassifying them to the discourse of mental illness.
5.22 SUMMARY

To sum up, power, as conceived by Foucault, is exercised within certain institutions and by individuals acting as conduits of power (Peerson, 1995). Foucault defines the principal agents of power as the State and the medical fraternity. Both of these operate jointly to preserve the political anatomy of the body for their own interests as well as to exert control of the individual in society. For Foucault, the issue is not the origin of discourses, but the implications of their power effects and the types of knowledge they produce and institutionalise.

Since power originates in discourses, it has no unitary source but is heterogeneous and pluralistic, coming from everywhere and being everywhere. Resistance to dominant modes of power develops through the production of new discourses which produce new truths, and counter discourses which appropriate categories of existing truths to claim legitimacy (Ramazanoglu, 1993).

Foucault reveals the ubiquitous and insidious operations of power; problematizes rationality, subjectivity and knowledge; explores the links between power and knowledge; and argues that ideologies of liberalism and humanism support and sustain deterministic social structures and apparatuses (Best & Kellner 1991). Foucault's vision has often been considered oppressive. His archaeological and genealogical works reveal the colonising power of modern rationality and its dispersed presence throughout the social field: since the classical age, modern rationality has operated in minute applications through surveillance, regulation and correction to reconfigure the human subject within homogenising norms that have transformed socio-cultural institutions and practices. At the same time, although
discourses reinforce power, they also provide potential for resistance, whereby the
disenfranchised can extend oppositional discourses and demand legitimacy, frequently
by appropriating institutional categories. Since resistance itself is a way of exercising
power, power is inseparable from resistance.

This research seeks to understand the private folklore of pain from which the
persistent pain sufferer, without a consensual medical diagnosis, is able to understand
their own life experience. This folklore may represent a resistance to the dominant
folklore in order to establish legitimacy in their experiences and a validation of pain
which is continuous. Feminist theories provide insight into the oppressive nature of
discourse, and an analysis of the concept of resistance will be attended in the
following chapter.

5.23 THE RESEARCHER CREATES THE DOCUMENT THAT IS
INTERPRETED

Significantly, the method advocated by Dolby Stahl (1985) for biographical analysis is
not concerned with the issues of reliability and validity of data contained in the self
story. It does not seek to generate theory. It simply accepts the self stories of
participants, and the records of these stories as material for interpretation. It assumes
that the meanings embedded in biographies are best given by the individual
experiencing them. Thus, the life of the storyteller must always be foremost in the
account, with structure and interpretation being blended with lived experience. The
researcher's preoccupation with method and theoretical relevance must be set aside in
favour of a concern for meaning and interpretation of the text (Plummer, 1983).
Denzin (1989a; 1989c) asserts that one must work back and forth between a concern for process and the analysis of the specific lives that are being studied.

5.24 CONCLUSION

This chapter has discussed the methods of data collection and outlined the means by which data will be analysed. Denzin’s (1989a; 1989b; 1989c) interpretive biography and Dolby Stahl’s (1985; 1989) literary folkloristic methodology have been discussed in relation to uncovering the life experiences of those who live with persistent pain, without a consensual medical diagnosis. The appropriateness of literary theories for the analysis of pain stories have been highlighted, in particular Marxist literary theory, Foucault’s discussion of power and the feminist concept of resistance.

The following chapter analyses the pain stories of David, Vince, Vicki, Steve and Joanne. Turning point moments will be revisited in light of Marxist literary theory, Foucault’s discussion of power and the feminist concept of resistance in order to connect their stories to the prevailing communal folklore of pain and signify the emergence of a private folklore of pain.
CHAPTER SIX

DISCUSSION & ANALYSIS OF STORIES

6.0 INTRODUCTION

The previous chapter outlined how Dolby Stahl (1985) contends that the interpretation of personal narratives involves the researcher in its entirety and that the researcher undertake the responsibility for hearing, listening to and interpreting the document. This document must share the narrator's point of view in order for the researcher to experience the world and its problems as they are seen by the individual living inside them. Denzin (1989c: 25) asserts that

the world does not stand still, nor will it conform to the scientist's (researcher's) logical schemes of analysis. It contains its own dialectic and its own internal logic. This meaning can only be discovered by the observer's participation in the world. The world does not stand independent of perception or observer organisation. In these respects, researchers find that their own worlds of experience are the proper subject matter of inquiry. This researcher participates in the social world so as to understand and express more effectively its emergent properties and features.

I have chosen three literary theories to critique, situate and deconstruct the stories outlined in Chapter Two. The stories of David, Vince, Vicki, Steve and Joanne will be examined to provide the threads of a life, its tapestry, for illuminating the meaning of living with persistent pain, without a consensual medical diagnosis. This intricate tapestry is composed of interlocking patterns of cultural-historical, individual-biographical, and interpersonal-relational threads, which are woven through the multiple strands of the subject's life. Turning point moments or epiphanies are identified in light of Marxist literary theory; in particular, the concepts of alienation and the influences of ideology will be used to deconstruct the plight of living with persistent pain. Foucault's discussion of power is also significant for the
understanding of the described pain stories and the feminist concept of resistance will connect personal stories to the prevailing communal folklore of pain and signify the emergence of a private folklore of pain through the unfolding of a distinct identity which sustains each participant in their present evolving life.

This chapter will describe persistent pain as illness, consider the chronologies of the persistent pain sufferer's pain experience, accenting personal turning point moments and presenting a discussion and analysis of stories using literary theories discussed in Chapter Five.

6.1 PAIN AS ILLNESS

Before a discussion can take place in relation to the consequence to self of, for the persistent pain sufferer without a consensual medical diagnosis, the relationship between persistent pain and illness needs clarification. Kleinman (1988) describes illness as the lived experience of body awareness and processes. Moreover, illness is described as a natural human experience of symptoms and suffering. In keeping with sociological thought, illness encompasses the person who is sick and their significant others, and those who they come in contact with, live with, and react to their condition and affliction. Pollock, Christian & Sands (1990) define chronic illnesses as conditions of long-term duration, not curable, and/or having some residual features that impose limitations on an individual's functional capabilities. Living with chronic illness is a complex process and implies a balance between the demands of the situation and the ability of an individual to respond to those demands. They also contend that most studies of chronically ill persons have examined either psychological or physiological reactions to a specific diagnosis. Collett, Cordle, Stewart & Jagger (1998), Brown, Robinson & Riley (1997), and McCracken, Gross,
Aikens & Carnrike (1996) describe numerous psychological variables which have been shown to affect living with chronic illness, including anxiety, depression, anger, past physical abuse, self-concept, locus of control, uncertainty, and hardiness. However, it will be shown that although the participants in this research have not been granted the validity of a consensual diagnosis, they have experienced psychological and emotional disunity which has significantly influenced their ability to confront the lives they lead.

In keeping with Morse’s (1997) conviction, and in contrast to the view that there are two distinct realms of reality one out there, without consciousness and purpose and the other in the mind, of consciousness and selfhood. This discussion will focus on the persistent pain sufferer and his or her significant others’ experience of pain, integrating experiential aspects of living with pain and the subsequent emergence of a private folklore, which gives voice to their experience. Hence, I will use the term “illness” synonymously with the term “persistent pain” because persistent pain is a human experience which encompasses the life of the sufferer and their significant others. Their persistent pain experiences affect how they live with, perceive and react to the world.

Vicki (Poem written 27/1/95) explains

Oh how quickly life can change, from one you know to one so strange, My life now is pain and stress, inside my head is a bloody mess.

I live and breathe the chronic way, it won’t go, its here to stay. Acceptance is what’s hard for me; pain is what I want to flee.

I live with chronic pain each day, “you don’t look it” you all say-You normal people cannot see, My life, I live, my world and me.

Persistent pain disrupts the taken-for-granted world of everyday life. In the stories told in this research, it is evident that pain sufferers attempt to make sense of what has

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happened to them, describe their actions and reasons for why particular choices have been made, and relate these choices to how events and choices have influenced them. Kleinman (1988:75) describes how “illness becomes embodied in a particular life trajectory.(soaking) up personal and social significance from the world of the sick person”. Each story, while sharing similarities owing to social context and shared cultural knowledge is unique and distinctive. However, if one is able to connect the biographical and experiential context with shared cultural knowledge, the stories told help those encompassed in the experience, whether as sufferer, carer, loved one, or health professional, to make sense of what is happening by providing an “arena for negotiation of reality” (Garro, 1994:775). Fordyce (1994) elaborates this view asserting that there appears to be an inadequate understanding of the nature of pain complaints and their relationship to extant suffering and the mood states of the complaining person, and that this misunderstanding is true of worker, employer, and health care provider, as well as insurance and compensation agency policy makers. However, it is timely to note that “narratives are always edited versions of reality, not objective and impartial descriptions of it ... and interviewees always make choices about what to divulge” (Riessman 1990:1195). Hence, the narrative informs us of what is paramount to the construction of the illness experience in the research interview, and how participants have made sense of these experiences.

Farmer (1990) and Garro (1994) demonstrate the valuable use of stories, or narratives, in establishing culturally shared understandings of AIDS and Tempromandibular Joint Pain (TMJ) and it is in this way that persistent pain stories are deconstructed. The intertwining of individual and cultural understandings within each persistent pain story is explored through interviews with persons living in the South Coast Regional
Health District of Queensland, Australia, who have suffered persistent pain, without a consensual medical diagnosis. The stories examined here are complex. Each recounts the struggle of individuals trying to make sense of persistent pain which is non-categorizable, nor effectively treated within the context of the Australian health care system.

The discussion and analysis to follow illustrate the ways in which David, Vince, Steve, Vicki and Joanne continue to search for meaning for their persistent pain; how their lives have become protracted in relation to future possibilities, and personal anxiety intensified in their repeated and continued search for meaning, through diagnosis, with conflicting interpretations for, and of their pain, including suggestions and or intimations that their pain is psychologically based, and not ground in the physical workings of the body - the conventional source of all pain. All participants' experiences, in relation to their search for meaning and treatment for pain, have resulted in either partial, or no alleviation of their situation. Therefore, their stories are stories-in-progress, beginning with the event or circumstance which occasioned pain and ending on the day of the second interview.

The participants interviewed represent individuals from two subgroups. David, Steve and Joanne were interviewed while participating in a Pain Management Course at the Belmont Hospital in Brisbane. Vicki and Vince were interviewed in their homes, after initial contact with them at the People in Pain Support (PIP) group on the Gold Coast. All complied with the selection criteria: that is, experiencing pain for longer than six months, not having been able to obtain a definitive diagnosis for their pain and were
English speaking. The following table summarises key components related to their pain duration.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Occupation</th>
<th>Event precipitated pain</th>
<th>Years with pain</th>
<th>Interventions sought to alleviate pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>David</td>
<td>Shearer</td>
<td>Fall while shearing</td>
<td>3yrs 6mths</td>
<td>Surgical intervention, Medication, Attendance to Pain, Management Course (PMC)</td>
</tr>
<tr>
<td>Vince</td>
<td>Council Worker</td>
<td>Fell at work</td>
<td>19 years</td>
<td>Surgical intervention, Medication, Exercise (gym), Psychiatric care</td>
</tr>
<tr>
<td>Steve</td>
<td>Truck driver</td>
<td>Truck accident</td>
<td>2 yrs 2mths</td>
<td>Surgical intervention, medic (drug dependence), Chiropractor, Attendance to Pain, Management Course (PMC)</td>
</tr>
<tr>
<td>Joanne</td>
<td>State Accountant</td>
<td>Horse riding accident</td>
<td>17yrs</td>
<td>Exercise (gym), Psychiatric care, Surgical intervention, medic (drug dependence), Attendance to Pain, Management Course (PMC)</td>
</tr>
<tr>
<td>Vicki</td>
<td>Bar manager, self employed</td>
<td>Car accident on way to work</td>
<td>3yrs</td>
<td>Medication (intra muscular), Physiotherapy, Psychiatric care, Failed attendance at PMC, Spinal injections</td>
</tr>
</tbody>
</table>

Participants were all aged between 26 and 52 years with all being educated to high school level, and described themselves as battling to make ends meet because of their inability to work. David and Vince had received compensation pay-outs, but the amounts awarded were stated to be incomparable to the loss of personal earning potential. Joanne relied on her husband for financial support, Steve was on an invalid pension and Vicki has been removed as a compensation claimant when medicos had failed to find a cause for her pain.
All participants stated that they were either in a pain management course or attended the pain support group because all other avenues open to them were closed, or were pending closure. All participants voiced the need to know about persistent pain and strategies for coping with the same.

6.2 TEMPORAL REPRODUCTIONS

The stories of David, Vince, Steve, Vicki and Joanne are temporal productions. They are reliant upon autobiographical memory. Like other processes of memory, autobiographical memories are best understood as reconstructions rather than reproductions of past events (Garro, 1994). When one speaks about personal experiences, the past is reconstructed in a way which is congruent with current understandings. The present is explained with reference to the reconstructed past, and both are used to generate expectations about the future. Similarly, the self-represented is the best self. That is, in story telling about oneself, one portrays the self in the best possible way, minimising or tempering any recollection which may cast doubt upon the stories told, or actions within the story being told. These limitations, of course, also encompass the researcher who interprets the stories told by way of restructuring past experiences and biases to represent the story as closely as possible to the story being heard.

Like other cognitive processes, autobiographical memories are mediated by schemas (or schemata), which can be thought of as guidelines for perceiving, organising, interpreting, representing, making inferences about, and acting in the world. Schemas may be individual or shared. Thus, autobiographical memories may be individual or shared. Shared schema evolves from the effect of context and culture. Thus, cultural
schemas for pain assist individuals make sense of given episodes of pain and provide the basis for actions taken in response to the same (Garro, 1988). Quinn & Holland (1987) contend that as a representation of shared understandings about the world, cultural models may invoke prototypical or simplified worlds where events unfold and people’s actions occur in an understandable and expectable fashion. Whether individual or shared, schemas are not static; they are created through experiences and are modified by new experiences.

Garro’s (1994) study into the representation of chronic illness of individuals suffering temporomandibular joint pain, identifies four broad schemas, which create the backdrop for understanding the pain experienced by those with TMJ. These broad schemas may also be applied to the persistent pain stories contained within this study. First, there is a shared cultural idiom that formed individual responses to the persistence of pain. That is, each participant expected to participate in a simplified world in which their pain would be alleviated. Second, as individual pain proved to be atypical, with questions being raised in relation to the reality of their pain, each individual was caused to question the validity of their pain. Third, as individuals tentatively acknowledged the persistence of their pain they found solace with others who shared their experience; and last, as all participants were unable to return to the status quo existing prior to the persistence of pain, their stories are concerned with how they feel about their lived lives, and their continued search for meaning, their sense of despair at repeated failures of treatment.

David, Vince, Steve, Vicki and Joanne’s pain chronologies and identified epiphany’s are as follows:

Pain: a Biographical analysis
Pain Experience timeline for 'Steve' (34 years old) 03/08/93 - 31/10/95

3/8/93: Truck Driving accident

Nov 1993: Trouble walking, numb from the waist down. Accident and Emergency visit. Homebound.

Dec 1993: CAT Scan.

April 1994: Spinal fusion x 2 & Laminectomy. Fell out of bed because he was a 'whinger'.


Pain: a Biographical analysis
Pain Experience time-line for 'Joanne' (31 years old) from 1978 - 12/09/95

1978: Horse riding Accident.
1979: Married older man.
1984: Developed severe limp. First marriage ends; commenced seeing second husband.
1986: Laminectomy.
1989: Severe pain returns.
1991: Retrenched from work. Looking for support.
1992: Developed thyroidism; commenced antidepressants.
1993: Married. Gained 45 Kg +.
Nov 1993: Pregnancy, 12 weeks, husband depressed, loss of mother finances depletion.
1995: Curette/hospitalised.
August 1995: Partner violent. Confined to wheelchair, 'terrible life'.
12/09/95: Loss of will to fight.

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Nov 1992: Evicted from home.
Dec 1992: Flies to Wondanga to live with Mother.
Mar 1993: Meets partner.
Jun 1993: Doctors reject compensation claim. No diagnosis available for pain. Becomes suicidal as is made to believe the pain is in head.
May 1994: Returns to QLD. Enters pain clinic. No help received.
Dec 1994: Pain is constant and intense. Regularly taking pain killers. Sees psychiatrist and is treated for depression.

Pain: a Biographical analysis
Pain Experience time-line for "David" (40 years old) from 30/04/92 - 25/10/95

- 30/04/92: Shearing Accident.
- 01/12/93: Myelogram.
- 06/12/93: Laminectomy.
- Sept 1994: Court claim
- Dec 1994: Sells house; leaves town.
- Feb 1995: Notice changes name and personal identification number.
- March 1995: Pain intense and constant; spends time alone and resting; feels lonely.
- May 1995: Returns to doctor for pain relief.
- 23/10/95: Today: Pain continues has become part of life.
Pain Experience time-line for 'Vince' (52 years old) from 1976 - 31/10/95

1976
- Fall (Accident).

1980
- Prostate problems related to back pain.

1981
- Could not work; crying with pain at work.

1982
- Compensation/ Laminectomy. (40 yrs.)

1983
- Living with pain.

1985
- Receives invalid pension.

1986
- Personal tension builds up. Pain described as severe.

1988
- Blackouts and collapsing at work.

1989
- Back pain flares again. Prostate problems exacerbated.

1991
- Looks for alternative therapies for back pain.

1993
- Describes self as coping with pain.

1994
- Daily activity precipitates flare up of pain.

31/10/95
- Back pain is intense and constant. Verbalises the need to talk to someone about living with pain.

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The above chronologies are representative of a cultural model for the response of sufferers to persistent pain. It is a model which insidiously depicts how people are understood to act when in pain, and may be seen as a prototypical sequence of events. That is, atypical body experiences become to be interpreted, drawing on culturally shared idioms, as signifying that something is wrong. Hansen & Gerber (1990) and Garro (1994) suggest that drawing on the appraisal of the situation, that is the persistent pain experience, by the sufferer and others, allows treatment choices to be made. If the atypical experience does not abate, the decision is usually made to seek help from a medical practitioner to rectify the problem. The individual follows the regime of treatment in order to restore the body to health. This sequence serves as an implicit standard for highlighting differences between people’s expectations and lived experiences. Galer, Schwartz & Turner (1997) poignantly emphasise this point in their discussion of the disparity between patient and physician expectations as a predictor to patient responses to pain-relieving procedures. This study found that patients’ pain expectation ratings did not correlate, pre or post procedure, with that of their attending doctor. This theme is recurrent in the stories of all participants. Interestingly, Galer, Schwartz & Turner (1997) suggest that it is the physicians’ assessment of pain which is accurate and not the stated pain levels of the pain sufferer. This is also a theme recurrent in the study, and this issue will be discussed under the influences of ideology.

The stories recounted in this study contrast significantly with the simplified sequence of events just explained. David, Vince, Steve, Joanne and Vicki’s stories tell of those who have unsuccessfully sought treatment and care. In the telling of their stories
participants were aware that their self stories did not fit the expected pattern of illness.

David explains

After the first few months I used to tell people, and then you know, when you've had something like that for a while and you go to bed with it and you wake up with it, it makes you stop and think you know and then after so long you know you're not gonna get rid of it, you know it's gonna be there. I thought with the operation I would get rid of it, like bang I'm gonna get rid of the lot of it, and as I said the first couple of months when I come home I was good, then it started again. Bang, in my back, my legs, just like it used to be. I don't understand why I did everything the doc said, but bang it is back. (Verbatim Transcript, September, 1995).

Joanne, whose chronology of pain spans 18 years and indicates widespread attempts to be relieved of pain through surgical intervention and medication explains. We enter her story after she realises that her second back operation has not alleviated her pain

By the time it got to July '91 I was retrenched. For that six months before July I could miss a couple of days easy. There was a couple of weeks where I just didn't even make it to work, the whole week, then the next week I would think I have got to try and make it to work and that is when I would end up at the physio and be home by 10.00. But I just had no where to go to get it better. I just didn't know what to do. I have had two operations, and still in all this pain. I just didn't know what to do, where to go. I just lived as much as I could.

I had a couple of specialists see me then because I was after an answer of what happened, and the same sort of answer from them was "oh well you know its just your old trouble", you will just have to learn to live with it. So um I went home and I tried to live with it and it is just getting worse and worse. I went back to my specialist again and he said exactly the same thing. So I went and got a second opinion. He was the one who sent me to the pain clinic (Verbatim Transcript, September, 1995).

David's and Joanne's experiences show that once the decision was made to seek help for their pain, it was not a simple matter of consulting someone, being diagnosed and accepting treatment. Garro (1994) and Seers & Friedli (1996) contend that persistent pain sufferers, when dealing with health care professionals, enter into a realm of endless consultations in an attempt to identify the source of their pain. In attempts to identify the sources of pain, that is pain that can not be validated via a consensual
medical diagnosis from a medical practitioner, sufferers are implicated in the world of the psychological. Interestingly, David recounts:

No, no, no it’s not in me mind. No, no, it doesn’t it just when you overdo something you pay for it and the next day I just laid around here because I was still in pain from the day before (Verbatim Transcript, September, 1995)

Vicki explains:

Important things that sticks out in my head. People don’t believe that I suffer pain, specialists because I had the accident on my way to work, specialists seem to treat you like dirt. Um, it was mid 93 I would say when I really started getting rejected from specialists. Um. Doctors saying I’m after the compensation money, not willing to help me but willing to prescribe heavy drugs, like Valium. Not helping at all, but at the time I thought they were because I was popping Valium like it was going out of fashion and drugging myself out, sleeping all the time and at that point I thought yes, pain relief, but now that I’m out of those doctors care and I’m back they weren’t helping me at all (Verbatim Transcript, September, 1995).

The gravity of searching for meaning is further exemplified by Vicki’s story when health professionals, unable to validate Vicki’s pain in the body, cause Vicki to doubt the experience in her life. She continues:

In the middle of 93 um when Workers' Compensation, nine months after the accident, when Workers' Comp took me off Workers' Compensation because they couldn’t find anything that’s when I just, that when I was thinking I shouldn’t be sore, they can’t find anything that’s causing the pain.

I shouldn’t be sore I shouldn’t have this pain, so and denial was quite strong then to, as in I don’t have pain, I don’t have pain, I don’t have pain, oh god, I have pain, you know, I can’t have pain, you know, they can’t find anything they know what they’re doing, they’re the specialists they’re saying to me that there’s nothing in all these bone scans. So I, obviously, am doing it to myself, you know, but as time went on, it just wasn’t right, you know, I’ve got pain, you know and they’re wrong, if they cant find something that doesn’t mean I don’t have pain, you know, it took maybe 12 months for me to hit that point where I’ve got pain, you know, I don’t care what you say, I’ve got pain you know, and if you cant find where it coming from then that’s not my fault that I’ve got pain (Verbatim Transcript, September, 1995).

Historically, health has meant the absence of disease. Theorising within this framework has been pragmatic. Pain is seen as the result of organic, psychological
and possibly also social factors, although implicitly true pain is believed to have its origin in the body and can be traced (Vrancken, 1989). Thus, Nelkin & Tancredi (1989) submit that the hallmark of the medicalization of the body focuses upon biological fitness or perfectibility. The ideal of biological normality or perfection is the measure against which individuals are assessed, and the mechanism through which complex human behaviour may be reduced to biological or genetic explanations, and through which behavioural deviations may be understood. Shorter (1994) exemplifies this by his attempts to trace the interplay of cultural and biological factors in psychosomatic distress. Biological reductionism is part of the pervasive tendency to medicalise social problems. Medical testing has become more refined and accurate, placing increased reliance on medical judgment to define the boundaries of ‘normal’ behaviour and thereby to identify competence, deviance, or capacity to work. Significantly, Vicki’s story suggests that Vicki continues to use the term normal as a yardstick to describe her inability to cope. Her previous self does not measure up against her lived pain experiences and, therefore, is inadequate in providing a meaning for her persistent pain. She explains:

I didn’t know what the hell was happening to me. Well I was really blinded at that time to what was going on, because I was trying to do things like a normal person would do, and because I was coping pain because of it. And it was excruciating pain. I was and still am in denial.

Denial means to me that if people say that your mind can you know like, people that have cancer that they change their thoughts and they change their way of life and change their eating habits and the cancer goes in very rare cases, and I thought my version of denial is that if I deny that I have the pain then I won’t feel it, but that doesn’t work. You see because I don’t want pain, I don’t want it there so if I can deny it’s there it will go away. Yeah. I know that doesn’t work, I know that sounds silly but I, its just something that I, its just the way I think at the moment (Verbatim Transcript, September, 1995).

The reliance on the psychological realm necessitates the classification of pain patients into three groups: Patients with real pain, malingerers and psychiatric patients. This

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point bares consideration in light of Holmes & Warelow (1999) contending that the expansion of psychiatry, via the DSM-IV, serves to deconstruct the traditional distinctions between the mentally disordered and the mentally healthy. That is, according to the DSM-IV, all people exhibit more or less psychological and behavioural phenomena which can be taken as indicative of mental disorder. Hence, the first consultation is of crucial importance in deciding to which group a pain sufferer belongs. First, the sufferer with real pain has pain which is traced to a biological cause, whether acute or persistent. All participants in this study were treated as real pain patients at the onset of their pain. However, it is illustrated that this label is truncated when medical intervention is not successful. Second, a psychiatric patient is recognised by the way in which she/he talks about her/his pain. Interestingly, Heath (1989) asserts that the medical consultation relies on the patient’s taking an analytic stance towards their complaint and delivering an “objective” exposition of their various signs and symptoms. Thus, the expression or experience of actual suffering of persistent pain during the consultation inevitably undermines the patient’s ability to deliver an accurate and coherent rendition of their illness and forestalls the possibility of the practitioner producing a diagnostic assessment of the complaint. Indeed, where patients are overcome by pain and suffering, practitioners unfortunately must rely on witnesses, to provide the necessary information to formulate an appropriate diagnosis and treatment. The delivery of health care in general practice, and in other forms of medical consultation, relies on a clientele which is able to manage the expression of personal suffering for the purposes of diagnostic inquiry and treatment. Furthermore, it is postulated that patients frequently justiy seeking professional medical help in terms of the pain caused by their complaint. In certain cases the absence of suffering during diagnostic investigations is
“accountable”, throwing doubt on the very existence of the complaint. Thus, despite the significance of pain to seeking professional medical help, it is found that diagnostic practice largely precludes the actual expression of suffering by patients. Hence, the pain sufferer is subject to two almost incompatible demands in the medical consultation: to provide reasonable grounds for seeking professional medical help, and in particular to detail the pain and suffering experienced, and on the other, he or she is obliged to take an analytic or “objective” stance towards his own difficulties and cooperate with the diagnostic investigations of the doctor.

None of the participants in this study have yet, been labelled as “psychiatric”. The third category, “malingering” poses other problems. This pain patient usually has a ‘correct’ story, or at least partly correct, and there are historical clues suggesting that she or he may have real pain. However, diagnostic procedures and treatment when instituted have failed, by the sufferer’s claim, to alleviate pain (Vrancken, 1989). Moreover, Hansen & Gerber (1990) purport that although the perception and interpretation of pain are subjective and private experiences, pain as an outward expression or communication includes, but is not limited to, the outward or public manifestation of one’s subjective experience. Thus, whenever one experiences physical sensations or symptoms that suggest illness, there is a need to make sense out of what is occurring since such experiences represent a threat to one’s well-being. Significantly, pain cries, like certain other forms of physical and emotional expression, achieve their significance, their factual status, by momentarily revealing the “natural” feelings and subjective experiences of the individual. Yet even at moments of severe physical or emotional suffering, the revelation of difficulty is context-sensitive and socially organised (Heath, 1989:114-6). Notably, Kleinman & Kleinman (1987:277 assert that experience is the inter-subjective medium of social pain.
transactions in local moral worlds and that it is the outcome of cultural categories and social structures interacting with psycho-physiological processes which creates the mediating world of lived experience. Thus, experience is the felt flow of the inter-subjective medium through which habitus is structured, and where shared mental/bodily states are in turn structured as social interactions.

Biomedicine is a socio-cultural system, which consists of distinctive elements which interact in a manner which separates them from other systems within society. Hahn & Kleinman (1983) purport that biomedical practitioners believe that their domain is distinct from morality and aesthetics, and from religion, politics, and social organisation and that medicine may be a more discrete system, an artefact of human society, founded in a cultural framework of values, premises, and problematics, explicitly and implicitly taught by the communications of social interaction and then enacted in a social division of labour in institutional setting. Consequently, the central concern of biomedicine is not general well-being, nor individual persons, nor simply their bodies, but their bodies in disease. It is noted that while patients suffer “illness” (the patient’s understanding of affliction), physicians treat “disease” (their reduction of problems in the patient’s life world to disordered physiology). Hence, attempts to recognise the experience and contexts of patients’ suffering have generally regarded the subjective realm as peripheral to the real work of medicine. Hahn & Kleinman (1983) argue that it is through these productive struggles that the society of medicine reconstructs the subject of medicine itself, the human body, its pathologies, and its suffering into a politicised body, bearing the divisions, wounds, and scars of social life. Similarly, what physicians call “listening to the patient” and “taking the history” are medicalized tasks directed not at the patient’s life world, but at diagnostic

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evidence. This attitude of interested distance or “detached concern”, in part, suspends the persistent pain sufferer to allow a one-way exploration of their intimate pain stories or history. Vickers (1969:10) states that “medicine began its meteoric rise when it ceased to rely on what the patient said and attended instead to observable happenings at much lower levels of the biological hierarchy”. Nevertheless, Kleinman (1988) and Bendlelow (1993) assert that the context and social organisation of pain eventually gives the pain suffering experience some unity. That is, for all pain sufferers, at some time the authenticity of their pain will be questioned. Similarly, Corbin and Strauss (1987:249) note that changes to the person wrought by chronic illness, in this case persistent pain without a consensual medical diagnosis, affect more than physical unity, but concepts of the self. In turn they coined the term “biographical body conception” to include biographical time - past, present, and future in which conceptions of self are embedded. The body thus includes the sensory processes by which we “take in” and “give off” knowledge, and the medium we form, and our conception of self, or identity. In this way, responses to chronic illness become “biographical disruptions” and a “loss of self”. This point will be addressed contiguously. Hence, it is always necessary to reconcile the theoretical with the view that storytelling is an imaginative and interpretive enterprise, a way that individuals actively shape and account for the biographical disruptions that disabling events have wrought in their lives (Reissman, 1990:1194). Accordingly, the moments, when the persistent pain sufferer inserts a story into the interaction with the researcher-representing a particular instance for the listener, are strategically significant because this discourse form draws a listener most fully into the immediacy of the persistent pain sufferer’s world, and into his/her point of view. Reissman (1990:1197) states that

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stories, more than other forms of discourse, effectively pull the listener into the teller’s point of view. They re-present a slice of life, often by dramatising and re-enacting a particular interaction, thereby providing “proof” of how it was. They draw the listener so deeply into the teller’s experience that often a kind of inter-subjective agreement about ‘how it was’ is reached.

In the interviews conducted these were reserved for quintessential moments, and depict events which were critical to the persistent pain sufferer’s sense of self as partner, family member and responsible worker - a reality which sustained the lives lived despite disruption (Reissman, 1990:1195). These moments constitute the realisation of a failing body imbued in persistent pain, and the discovery that prior life ambitions and pathways will not be realised. Unwelcome discoveries of self, precipitate feelings of loss and culminate in alienation from the world that is known. Charmaz (1994) and Denzin, (1989a, 1989b, 1989c) assert that these unwelcome discoveries constitute turning point moments for the reconstruction of self, when unfolding events are connected to a personal sense of identity. This sense of self is endangered, however, for the persistent pain sufferer whose experiences, in sociological terms, are atypical of the discourse in which the experience is constructed and validated. This quandary may be best captured in the words of Scarry (1975:4)

when one speaks about ‘one’s own physical pain’ and about ‘another person’s physical pain’, one might almost appear to be speaking about two wholly distinct orders of events. For the person whose pain it is, it is effortlessly grasped (that is, even with the most heroic effort it cannot not be grasped); while for the person outside the sufferer’s body, what is effortless is not grasping it (it is easy to remain wholly unaware of its existence; even with effort, one may remain in doubt about its existence or may retain the astonishing freedom of denying its existence; and, finally, if with the best effort of sustained attention one successfully apprehends it, the averseness of the ‘it’ one apprehends will only be a shadowy fraction of the ‘it’. Thus, pain comes unsharply into our midst as at once that which cannot be denied and that which cannot be confirmed.

Consequently, physical pain, unlike any other state of consciousness has no objective referential content, other than that which is constructed by discourse, sustained by
language and subsequently learned as behaviours. Good (1994) stresses that often the persistent pain sufferer describes him or herself as “inhabiting a world that others can never know”. This sense of isolation is intensified when the persistent pain sufferer seeks to name their pain. An individual name, which accurately represents that pain, describes it with such clarity that its origins and contours are expressed, a representation possessing enough power that the pain can be controlled. The inability to control one’s pain removes the persistent pain sufferer from the known world and alienates them from the aesthetic fabric of living.

6.3 ALIENATION

Marx coined the term alienation to denote a worker’s sense of removal from the production of goods and services (Haralambos & Holborn, 1991:126). This term, however, has evolved today to encompass the general emotions of an individual who experiences powerlessness, despair, a sense of non-belonging, exclusion and loneliness. The use of this literary concept is particularly effective for contextualising the event of persistent pain in Western discourse because of Western society’s inability to normalise the persistent pain experience within its ideological practices or communal folklore, particularly for those who do not have a consensual medical diagnose. Within this framework the persistent pain sufferer is isolated and alienated from self, family and society, which constructs pain in language and behaviours.

Pain itself may be said to have an extensive history of development originating in revolutions in the modes of production and of exchange. Figlio (1984:175) describes the development of illness in light of the social relations of production. He states
a new theory, or set of procedures, or even a metaphysical shift which opens up a recasting of scientific discourse, follows elucidately from a social context in so tightly a determined way. (Thus) every social construction of science (pain experience) becomes a scientific analysis of the social parameters in the elaboration of knowledge.

Contemporary understandings of pain delimit the experience as simply the symptom of disease yet, persistent pain without a consensual medical diagnosis continues, and by definition lasts longer than six months. David explains his anguish at the realisation that despite medical intervention his pain persists:

Never, no way possible, I thought getting rid of the pain would be just mean going to the doctors and getting rid of it. That’s all I thought. I never thought for a second that three years down the track I’d still be having the pain (Verbatim Transcript, September, 1995).

David continues:

No, I can’t cope with pain, I don’t think anybody can, can they? It disappoints me that I can’t. When I seen me wife in that operation a few months back she was in pain too, but she, as she said it was only six weeks and she was you know, fit as a mallee bull you may as well say and she’s got no more pain. It’s hard (Verbatim Transcript, September, 1995).

Vince reflects on statements made to him by his doctor in relation to being retired and labelled an invalid:

I was still going to work, then in 1982 I went off on Compensation and had the laminectomy in 1982. I can’t remember now about September 82, and he said four months after the operation I’d be back at work but four months later I couldn’t even walk upstairs, ah. 12 months after the operation they said, the specialist said it’s something I’ve gotta live with, so um, where’d I go to from there, about in 1985 they pensioned me off, as an elderly pension from the Council and I was only in my forties.

For every time, after that I used to collapse. I could be down the yard, I could be upstairs I used to collapse and they thought it was heart attacks and things like that and then they found out when I was in the Gold Coast Hospital. They sent me to the psychiatrist, they turned to me and they said if you accept the way you are the better you’d be. I couldn’t accept it, so I used to have these tension build ups and I used to pass out, and they thought heart attacks for a while, but it was just tension. It took me two years to accept it. Ah I had to accept that I was. Which was in pain, and that’s something I’ve gotta live with (Verbatim Transcript, September, 1995).

Joanne presents an extant view, describing the significance of pain in her life:

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I was retrenched because of my back. I was only making it to work two, maybe two, or three days a week and always going home sick in pain. So it got to the stage where I just couldn’t handle work, and they retrenched me. I wasn’t happy at the time to be retrenched, but looking back, it was the only thing because I wasn’t functioning. It was upsetting.

My pain. It’s um. Yeah, I can talk about it, yeah. It is depressing, very depressing. Um it made me feel very useless. It was because I couldn’t do anything. I was in bed most of the time and my mother would come over and look after the house, and clean and wash and cook and everything for my husband and iron. I was just in bed. So it got to the stage where I think I more or less just gave up and thought well this is how I am going to be. I really went bad I suppose by July - August this year (1995). That was the lowest point because I went to the doctor again and he just said oh you have just got to live with it. He said it is just scarring tissue left from the other operation and no more can be done, surgery wise so it will um what did he say? I think he said that just the nerves would work themselves out. I had had enough and they would just shut down and then I would stop feeling pain. I was really upset about that. It was not the answer I was looking for (Verbatim Transcript, September, 1995).

Vince, David and Joanne express the need to be pain free, in order to return to a life in which they could function and actively participate. All believed that their pain would get better with David even saying:

Ah, Dr T and Dr W said you know its all chronic pain, at first I didn't even know what chronic pain was. I still don't know, all I know is that it is just continuous pain, I think and I don't get any relieve from it, you know, I don't get, some days I might get a light day of it its just, I've heard other blokes say they're alright for a couple of days, for a week, and then they just get them back. I haven’t had a weeks break from it since those three months when I had the Laminectomy (Verbatim Transcript, September, 1995).

He further explains the extent to which pain has become part of his integral life:

I'm just lonely without if I ever get out of it I'm lonely without it, its that way with me now, nights are me worst. I just cant sleep of a night (Verbatim Transcript, September, 1995).

A plethora of studies demonstrate that chronic pain tends to be treated within an acute framework model (Fagerhaugh & Strauss,1977; Seers & Friedli, 1996; Turp, Kowalski, & Arbor, 1997; Moore & Shurman, 1997). Merskey (1990) explains that if pain is easily tied to an external source then it is more acceptable, but this tying to

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external sources does not prove its occurrence. Kleinman (1988:3) elaborates this position asserting that chronicity is not simply the consequence of a pathology inside a person, rather it is the outcome of lives being lived under constraining circumstances in relation to others; of individuals learning to act as the chronic sufferer, and significant others learning to reflect this view. Vrancken (1989) notes that persistent pain should be seen as a quite different disease entity, separate from the initial nociceptive stimulus because the persistence of pain becomes largely dependent on behavioural changes, which in their turn may be induced, maintained and reinforced by environmental reward responses. The following excerpt from Vicki’s transcript exposes Vicki’s reliance on Bill, her husband. During the interview Bill returns from work and enters the dialogue I am having with Vicki. She explains:

I haven’t coped being a mum in the last month, I can’t change his nappy, You don’t mind him. I need him today Joyce cause I’m having one of those days when I can’t get it together. BILL SITS DOWN AT TABLE. Bill and mum have taken over in the last month. I feel bad about this. I cried a lot, I cried a lot because I can’t participate in like., all I can do is lie down and watch him play and watch Bill play with him, you know if he needs his nappy changed I’ve gotta go mum he needs a nappy change, you know, Bill he needs a nappy change, you know, how long I held him for this morning that’s it, that’s it as you can see my walk changed after I passed him over to mum because my the pain in my back got worse and that was only a few minutes I was holding him. I just can’t, that’s why I gave him to mum. That’s how it’s been ever since I had that 3rd injection. The 3rd injection was right down in the lower part and whatever he touched has made my soft tissue worse, if that makes any sense at all, with just one, Bill said that he put the needle in and then he said just hang on I’m gonna try something and he pushed the needle in a little bit more and that’s when he hit something in there and I’ve just let out an almighty scream like it was just and gee the pain, and like it hurt it really hurt and from then I’ve been down hill (Verbatim Transcript, September, 1995)

Vicki uses Bill’s belief in her pain to validate her experience. Bill’s belief and support of Vicki according to Vrancken (1989) encourage Vicki to sustain the pain role through a learning process and the potential for rewards earned. Turner & Chapman (1982) concur, suggesting that pain behaviours do not solely reflect underlying pathology but are subject to influence by a variety of factors including

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systematic environmental consequences. It is assumed that the pain, defined only in terms of behaviours, will be greatly diminished if the patient's physical and social activities are positively reinforced, and behaviours indicative of pain and invalidism are no longer reinforced. Cognitive-behavioural therapies have been applied to pain problems on the assumption that both the private suffering associated with pain and overt pain behaviours are influenced greatly by such variables as attention, expectancy, beliefs, and memory.

Vicki is characterised as someone who has some interest in complaining about pain and/or whose coping strategies have failed. It may be argued here that persistent pain may have given Vicki an identity, or that Vicki may avoid situations, which are cognitively linked to pain. The issue of altered identity will be discussed later in the chapter. However, a brief discussion of cognition and the persistent pain experience is now warranted as Vicki, Steve, Vince, David and Joanne all express the physical limitations of living a life with persistent pain. For example, Steve states:

Oh we went out a couple of Saturday nights ago down at um, what do you call it, Tweed Heads, and there was a band on there, I dunno if I was just worn out from here or what I was, and I got up, and I lasted five minutes not even that, the bottom of me foot went numb and its really, really uncomfortable when it goes numb cause I can't walk on it properly, I can walk, but I've got no feeling whatsoever and it just feels like walking around with a bucket of water on your foot (Verbatim Transcript, September, 1993).

Vince explains:

I'd like to go out on the boat every weekend with the family, every Saturday night out in the boat, in was our boat so everything we used to do we done as a family. We used to do everything as a family, then when this started and even after the operation. The boat sat on the grass for 12 months so then we decided to sell it, cause I couldn't use it. I couldn't stand the rocking in the boat, so we decided to sell. Our whole life changed completely. After that I did nothing. The whole family stopped doing things. Our whole lifestyle changed. The pain worried me all the time, or just thinking about it flaring up again. Always thinking about
doing something that would start it up again (Verbatim Transcript, September, 1995).

Turner & Chapman (1982) contend that a significant proportion of individuals with persistent pain, develop a complex constellation of symptoms involving affective, cognitive, and behavioural domains. Vrancken (1989) would argue that Vicki, Steve and Vince personify ‘typical’ persistent pain patient behaviours, which enhance and sustain their perceptions of being ill. They would not be considered ‘ideal’ patients, because they can not be convinced that the pain suffered is linked to particular situations, or are willing to cooperate with the proposed treatment. Contrastingly, Charmaz (1995) would purport that feelings about visible disability influences personal identity goals. That is, when men could not bide nor minimise their changed appearance, they often withdrew. This behaviour symbolises the actions described by Steve and Vince. Steve no longer went out or danced, as he once enjoyed; and Vince no longer participated in family pursuits. Charmaz (1995:664) continues stating that women withdrew less and dwelt upon appearance issues much more than men. Women tried to manage their appearance to handle their feelings and to bolster their confidence. During my second interview with Joanne, in her home, I noted a number of photographs of her prior to her persistent pain experience. The physical changes in her appearance were astounding. In fact, I was hardly able to recognise her. When Joanne saw me looking at the photographs, she reddened and said:

You didn’t know that was me, did you? I used to be really slim and I always took time to look after myself. But now I have trouble even getting to the shower and I have put on so much weight that I hardly know myself (Verbatim Transcript, September, 1995).

Like others who have experienced chronic conditions, Joanne experienced her body as more than altered--she felt it was alien, and the experiencing of this bodily alienation
led her to rethinking explicitly about her previously held notions of body and self.

Joanne describes her rapid weight gain and plummeting physical activity in the following:

He (the specialist) didn’t believe in physiotherapists so he just said to me. Oh just go about living the way you should live and he said you will eventually get back to normal soon. But I didn’t because my muscles were gone from all the years that I just didn’t get about to living to what he thought I was up to. So it was just more or less … just I could see each month I was just getting worse and worse as the time went on after the laminectomy. I did keep going back to him and he kept saying well the operation was a success, but you know you have got to get out and exercise and lose weight, and I just couldn’t do it by myself.

I took lots of painkillers. They did decrease some pain and made me feel a bit better but it didn’t, I had the impression it would take away all pain so I could get down and exercise but it was nowhere near enough to try and pull myself out of the bed and get down on the floor and do some exercises. It was just so hard to get down onto the floor, and of course, I couldn’t because of the pain. And now I’m so heavy- I’m heavy in a way that I have never been before.

Participants in this study have described experiences of multiple bodily losses and feelings of estrangement from their past lives. Charmaz (1995:661) asserts that when pain is wholly unanticipated, bodily changes are construed with a sense of betrayal. Past bodies are viewed as “invincible”, “indestructible” and “immortal” and the sufferer now expresses regret and anger about their losses.

The body, once considered a taken for granted possession to control and master, is out of control. Interestingly, Skevington (1983a; 1986) and Walker, Akinsanya, Davis & Marcer (1989) identified the persistent pain sufferer’s sense of perceived control as a central issue for constructing their lives. This induces the symbolisation of the body as an object to be mastered. The body is now a failed machine, an obstacle to be repaired and overcome. Vrancken (1989:438) asserts that pain is that mode of being in which the body becomes the centre of one’s life-world. Everyday life is pushed

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into the background and the body comes to the foreground, separated from the life-world. Isolation of the body and interruption of the inter-subjective contact, which goes with it, are the two main features of the pain experience. The isolated body loses its status of subject of the self-evident, hardly noticed but indispensable part of inter-subjective life. Pain hits in the first instance as a chasm in the continuity of existence. The persistent pain sufferer experiences the body out of its context, it is clear that he or she cannot speak: he or she cannot communicate his or her pain, it is as if the ‘physical’ pain experience seems a registration of a defect, and pain seems to reside in the body, but always takes place within the framework of existence, of the symbolic life-world. The meaning of a painful event plays a decisive role in the occurrence of pain. Pain is seen as an answer to a certain situation, an interpretation within the framework of existence (Vrancken, 1989).

The framework for experience is augmented by the interplay of the subjective and objective worlds of the persistent pain sufferer. Denzin (1985:223) asseverates that the resources for empirical analysis are drawn from the lived experiences of interacting individuals. These experiences are woven through the biographical structures of the subjects in question. He describes emotion as-feelings which are grounded in the social acts which individuals direct to his or herself, and those which are directed towards the self by others (Denzin, 1985). Consequently, Denzin (1985:225) continues, stating

emotionality draws the subject into social, moral, and emotional relations with others. These others are termed emotional associates. There are others who are implicated in the subject’s emotional world of experience. They may be witnesses to an emotional experience, or others with whom the subject shares the experience after the fact. They may be the interpreters of the individual’s emotional experiences. The emotional associate is a significant emotional other because his (sic) presence in the
subject's emotional experience becomes an integral part of that experience. These others aid in and contribute to the embodied feelings the subject experiences in the emotional situation.

Emotion's lived body is a corporeal schema for lived experience. It is a structure of lived experience, a repertoire of choreographed actions, movements, and feelings. Further, Denzin (1985: 226) claims that "the subject has a three-fold relationship to his body: He is his body, he is in his body, and he is outside his body (sic)".

Moreover, Denzin claims that the lived body is owned, cared for and dressed by the person. It is the subject's presence in the world; although seen by others, it cannot be fully grasped by the person. Thus, it may be said that the persistent pain sufferer's lived body is an expressive, instrumental, affective embodiment and extension of their inner and outer worlds of experience. This outer world consists of structures of behaviour, movements, mannerisms, gestures, and feelings that are uniquely the person's. This lived body is temporal structure that moves through the social situation, yet it is inter-woven with the subject's emotions, moods and self-definitions (Denzin, 1985: 227). The subject has a circular relation with emotion's lived body. What he defines in it - a pain, a sensation, a discomfort - comes to take on a localised meaning in a part of the body and in consciousness. Once interpreted, this feeling is given new meaning for it is externalised, symbolised, and made a social object in the field of experience of the subject (Denzin, 1985). The social science viewpoint suggests that illness and therefore pain manifestations are shaped by personal, interpersonal and cultural reactions to disease within a socio-cultural context (Anderson, 1981; Garro, 1994; Shorter, 1994; Holmes, 1996). It is in this way that society is able to learn how to identify and react to pain, how to label it and communicate dysfunction, or how to deny it and smoother it in silence (Kleinman,
1988; Pappas, 1991). Hence, it may be postulated that the persistent pain sufferer
draws on the resources of his or her body for the interpretations he or she brings to the
emotionality he or she is experiencing. Thus, as a desiring, feeling, interpreting self,
the persistent pain sufferer brings meaning to embodied experiences as they are
interpreted. This interpretation encourages not only the persistent pain sufferer, but
the medical investigator to speak in this double language in order to relate the
subject’s report of pain to a malfunctioning of his or her body. Notably, Szasz
(1975:xiv) contends that emotion does not exist, considered as a physical
phenomenon, for a body cannot be emotional, not being able to attribute meaning to
its own manifestations. Thus, to assert that it is only its particular meaning that
renders an experience “painful” is tautological; and yet it must be said in order to
clarify the endlessly repeated phrases in medical, physiological, and surgical texts
which report having “painful wounds”, or no “pain”, or of individuals having
undiminished “pain sensation” but diminished “reaction to pain.” All such accounts
suffer from mixing the vocabularies of physic and psychology. The pervasiveness of
this double language must be relinquished, or at least suspended, if a deeper
penetration into the personal meaning and social significance of painful feelings and
reports of pain is to be gleaned for the persistent pain sufferer’s life trajectory. What
is required is an emotional experience which joins the mind, body and lived sensations
of those who suffer persistent pain.

Subsequently, pain may be considered as a problem of consciousness. Vrancken
(1989:442) claims that pain is still a mystery, but its existence constitutes our being
human. In pain a part of the body enters our here-and-now awareness. Buylendijk
(1973:439) stresses that in the case of pain “man (sic) is hit in his psycho-physical

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unity, he lives through something to himself, not opposite himself”. At this point it is poignant to elaborate upon Denzin’s construct of emotionality and the development of self feelings. This is mandatory given that the persistent pain sufferer without a consensual medical diagnosis, interprets the self in relation to the constructed world. Denzin (1985: 224) states that emotionality

arises out of inhibited, interpreted social acts in which the subject inserts self-conversations between the perception of experience and the organisation of action. In these conversations, feelings directed to the self mediate action and interpretation.

Deep and surface meanings of the person are revealed through this interaction process. Deep and surface meanings refer to the private, inner self and the public, observed self, respectively. Surface meanings reflect the taken-for-granted feelings of the person. That is, the glossed, structural self of Goffman (1959:1). The deep, inner, moral self, however, the self of deep pride, shame, guilt, anger, remorse, or resentment is given in those experiences which reflect turning point moments for the individual (Denzin, 1985). These feelings cut to the core of the person, revealing profound inner meanings about the self. This selfness attaches the person to the world, and it is through this relationship that emotionality, self, and meanings are revealed. The persistent pain sufferer thereby enters the world through a relationship with themselves, as pained, and with their lived bodies. This is the body as experienced which, while a physical entity, is also an existential reality. Embodied experience reflects the individual’s current felt attachment to the situation in which he finds him or herself. This is a moving, unfolding process that turns back upon itself, trapping the persistent pain sufferer in emotional feelings that are both desired and not desired. When pain does not abate, the sufferer may view the body as a deadly enemy or an oppressor (Lum, 1997). The body as a physical entity is now alien to the

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persistent pain sufferer. The existential body causes anger, regret and guilt. Glassner (1988) states that perhaps more destructive than the anger is the shame followed by self-abasement that ill people with failing bodies experience: guilt because they share cultural standards of ageless bodily perfection and correct appearance; and shame because their existence testifies to a failure to meet these standards. Self-abasement follows and intensifies the humiliation. The unknowns of the past echo in the uncertainties of the present. Fear and hopelessness. Vicki (Verbatim Transcript, September, 1995) captures the essence of this sentiment in the following poem:

*Two Worlds*

*Oh, how quickly life can change, from the one you know to one so strange*

*My life is now pain, and pain; Inside my head each days a strain*

*I live and breathe the chronic way, it, the pain won’t go away*

*Acceptance is what’s hard for me, pain is what I want to flee*

*I live with chronic pain each day, “You don’t look it”, you all do say*

*YOU normal people cannot see: My life, I live, My World and Me!*

Vicki’s poem not only describes her sense of despair at being entangled within the worlds of pain and non-pain, but she expresses the melancholy of having a body which does not conform to the accepted construct of the *pained* body. Interestingly, during my interviews with Vicki, she exhibited the objectification of pain: that is, she limped, used crutches, alternated her position from sitting to standing to lying and most significantly provided me with a rich description of her pain.

*Um. It’s an ache, its a deep heavy ache, pressure um pin-point pain on the right side that goes down my bottom down my leg underneath my foot. It’s paralysing it doesn’t matter where I am when it gets that bad, I’ve gotta lie down, I’ve gotta get someone to help me lie down because I just can’t move, it’s that bad. It’s, the ache gets heavier and deeper and its right inside, its like, its not like, you know when you go for a run and you overdo.*

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it and your calf muscles ache, but that's surface hurt, this is right inside you know right inside your body like that Deflame commercial when you...and you can get right inside. yeah. Its right inside where you can't get to it. Yeah.

I have different sorts of pain I've got pain that goes down my spine either side of my spine, I can't describe the pain, but I can draw it for you. That's the inside of my spine and like there's just no missing in there at all on both sides all the way down, and like my shoulder blades I don't know where they'd come out. And that ache will head out but its not as sharp as close to my spine, its sharp, sharp wouldn't be the right word. It's like winding really bad, winding aches you know I can't put a word on it, but as it comes out the further it comes out of my body the deeper the ache is, and that goes all the way down until it hits that lump that I've got and that lump is deep and heavy and pressured really excruciatingly crushing at times, that pressure in there. If I can get into a corner in the kitchen and take the weight off onto my arms it relieves that pressure, doesn't relieve the ache, but it relieves that pressure, you know, which is oh, and like its ahhh (Vicki. Verbatim Transcript, September, 1995).

Having a visibly altered body provides the experiencing person, as well as family and friends with immediate images of change. One’s appearance is considered symbolically as well as literally since knowledge of loss can cast new light and force new self images upon an individual. But not all people with serious chronic illnesses have visible symptoms and disabilities. Looking healthy can undermine a person's credibility with health practitioners.

As a process, embodied experience reaches outward to carry the persistent pain sufferer into a desolation of experience that attaches him or her to others; that is, experience draws the persistent pain sufferer into a social, moral, and emotional relation with others. These others are implicated in the persistent pain sufferer’s emotional world of experience. They are witnesses to an emotional experience, or others with whom the subject shares the experience after the fact. They may be the interpreters of the individual’s emotional experiences. The other in the world of the persistent pain sufferer is significant because their presence in the persistent pain sufferer’s emotional experience becomes an integral part of that experience. These
others aid in and contribute to the embodied feelings the subject experiences in the emotional situation (Denzin, 1985:223).

Denzin (1985:224) describes four modes of lived emotion: sensible feelings; feelings of the lived body; intentional value-feelings; and feelings of the self and the moral person. Sensible feelings describe sensations felt in the lived body, but they are not deliberately produced. They are extended throughout, or located in the body as pain is, for example, but they do not originate in the self-conversations of the subject. They are part of the lived body. Others cannot directly share in them, nor know how they are felt by the person (Denzin, 1985: 228). However, these sensations are public to the extent that the word pain designates for the other an experience they have had in the past. Such expressions as “ouch”, “damn! that hurts!”, are forms of self-talk which allow the pain sufferer to establish an “emotional footing” (Denzin, 1985: 229). Importantly, sensible feelings may become symbolic tokens or symbolic representations of other events occurring in the subject’s world, including the appearance of a psychosomatic pain when a field of tension is about to be entered.

Feelings of the lived body, while accompanied by complexes of sensible feelings, are not located in a particular part or section of the subject’s body, but are given in the total extension of the body as a unitary field of experience (Denzin, 1985: 230). Because feelings of the lived body express an orientation to the interactional world of experience, they are accessible to others and they can furnish foundations for socially shared feelings. Others are able to vicariously share in the subject’s feelings. Lived feelings communicate an emotional definition of the situation that others can enter into. Hence they move emotionality out of the private, inner world of pure sensations.
into the public realm of interaction and emotional inter-subjectivity. The subject can communicate and 'give' these feelings to others, thereby allowing them to enter into a field of emotional experience with him (Denzin, 1985: 230).

Intentional value-feelings are feelings about feelings, and might be termed 'interpreted emotions'. They are felt reflections which are cognitive and emotional in nature, whereby the subject seeks to isolate the core meanings of personal experience. Here, the individual calls upon their field of experience to make sense of their world. Denzin (1985: 232) states

> intentional value-feelings originate in values that are outside actual emotional experience, located in the culture or the interpretive framework of the individual. Again, two levels to the self, the surface and the deep, may be distinguished. The surface, public self is given to others through the subject's communicative acts, and managed through emotional-management rules. The deep, inner, moral self is revealed through self and moral feelings which involve a feeling for the self as a distinct moral object and subject in the world.

The self of the moral person is the self that has dignity, self-respect, self-responsibility and an inner sense of moral worth. Moral self-consciousness or value-awareness is at the core of the person at this deep level. The moral feelings of the morally self-reflective subject involve a respect for the moral codes of the everyday lifeworld. By subjecting himself to this moral code the subject gains self-dignity and self-respect. This internalised self-respect, which comes from the inner and outer moral codes of the world of daily interactional life, constitutes the inner meanings of the moral person. Denzin (1985:233) asserts that the interpretive interactional life provides phenomenological accounts of lived experience. The self is depict as a complex structure that cannot be reduced to its social roles, its rituals and its acts. The world of lived experience is a world of passion, feeling and engagement, a world lost to the sociological inquirer who describes life merely from the outside.

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Gadow (1982) and Vrancken (1989) would claim that the persistent pain sufferer is removed from the symbolic order and relies on a dualistic relationship with the body. This mode of being produces alienation, an existential vacuum; being cut off from the outer world, thrown upon the body in itself, is isolation, disintegration, pain. As a consequence of this, pain requires an opponent, an antagonist. Pain inevitably creates a split within the individual. Immediately a dichotomy is brought about, the very dividing line between that which is hurting on one hand, and that which is submerged in pain, dealing with pain and trying to control it, on the other. Steve illustrates the dualistic construct of his persistent pain experience:

Well if you go and buy stuff you go and buy a new car or do something like that well this is my body I wanted to make sure that I was doing right thing and having the best people work on me, I wanted to be right and go back to work (Verbatim Transcript, 1995).

David also describes his body and the experience of persistent pain in a mechanical way:

I expect my body to be maximum efficient too. Yeah, I wished it was, like as I say I can't lift the things that I used to do, as I said I went and had a go at shearing sheep, I had to give it to me bloke, my young fellah he had to drag it out for me and that and I just couldn't finish it you just walk away disheartened, cause you used to be able to shear over 200 a day you know, now you're like a kid you've got a job to get off one (Verbatim Transcript, 1995).

Pain makes us believe that we can cut ourself off from the body. Through rationalising pain as I, and my body, pain can be depicted as the experience of psychophysical dualism. The antithesis of body and mind, body and soul, body and person becomes phenomenologically manifest in illness and suffering. By the triangular positioning of pain, ‘I’ and the body, the persistent pain suffer is able to gain communication with the outer world. Thus, pain becomes expression. Vrancken (1989:242) states

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Pain can be seen as the experience through which a person manifests him or herself as a human being. It is the only bridge to the world which is its source, the only trace that points to what is lost. The word pain, as language, as part of the culture, is a universal sign with the connotation of something lacking, and the impending violation of connection.

The person who suffers from pain and turns to a health professional is appealing to the other for help to return to the known world. Interaction with the physician may be successful if the pain has been placed in a context which makes sense not only to the sufferer, as he/she tells their pain story, but to the listener. In the case of participants it may be seen that the genesis of pain was tied to an accidental cause. This is in keeping with Garro’s (1994:778) claim that after establishing the genesis of illness the search for diagnosis assumes a different character. That is prior to help seeking behaviours, the pain and/or dysfunction remained for the sufferer, to a great extent, in the background of the individual’s life. After seeking help, the illness takes on more significance in the individual’s life and the search for diagnosis and treatment intensifies. It is only when the persistent pain sufferer is able to integrate the experience of pain in his or her life, are they able to shift priorities to the world from the body. If the persistent pain sufferer is unable to do this, the interaction proves to be a disappointment and complete reunion with the world may fail, and the pain remains, as an unanswered request (Vrancken, 1989). Scarry (1975:12) claims that pain through its unsharability, and its resistance to language destroys communication. Leaving the person in persistent pain to a world that is collapsing.

To return to Denzin’s point, lived feelings communicate an emotional definition of the situation into which others can enter. Through the process of emotional sociality the persistent pain sufferer makes a lived social situation, a symbolically objectified social process and, thereby communicate and ‘give’ these feelings to others allowing them to

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enter their personal field of emotional experience. Interestingly, Szasz (1975:xvi) asserts that it is the primary social function of the doctor to relieve pain, but that this function is called into question when the persistent pain sufferer is unable in the first instance to describe their pain, and eventually when able to do so via rational verbal objectification, remains in pain despite medical interventions. He describes these individuals as individuals who have made a career of suffering. A perspective eluded to by Freud in Studies on Hysteria (1983-95). Choosing pain as a career means attending to the dysfunctions of the body, real or imagined, and their repair. Thus, the health professional is required to treat the persistent pain suffer despite their apparent inability to do so. In quintessence, if persistent pain sufferers’ are not believed, and if a curative pain model is adopted and if health professionals become desperate to find a cure within this model, it is not surprising that persistent pain sufferers are coerced into looking for meaning for their pain and for accepting blame for their pain (Seers & Friedli, 1996). This is in stark contrast to that which pain sufferers are encouraged to believe by Western medical discourse. The disillusionment which occurs as a consequence of the medical nemesis, spirals the persistent pain sufferer further into an alien and isolated world in which subjective and social meanings require re-evaluation. Vicki (Two Worlds; September 1995) describes experienced isolation in the following poem:

Two Worlds

Isolation is a horrible thing, loneliness it seems to bring,
To be alone in this world of mine, it’s scary and its so unkind.

You make me mad the way you think, you push my anger to the brink.
I dislike everyone of you-

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As you’ve judged, so I’ve judged you.

So shut your mouth and that means you, you’ve had no idea what I am going through

How dare you disbelieve what I say—

I’d glad swap and live your way.

The perception of being devalued by others originates through the processes of interaction and influences how a life is re/structured. Anderson (1991:710) asserts that the feeling of being devalued results from a sense of not “being taken seriously”, “not being treated as a credible person”, not being listened to.

From 1977 to 1984 I was in severe pain and looking for alternative ways of dealing with it. It was the fact that my disc actually herniated, that is when I went to the first orthopaedic surgeon. I was just at work one day and um I just started to go like this, you know lean forward further and further and just couldn’t straighten and um within a couple of hours, I was right over and just couldn’t straighten so I suppose just whether I had just been sitting down at work and just sitting in the chair, that is when the disc actually herniated when I was at work one day and that is when I first started seeing the orthopaedic surgeon. Until that day it had just been all the other doctors. I hadn’t been to an orthopaedic by then.

After the disc herniated, I started going to the orthopaedic surgeon and he kept putting me into traction in hospital, ten days at a time. I must have gone I would say in three or four times before I had the first operation. I was having quite a bit of time off work. He didn’t operate until 86 because he thought I was too young to have anything wrong with me and he wouldn’t do any tests or anything like that. He said oh no you are too young to have a back complaint so eventually the pain just got so bad I booked myself into myelogram and a CAT scan at the hospital. He had said to me I won’t do those tests because you are too young and you can’t have that sort of a problem at your age. It just got to the stage where I couldn’t walk. I had this terrible limp. I mean people were laughing at me because of my limp but I wasn’t so embarrassed about it, it was that I was just dragging my left leg and yeah that is when I decided I just couldn’t take it any longer because I just couldn’t sit at work or do, and notified him and he got the results that night and I had the first laminectomy the next day.

I got to the stage where I couldn’t stand it any longer. I was just going down and he kept putting me in traction and after the traction I would come out and I still wasn’t better and he would sort of said oh well just start going back to work and all this sort of thing and he kept saying to me you know, you are just too young to have this problem. He just wouldn’t accept it and when he actually saw the test results that night and he said I will operate the next day. He actually did apologise, he said I am sorry about making that incorrect diagnosis, he said I thought you were just too
young to have a problem like that. I was furious because I felt age didn’t matter and especially since I had such an accident when I was eighteen years old. I knew the accident had something to do with it. I just couldn’t understand why he couldn’t understand that it can happen and at different ages. You don’t have to be a certain age for it to happen (Joanne, Verbatim Transcript, September, 1995).

Joanne expresses the view that her pain was not taken seriously because of her age, and up to that time the lack of visual cues. In short, she was not being given recognition for her expressions or representation of her persistent pain, despite her markedly visible limp. Szasz (1975), Vrancken (1989) and Shorter (1994) suggest that pain patients have a complaint about life: they are dissatisfied and disappointed in their belief in doctors, although, Holmes (1996) asserts that the strategies adopted by those without the legitimacy of a diagnosis is more a reflection of the overriding importance attached to the identification to a consensually validated physical diagnosis. Holmes (1996:115) states “such individuals crave personal meaning in the face of polysemous uncertainties”.

Vicki also expresses sentiments of devaluing and a sense of personal loss. In the poem Two Worlds, Vicki, like other persistent pain sufferer’s, reflects upon her life. She has re-assessed the costs and benefits of relinquishing activities and responsibilities, and although angry with the you reaffirms her wish to be like the you. This crucial point represents the tension between acknowledging bodily limits and needs and the construction of a preferred identity. Charmaz (1995:663) asserts that in order to handle their lives, chronic pain sufferer’s must be able to integrate self and illness without having it consume their self-concepts. However, as transcripts demonstrate, Steve, David, Vicki, Joanne and Vince continue in their struggle to resolve prior beliefs of self with living a life of persistent pain.
Charmaz (1995:) asserts that people with chronic illnesses resist altering images of
themself, especially if they perceive that others need them to function as before.
Further, Charmaz (1991, 1994, 1995) suggests that changing of self image requires a
threefold consideration. First, the individual's definitions; second, significant others' views and wishes; and last, the interactions and negotiations among them. This construct ties neatly with Denzin's (1985) concept of social emotionality. Once chronically ill people have altered their lives to accommodate altered self images, it takes substantial support to move beyond them. Thus, Joanne describes a life in which her identity and concomitant self image have been relinquished, and she has developed intricate strategies to preserve her sense of self. For years after having been immobilised by pain, Joanne balanced her work productivity with her ability to work. When necessary, she simply took time off from work to avoid being seen by others as not coping. By attempting to conceal her dysfunctional body Joanne was maintaining her sense of self. Persistent pain sufferers often exclude themselves from daily activities of life, thus closing their world. Vicki, for example, describes her inability to look after her child; David is no longer able to shear, to drive or to mow the lawn; Steve cannot return to truck driving or to riding his motor bike; and, Vince is unable to go fishing, climb the stairs or spend quality time with his children. The isolation of living in a closed world is intensified by fear of exacerbating their pain, so even when participants were able, from time-to-time, to cope with their level of pain they were reluctant to attempt activities which they considered to be beyond their capabilities.

Vicki states:

On a good day the pain in my back and shoulders is still there, not a burning - more like an ache. A couple of times when I've felt like that I tried to help mum with my baby, you know to bath him. But half way through the bath the pain returns worse than ever and I have to go lie down in my room and take some painkillers. So on most days now it doesn't

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matter how I feel or how good or bad my pain is. I let mum look after him.
I am just so worried that the pain will get worse. So really in a sense it
doesn't matter now. Either way I can't look after him (Verbatim Transcript, September, 1995).

David states:

I've been with horses all my life. I went, I was always camp drafting I used
to train race horses I was at the races every week, I've only just let me
licence run out I shouldn't of but ... I can't go riding any more. I am to
frightened I thought if I got on something happened you know I'd be back
where I started and um I still have me sheep dogs and that they are only
pets now, they're the only things that have been keep me, I just, I don't go
out anywhere I can't mix with people I just get too irritable and that, me
wife she wants to go out, I just say, go on go for your life, but she wants me
to come you know and I'm just not up to (Verbatim Transcript, September,
1995).

Weitz (1991) states that people with chronic illness may for a time, form separations
between their impaired bodies and their self-concepts. In this way, they are able to
keep their illness separate from themselves and their lives. By keeping illness
separate, they allay disquieting feelings about themselves and their bodies. Charmaz
(1980, 1994, 1995) believes that struggling against illness differs from struggling with
it. When people struggle against illness, they view their illness as the enemy with
whom they must battle, hoping to regain their past identities and to restore a now
missing sense of self. Usually at this point, they can neither face nor accept more
restricted lives and lesser identities than they had before illness. Not only do their
bodies become objects to mend, but they are also work-sites in which to do it. Vicki
provides valuable insight into the way in which bodies are viewed as objects to mend.

She states:

After the accident I could not move the pain was all through my back and
down my legs and into my shoulders. I went to the doctor and thought that
he would give me something to fix it. But no, nothing has fixed it. I tried a
chiropractor, a physio, and I've been on heaps of tablets to stop the pain.
Last week I went to a doctor and he said he thought he felt a lump on my
back and he said that that was a good sign. He took some x-rays and I am
going back next week for some injections into the lump. I really feel
positive. At last someone has found something that they can do something
about (Verbatim Transcript, September, 1995).
The situation differs for people who have already struggled with bodily oddities or "psychological" quirks, now redefined and legitimated as *bona fide* physical symptoms. Their initial diagnostic relief turns into the sobering experience of adopting their medical label and of defining what it means to them. As they do so, they may make the label their own while simultaneously objectifying their symptoms to fit the diagnostic label (Charmaz, 1995:665). Joanne illustrates this point in the following:

I felt pleased when all of a sudden this x-ray result said I have pain because I finally felt as if I had proved something. I was sick and that I was in this terrible pain and I wasn't putting it on and I just wanted something done about it. It felt good because I knew people close to me believed me. I believed it myself that it felt good when I could actually prove it. That I wasn't putting any of it on, and it was all really genuine and to just get out of the suffering and the misery that was really good. I was just in such much pain and to get out of that misery. The thought of it was good after the operation there was a hell of a lot of pain anyway so I thought I would be pain free as soon as I had the operation which took a while to comprehend. Just actually the thought of having the operation and having all this relief, pain relief, the before the operation.

I believe it (the pain) affected my self esteem. I wasn't as outgoing and as fun loving and joking around. I became very withdrawn and very quiet and alot of the time suffering the pain... I didn't want to tell everybody about it. So I, more or less, suffered in silence. Yeah it is hard, you don't want to burden it on anybody and you feel as if it is better off for everybody if you don't tell them. Family members knew what I was going through but it was very lonely, very lonely (Verbatim Transcript, September, 1995).

Interestingly, Vince, already the recipient of failed surgery, believes that if offered the opportunity for a repeated surgical attempt to remove his pain that he would gladly accept the alternative. However, he realises that surgical intervention would need to be pre-empted by evidence of another disc prolapse. He explains:

Yeah. It's probably been the worst it's ever been cause that's the reason they said you come in tomorrow for an operation, like I said, the doctors in Brisbane there a couple of months ago I said, he said what will you do if I said come in for an operation, I said I'll go home and pack my port now that's the way I felt. It was almost like a promise. You know if I find another reason for you pain would you come in and get it fixed. I would've done anything!. Now as far as I'm concerned they said the same thing last
time, and it just made the pain worse (Verbatim Transcript, September, 1995).

The objectification of subjective pain experiences may be explained by the conflicts and contradictions inherent in the influences of ideology. This point will be subsequently addressed, but suffice to say that the construction of the body in Western society has played a significant role in this mind-body split. Turner (1992:115-118) asserts that the body is shaped, constrained and even invented by society and as such may be seen as a social product. Moreover, Foucault (1979:37, 141) purports that the body is not only given meaning by discourse, but is wholly constituted by discourse and provides the link between daily practices on the one hand and the large scale organisation of power on the other. In effect, the body vanishes as a biological entity and becomes instead a socially constructed product which is infinitely malleable and highly unstable.

Foucault's discussions of sexuality (1978) and the study of contrasting systems of punishment (1979) emphasise the transition of discourses which directly constituted the body as flesh to discourses which indirectly controlled the body by constructing the body as a 'mindful body'. The construction of the 'mindful body' precipitated the enhancement of a professional discourse which was granted the ability to intervene in, and to control others' behaviour. Moreover, the 'mindful body' possessed consciousness, intentions and language, and thus as a social product could be controlled via practices which supported the dominant ideological influences of that particular discourse. Poignantly, Bates, Rankin-Hill, & Sanchez-Ayendez (1997:1433) assert that a world view which signifies the inter-relationship between the mind and body, and the consequent stress and alienation from self and society

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experienced as a result of this world view, are significant to the understanding of chronic pain in Western society and the place of the sufferer’s self within this context.

6.4 THE NATURE OF SELF

Witherell (1992) asserts that the self may be formed by two processes. First, through social formation, or the ways in which an individual is defined by social and cultural contexts. These contexts include the collective norms, mores, values, prejudices, and preconceptions that evolve over time and which are sustained by minimal consciousness. Moreover, these contexts are dynamic and influence the ways in which we interpret our world, act and grow. Second, the self involves one’s relations with others- our sense of connection with ourselves and with meaning systems that evolve from humanity’s mutual predicaments and possibilities. These processes together give structure to an individual’s daily existence by ordering the ways in which they learn, what they perceive, what they value and how they relate to others. Furthermore, Turner (1992:119) asserts that the self may also be considered in terms of product and process. The process occurs as the individual interacts with others, feels cultural constraints and imperatives, and evaluates herself or himself relative to experience, situation, others and general society. The self as product is construed as an organised stable entity with boundaries and parts which are integrated through memory and habits. Accordingly, the stable nature of the self is resistant to change. It is this aspect of self which is presented to the world and represents the measure against which one defines themself. Steve’s description of the impact of persistent of pain in his life demonstrates the ways in which his present self is being influenced.

The pain has stopped me doing just everything. Before August 1993 I worked six days a week, and actually I used to work. I used to start work on Monday night and finish on Saturday morning, I worked night shift, permanent night shift. I’d get me daughter, we’d go swimming, we’d go to

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the beach, I used to water ski, ride motor bikes all the time, that's been me life from the word go riding bikes. I can't ride a bike any more, I just can't do it, I scream with pain and my whole side goes numb. I had to sell me bike.

I used to ride a push-bike, I liked taking the kids out on push-bikes sorta thing, I can't do that, there's just no social life, you go out and you'd be miserable, you couldn't drink, if you did drink it would affect the medication you're on, and before you know it you're in that much pain and your sort of, and someone would bump me and you'd turn around and brrrr sort of thing, sort of burried up at everybody, always cranky, always, like not sleeping either, I've never been a person to sleep, but just being in so much pain, violent headaches all the time, and it got that way that I got sick of people saying like you know what's wrong with you, what's wrong with you, I said I've got a crook back, oh yeah. Sure they'd say (Steve, Verbatim Transcript, September, 1995).

The continued denial of Steve's pain meant that the significance of the event in Steve's life assumed dichotomous proportions. First, the actual living with pain and search for diagnosis; and second, his felt need to justify his pain experience to others.

David also describes his sense of self in the following excerpt captures the ways in which the interaction with others have precipitated life events since the occurrence of his persistent pain. He states:

When we were flat out shearing at other peoples shed, he'd ring me up and say oh can you, get someone to take your place and come up here and help me do the crutching because the flies were eating them and that. Righto, I'll look around and get another bloke and I'll slip up there for a couple of days just to help him out, I done everything for him he turned dead set against me, never came to see me after I had the operation, never come near me, he just told all his neighbours what happened and they said it got to be settled you know, and all the other people I shore for after the operation I was walking down the street with me wife one day and this other bloke Billy Green, I said How are you going Bill and just looked at me and I shore for him for about 18 years too, he just looked at me and I could hear him saying he's only going for a back claim, you know, after that I just come home and I said that's it, I'm selling me house I'm getting out of here. I sold me house, put me house on the market, sold me house and bought a place in another town (Verbatim Transcript, September, 1995).

David saw himself, and indeed held the reputation as the best Shearer in his locale, as a well respected man with friends who would be supportive of him following his injury. However, life events after his surgery caused him to review his sense of self and as a consequence of this review David sold his home and up-rooted his family and
moved to another town. Morse (1997:26-7) contends that from the patient's perspective, concepts such as uncertainty, coping, enduring and suffering, loss and illness act as transformative experiences which either assist or hinder the development of self because all reflect the dichotomous nature of the mind-body world view and the establishment of an individual's preferred identity (Charmaz, 1994:227): the individual basically desires to "maximise leading a normal life". Steve and David, for example, were unable to maximise leading a normal life within the constraints of their previous, or preferred identities. This dichotomy became the centre-point for all participants' pain stories and had poignant implications for personal identities.

Hewitt (1992) describes personal identity as the means by which an individual defines, locates, and differentiates self from others. The concept of identity implicitly takes into account the ways people wish to define themselves. Wishes are founded on feelings as well as thoughts. If possible, ill people usually try to turn their wishes into intentions, purposes, and actions. The concept of identity goals assumes that human beings create meanings and act purposefully as they interpret their experience and interact within the world. Charmaz (1995:663) contends that changing identity goals and thus held notions of self, take into account the individual's definitions of who they are and were; significant others' views and wishes; and, the interactions and negotiations among them. Given personal definitions, ill people only relinquish their identities and their accompanying identity goals when forced to do so, and may develop intricate strategies to preserve their identity goals. For years after having been immobilised by pain, Joanne balanced her work productivity with her ability to work. When necessary, she simply took time off from work to avoid pain, only to be confronted with pain which would not abate. She states:

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For months before July I could miss a couple of days easy. There was a
couple of weeks where I just didn’t even make it to work the whole week,
then the next week I would think I have got to try and make it to work and
that is when I would end up at the physio and be home by 10.00am. So it
did happen alot. And they just said, they believed for my own sake I
should have had time off to try and get my back better, but I just had no
where to go to get it better. I just didn’t know what to do. I’d had two
operations, and still in all this pain. I just didn’t know what to do, where
to go I just lived as much as I could (Verbatim Transcript, September,
1995).

Vince continued working despite excruciating pain. He states:

I’d wake up in the morning in pain, probably take some pain killers and get
ready and go to work. I’d think at that time, but I’d get up in the morning,
I’d still be in pain. I’d take a few pain killers with me to work, then when it
got to a certain stage I’d take’m. I’d take pain killers at work when I
couldn’t stand the pain. And when I couldn’t and they didn’t work, then I’d
be upset and crying at work. I didn’t come home. Oh no, I stayed at work.
I kept it (the pain) to myself. The blokes at work they didn’t know I was in
pain (Verbatim Transcript, September, 1995).

Furthermore, Charmaz (1995:660-661) asserts that people with chronicity resist
lowering their identity goals if they believe that others need them to function as
before. Joanne explains:

Um made me feel very useless it was because I couldn’t do anything. I was
in bed most of the time when my mother would come over and look after
the house, and clean and wash and cook and everything for my husband
and iron I was just in bed. So it got to the stage where I think I more or
less just gave up and thought well this is how I am going to be (Verbatim
Transcript, September, 1995).

Interestingly, in contrast to the view articulated by Charmaz (1994), Morse (1997:22),
believes that the focus on identity level, rather than the self, limits the scope of
understanding self to the “public self”. Morse (1997:23) asserts that the maintenance
of the integrity of the private self should be the primary concern of health professionals
when life itself is in jeopardy because the self is inner and private, and unique to the
individual, which is constituted as an object or product of itself. Comparisons may be
drawn with the work of Garro (1994) who explored hidden disabilities in two
populations of women with temporomandibular joint syndrome and “hidden” multiple
sclerosis with those suffering persistent pain, without a consensual medical diagnosis.
Here, all groups suffer pain which in all cases is non-verifiable. In Garro's (1994) study, women described the difficulty of maintaining a "public image of self" and fulfilling their work roles without revealing the identity that would place them in a sick and devalued role. In consequence, this choice requires maintaining a public face without social support or sympathy. Persistent pain sufferers without a consensual diagnosis also strive to maintain a public image under the influences of dominant ideological practices. That is, unfortunately, when persistent pain cannot be traced to a cause the sufferer is left with a sense of betrayal and the need to continue the search for the meanings of their pain. Vrancken (1989:442) states

when cures repeatedly fail, or when the explanations patently fall flat, we [sic] must confront again - with renewed seriousness, even desperation - the ever-implicit question of meaning. Moreover, pain, despite the myriad of implications it not only suggests, it always demands interpretation, like an insult, it seems to require an explanation.

For David, life revolved around being work, marriage, children and being a respected member of the community. His outdoor life was embedded in physical strength and the ability to shear sheep. He states:

I know I could go out and earn a good quid you know, keep things going because I was earning good money before this happened, real good money actually. I've heard all these other blokes you know they were all earning 7, 8, 900 dollars a week well you know I could earn 15 - 16, sometimes 2,000 dollars a week it all depends on how hard you wanted to work. I paid me house off, went on holidays always had a good car, a new car, bought a new car every couple of years. I had it paid off in two years, I went to the races a bit too, which we all do every now and then, never had to worry. The kids were good. Jeannie and I had our problems like any couple by we been together since we were young. I would be here today if it weren't for her. Yeah. I had some good days and some bad days too (Verbatim Transcript, September, 1995).

David's inability to maintain his persistent pain experience in the background of his life is supported by his belief that he was unable to function in the roles he was comfortable with. His view of his past self coloured his present view of himself. Gelvin's (1983) discussion of Heidegger's (1962) inauthentic self, as a way of being
in which the meaning of existence is lost or covered up is significant to understanding the stories of persistent pain sufferers. The inauthentic self lives in such a way as to avoid realising what it means to exist, as well as the realisation that one's non-existence is possible. The inauthentic self searches for answers and loses sight of the sense of the self (Gullickson, 1993). All participants in this study are consumed with the search for meaning for their pain, and herein lies the cover-up! Gullickson (1993:1387) affirms that the exhausting search for answers objectifies the self and experience, and closes down understanding rather than keeping them open to the possibilities for new understandings of being. Charmaz (1994:228) states

the self is both objective and subjective. It is objective in the sense that the person internalises the language, cultural, and meanings of his or her group. As a result, one makes objective appraisals of oneself and one's actions and responses in the same manner as any other object. Hence, estimation of self-worth affects the unfolding self. Sentiments shape self-worth and are subject to revision and even reversal when people do not have strong anchors to fixed and stable social organisations, communities, and other individuals. Without firm anchors, the self is more vulnerable to ongoing definition and redefinition.

Gadow (1982:86) points out, that although inseparable the body and self are not identical. The relation between body and self becomes particularly problematic for those who are chronically ill and realise that they have suffered lasting bodily losses. The problematic nature of such realisations intensifies for participants, who have previously pursued and preserved an endless vigour for life through personal abilities of being able to control and construct their bodies. Denzin (1985; 227) states

the body is both the vehicle for this movement forward and the structure that radiates and expresses the feelings that (one) feels. Hence embodied experience is situated, circular, temporal and dialectical, for it turns back upon itself. affirming, denying and elaborating what is and is not felt.

Foucault (1973, cited in Nettleton, 1991) contends that irrespective of the time or the place, the body is available as a site which receives meaning from, and is constituted by, external forces. That is, the body is a real entity which is constructed by the

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ideological influences of discourse a point to be subsequently discussed. Thus, the bodily experience of persistent pain is shaped by meanings and displayed pain behaviours which act as visible markers to legitimise changes to self. For David, Vince, Steve, Joanne and Vicki the encounter with persistent pain is intensified by multiple bodily losses, feelings of estrangement, of separation from their past familiar body and of loss of self since their pain is compounded by invisibility. Lum (1997:78) says

that the body once viewed as a taken for granted possession to control and master spins out of control. At best, the body is now a failed machine, an obstacle to be repaired, overcome, or mastered. At worst, it has become a deadly enemy or oppressor.

Let us return to Denzin’s (1985) point that experiences are woven through the biographical structures of the participant’s life. Emotion-as-feelings are grounded in the social acts which individuals direct inwardly, and to the self shown to others. Mordantly, Szasz (1975:xv) asserts that “emotion does not exist, considered as a physical phenomenon, for a body cannot be emotional, not being able to attribute meaning to its own manifestations.” Rather, to assert that it is only its particular meaning that renders an experience “painful” is tautological and this stance should be relinquished, or at least suspended, if a deeper understanding of the personal meaning and social significance of painful feelings and reports of pain are to be gleaned. Thus, it is as Denzin (1985:224) posits, that is the emotionality of persistent pain:

arises out of inhibited, social acts in which the subject inserts self conversations between the perception of experience [persistent pain] and the organisation of action. In these conversations, feelings directed to the self are mediate action and interpretation. Emotionality becomes a social act lodged in the social situation.

Foucault's epistemological view of the body means that it disappears as a material or biological phenomenon inasmuch as the body's existence is permanently deferred to
grids of meaning imposed by discourse. It is this signification which constructs our ‘forms of life’ guiding what we do and gives meaning and rules to our pain language and experience. Thus, emotion’s lived body is a corporeal schema for lived experience. It is a scaffold which structures the repertoire of choreographed actions, movements, and feelings which signify pain. In keeping with Sartre’s (1974, cited in Nelkin & Tancredi, 1989) opinion of a body-for-the-person and a body-for-others and the manifestation of Foucault's view of the mind/body relationship, the body tends to be reduced to an inert mass which is controlled by discourses centred on the mind. Once the body is contained within modern disciplinary systems, such as the Western medical system, it is the mind which takes over as the location for discursive power, because lived pain experience is constructed and, therefore, amenable to control and domination through a normalising gaze which introduces the “constraints of conformity .. (that) compares, differentiates, hierarchises, homogenises, excludes” (Nelkin & Tancredi 1989: 8).

Kleinman (1988), Cassell (1991; 1993) and Bendelow (1993) have discussed the discursive power of the medical diagnosis in maintaining the conformity persistent/pain experience, and Bendelow (1993) asserts that it seems ludicrous when a biomedical diagnosis is not possible to the exclusion of all else as is the case for individuals who are experiencing persistent pain, especially if it cannot be traced to a medical cause that the unifying aspect for all these sufferers is that at some time the authenticity of their pain will be questioned. The issue of whether pain is of the body, or of the mind, arises when actual events diverge from those predicted by the simplified world of the cultural model for what happens when someone has pain. The discrepancy arises, for example, when the health professional consulted is either

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unable to detect an underlying organic problem or when the patient does not improve with treatment. Vicki explains

People don't believe that I suffer pain, specialists because I had the accident on my way to work, specialists seem to treat you like dirt. Um I felt like dirt and I didn't know what to do or where to turn.

It was about the middle of 93 un when Workers Compensation, 9 months after the accident, when Workers Comp took me off Workers Compensation because they couldn't find anything, that's when I just, that when I was thinking I shouldn't be sore, they can't find anything that's causing the pain I shouldn't be sore I shouldn't have this pain, so and denial was quite strong then to, as in I don't have pain, I don't have pain, I don't have pain, oh god, I have pain, you know, I can't have pain, you know, they can't find anything they know what they're doing, they're the specialists they're saying to me that there's nothing in all these bone scans so I obviously am doing it to myself, you know, but as time went on, it just wasn't right, you know, I've got pain, you know and they're wrong, if they can't find something that doesn't mean I don't have pain, you know, it took maybe 12 months for me to hit that point where I've got pain, you know, I don't care what you say, I've got pain you know, and if you can't find where it coming from then that's not my fault that I've got pain.

When they told me that there was nothing wrong with me I was really upset, really upset, devastated, mad. Then I realised I was alone, um, pushed aside, disbelieved, they made me feel like I was out for the money, I was, and that was what I was doing, I was wasting their time because all I wanted was the money from the compensation, yeah (Verbatim Transcript, September, 1995).

Joanne states:

If the medical profession can't put the finger on what's wrong, they say it is in your head and send you to a shrink. But the shrink just puts you on medication, but the pain doesn't go away. You go back and tell em and they just put you on other tablets. No one really cares they just want to put you in a slot so that you just go away (Verbatim Transcript, September, 1995).

McCracken, Klock, Mingay, Ashbury & Sinclair (1997) studied chronic pain sufferer's satisfaction with treatment and found that satisfaction predictors included confidence and trust in the provider and pain reduction following treatment. Vicki's and Joanne's experiences reflect neither of these components, but are consistent with the findings of Roth, Horowitz & Bachman (1998) whose study revealed that patients with chronic myofascial pain were significantly more dissatisfied with the treatment
of pain by physicians and reported particular dissatisfaction with the informational aspects of doctor-patient interactions. Large (1986:295) asserts that interviews with people in chronic pain are fraught with difficulties in making rapport and managing denial. Pilowsky & Spence (1975) and Seers & Friedli (1996) note that not only are patients affronted by doctors who are unable to alleviate their pain, but doctors are confronted with the almost inevitable hostility of patients and experience guilt and resentment when unable to treat the persistent pain sufferer’s pain. Rose & Fitzgerald (1987) contend that most doctors who encounter patients with chronic pain are frustrated both by the patient and by the failure of traditionally prescribed treatments. Moreover, doctors often write these patients off as hopeless cases, beyond medical help. Here, medicine is silenced because it cannot nominate pain, the ‘private’ experience, and therefore cannot objectify pain. What it can do is relieve pain by sophisticated methods, because pain seems to leave it no choice. What it can do is classify persistent undiagnosed pain into an extensive list of syndromes, as if, by putting pain into the medical discourse, its grip on pain is restored (Vrancken, 1989:437). Conversely, sensing the doctor’s hostility, patients may respond in similar vein. Often expecting some miraculous cure, they do the merry-go-round of doctor after doctor in a futile effort to find relief. What the persistent pain sufferer defines is a pain, a sensation, a discomfort. This experience comes to take on a localised meaning in a part of the body and in the individual’s consciousness. Vicki and Steve externalise and localise their persistent pain in the following:

Its an ache, its a deep heavy ache, pressure um pin-point pain on the right side that goes down my bottom down my leg underneath my foot. It’s paralysing (Vicki, Verbatim Transcript, September, 1995).

Steve explains:
I went numb from the waist down I couldn’t feel anything like I couldn’t feel anything from the waist down, but from there up it was just like a red hot burning sensation in the lower part of my spine, and just gradually got worse and worse and in me hand. I’d get all this tingling feeling through me hands and in my arms. On me left side of me head I’d get violent headaches (Verbatim Transcript, September, 1995).

Denzin (1985:229) states that the feeling of pain, once interpreted, is given new meaning because it is externalised, symbolised, and made a social object in the field of experience of the subject, casting the persistent pain sufferer further into the quagmire of a search for validation of their private self, and conformity with dominant modes of constructing pain. Turner’s *Theory Of Bodily Order* (1984:206) provides an interesting account of the minimal bodily tasks societies must fulfill in order to reproduce themselves, that is the body must be pain free in order to function within society. This theory explains how the body may break down and become ill as a result of the modes of control imposed on it by society, and provides a clear sense of how the material body is implicated in structures of socially acceptable modes of presentation. Goffman (1969) and Turner (1992) assert that the management and moulding of the body has become increasingly central to the presentation of self-image and in consequence it may also be argued in keeping with the works of Charmaz (1987) and Shorter (1994) that persistent pain is a paradigmatic illness, much like Repetitive Strain Injury (RSI), which expresses the breakdown of the body under the competitive pressures of self-presentation. In the true sense of the word the persistent pain sufferer encounters a shattered reality, attempting to reconcile their private with their public self. Garro (1994: 178) states:

that through illness, the body is transformed, no longer “the subject of unconscious thought”, rather the hierarchical relationship of the mind directing the body’s actions can no longer be presumed in a body that is “rebelling” and that “turns on you and you can’t depend on it.”

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That is, the persistent pain sufferer longs to return to a situation where the body is not actively considered, but simply taken-for-granted. Vicki recounts her dreams and aspirations at leading a life, previously taken for granted:

I used to be really independent. For me that means not having to rely on anybody, confident in my own decisions, like I would make decisions that my friends didn't like or didn't agree with, but as long as I was happy in myself with my decisions with the things that I did I did them, and I would explain to them, you know, if you don't like it, you know it's not my problem. You know, but I'm going to do it anyway, you know um yeah just not having to rely on anyone for anything, financially or um I wouldn't say emotionally, because that what your friends are there for, for a hug here or there, or a joke, and but um just not having to rely yeah on people for things, like other than getting your car tuned you've got to take your car somewhere to get it tuned - things like that - you know you've got to rely on other people for things like that, but just everything in general you know in relation to your own life. I miss that (Verbatim Transcript, September, 1995).

She continues by describing what her future identity goals:

At 35 I was going to run my own business, um, have my own house, have achieved the small little goals along the way where I wanted, um, like doing the nail course so I could set myself up eventually so I could work from home when I had a family, work my own hours to fit into my lifestyle, um I wanted to do a little bit of modelling, um learn the drums, you know just all these little things that I had planned to do along the way, but by the time I was 35 I was going to have achieved everything that I had planned, I had booked in to do a fantasy make-up course in February of '93, that went from February to August and that's like cuts and bruises that you see in the make-up on TV. Um, it was going to cost me $1100 to do, and then I was going to harass Movie World to work voluntary on weekends so I can learn more, plus the people down there I'm quite sure would like their nails done, so my nail business would pick up as well. Just things that get back into squash, um, get back into netball, just little goals you know that I've wanted to do that I've set myself to do along the way. If I was still playing squash and netball when I was 35 that's great, you know, that's an added bonus. But, you know just doing things that I enjoyed doing, you know, its like people that have jobs and have been in that job for 10 years and they hate it, you know I always think why don't you change your job instead of coming home and bitching and whingeing and moaning to everyone about your job, why don't you just change your job, you know to one that you like, you know, I'd change jobs but that was with um like I'd go for interviews where they would promise promotions and grading from receptionist work to computer work, you know up the ladder to um credit department you know things like that just didn't happen, you know, you got that job and that's where you stayed and I would apply for whenever the jobs came up I would apply and I always got knocked back. you're too good with job that your doing you know, so from then on my work with that company would deteriorate and I would go out and find another job where I could improve and get better and when I found that that was never happening that's when I thought well right I'll go into business for myself. What is it that I would like to do in my own business, in my own time, from

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Characteristically, for Vicki, attempts to reconcile her private and public self engendered a sense of being governed by forces outside her control and pre-empted feelings of helplessness and hopelessness. Furthermore, Charmaz (1995:263) suggests that until individuals are able to achieve at least some control over their illness, they remain orientated to the present and to finding ways to procure some relief. The search for an answer is described by Joanne as “a full time job”, by David as an “ongoing thing that is never going to end until I get better” and by Steve as “something he would pay a million dollars for”.

To sum up, persistent pain is a phenomenon which is socially constructed as a product which calls into question the dichotomous nature of the mind and body, or the private and public self of the sufferer. It is the public self which needs to be managed and when attended to successfully brings compliance of the persistent pain sufferer and conformity to the pain experience. In attempts to gain compliance and conformity to the experience of persistent pain which does not abate, is again re-constructed, within discourse, to be an affliction of the mind. Contemporary terms which encompass this perspective include syndrome and myofibromyalgia, or psychogenic pain. Under the antiquated DSM-R classification, terms synonymous with psychogenic pain disorders. All so-called psychogenic pain resembles, of course, certain older concepts of malingering, conversion hysteria, and hypochondriasis, according to which patients of this sort are like imposters: though healthy, they deceive others, or even themselves, with faked illnesses. Large (1986) asserts that this view is substantially correct, but incomplete because it neglects the complementary deception of patients by physicians.
which is the soil in which the patient's deception grows and flowers. This simply implies that the physicians do not clearly inform their patients that they cannot help them, or that patients do not make themselves clearly understood to their physicians.

Psychogenic pain disorders are defined as psychiatric disorders in which psychologic factors appear to be primary in the generation of pain complaints. Psychologic factors are considered to be involved in the pain complaints when there is a temporal relationship between the onset of pain and an environmental stimulus that is apparently related to a psychologic conflict; when the pain appears to enable the patient to avoid some noxious activity, event, or responsibility; or when the pain promotes the individual gaining emotional support or attention that might not otherwise be received (Stoudemire & Jeet, 1987). Interestingly, this classification is only evoked when the presence of severe and prolonged pain is the primary complaint. In addition, the pain experienced is not consistent with known neuroanatomical distribution of pain receptors; no organic aetiology is detectable to explain the pain; and no known pathophysiological mechanisms can be invoked to fully account for the pain. To return to the pain chronologies presented earlier in this chapter it is seen that all participants except Vicki have unsuccessfully undergone surgery to relieve their pain. Thus, it is may be said that a pathological cause had been determined for four of the participants, although at the time of interviews all participants were, or had been treated for depression. Vicki explains:

From there we just sort of coped day by day and that's when the depression really started to set in. I would get these half days where I'd cry you know for like half a day, and then I'd be fine for two weeks, and that went on for a few months, and then it went to a full day of crying, and then it went to two days, then it went to three days, as time went on the depression got worse and I didn't realise it was depression at the time. The psychologist
that I got hold of, he's down at Pacific Fair explained that's how depression starts and that's how it works if you don't get help, you get worse.

My depression was caused by my lack of independence, with lack of independence comes invasion of privacy, um inability to do things, too scared to do things because pain might intervene um, I'm not the person I used to be and I believe the person that I used to be and hating the person I am now (Verbatim Transcript, September, 1995).

Joanne says

When I was at a low I was cranky, depressed, upset and crying, bad tempered, didn't laugh, even up until coming to the pain clinic. I have been on medication on Prozac for awhile to try and help me through but I still have bad days. I mean I am sure they are healthy but still have a lot of bad days. Actually I have been on another anti-depressant before Prozac (anti-depressive) um about 92 I went and saw a psychiatrist because of my depression. I was just so low and he put me on something I don't know what it was but it was one of those anti-depressants that slowed you down and made you really tired and this sort of thing. He treated me for a good twelve months and I just felt as if I was going absolutely no-where. I was always tired from the drugs and all this sort of thing, so I tried another psychiatrist out near where I live and um he was really good, he was just a young bloke and he was easy to talk to and um he suggested the Prozac when it came on the market. Probably another eighteen months, about eighteen months ago now I guess when it was pretty new (Verbatim Transcript, September, 1995).

Vince recollects:

Well I don't think I was worried about the family during the two years I didn't accept it, I mean I was more worried about myself. I didn't know about the family what they thought of the whole thing at that time. I think I was more concerned with number one. I was depressed, I'd say 99% of the time. They tried to treat me for depression with medication but the side effects from the medication was worse than the depression. I refused to take the medication then. The medication it effects your brain, your not with it, seems to make the depression worse, you can't think, don't feel like doing anything or going any where, so that's what makes me stop taking the medication, the doctors used to go crook.

Ah, at the present time, I'm not taking anything for depression. I'm seeing a psychiatrist in Brisbane who specialises in pain, I've had two visits now but I think I'm just about ready to stop going to him, cause he's trying to treat me with medication too. I thought he could actually talk to me to get things out that way, not being able to deal with pain, but he's not, he's just trying to treat me with um medication.

I need to talk with someone about what's going on. Yes, I think I want help but I didn't know where, cause I used to ask the doctors I'd say I wanna see a psychiatrist I wanted help, and they said there's nothing wrong with your brain, you don't wanna see a psychiatrist, that's what they actually told me (Verbatim Transcript, September, 1995).
Depressive illness is often touted as the reason for unrelenting pain and the inability to cope or function with life's problems, although recent studies effectively argue that instead of the pain being secondary to and a manifestation of the depression, the depression is a consequence of the chronic undiagnosed pain (Stoudemire & Jeet, 1987). The persistent pain stories, contained herein, attest to this premise. All participants described a life, prior to the development of pain, full of promise and unending possibilities.
When I asked Steve whether he had any plans for the future he responded:

I wanna get on with me life I know that. That means going back to work. I don't know what I want to do that's my biggest problem. I'm not well educated. I think it's too late to be educated. I don't know what I can do, all the jobs I can do mean I've got to work long hours like of a night and stuff like that, I don't wanna do that. I wanna be like normal people, I just wanna go home at five o'clock at night, sit down with the kids and spend time with em and grow up with em instead of being this mess that sits on the lounge asleep all the time, that's what I've been like for years, and I just sit, I wanna be like a normal person and get on with me life you know, go to the beach, go on picnics, go for walks in the bush, push bike riding, fishing. But at the moment I just need to find a way to deal with my pain (Verbatim Transcript, September, 1995).

Steve has been the recipient of anti-depressive treatment regimes, but prior to developing persistent pain had not demonstrated depressive tendencies. Suffice to say that all participants had not demonstrated depressive tendencies prior to developing persistent pain. Teasell & Merskey (1997:229) state that many chronic pain disorders have been characterised by a lack of readily demonstrable pathology, resistance to treatment, and associated psychosocial difficulties. The difficulties inherent in the diagnosis, or lack of diagnosis precipitate depression in persistent pain sufferers, but orchestrate their experiences within the confines of dominant ideological practices, although Brown, Robinson, Riley & Gremillion (1996) in a study of Tempromandibular Disorder (TMD) found that with a learnt or behavioural model of suffering the negative affect is an important mediating variable in the relationship between pain and life interference. Stoudemire & Jeet (1987:82) that psychogenic pain as a variant of a depressive illness often responds to antidepressant medication. However, data suggests that the response to antidepressant may be due to alteration in serotonin and endorphin levels in the central nervous system structures modulating pain awareness rather than to improvement in the depression.
The attribution of the persistent pain problem to a malfunctioning mind rather than to
the body implies that it is the sufferer is to blame both for the pain being suffered and
for the failure of the health practitioner to achieve a cure (Garro, 1994; Seers &
Friedli, 1996). In fact, Garro (1994:) states

While one may not be responsible for a problem of the body, the same
cannot be said for a problem of the mind as the mind is integral to the self.
A problem of the mind, based in the psychological response of the
individual to life experiences, reveals the inadequacy of the sufferer. It has
been reported that when a doctor could not find anything wrong or if the
patient did not respond appropriately to treatment, the standard procedure
was for the physician to ask something like: “Have your been under any
pressure lately?”

Not surprisingly, persistent pain sufferers were reluctant to accept blame for their
pain, they are socialised not to do so (see Illich, 1976), and vehement in their
declarations that their pain is not in their heads. Vicki describes her feeling in relation
to others saying that her pain was in her head:

I really did start believing it's in my head, I'm obviously after the money,
you know, and it was screwing me up even more thinking that way, because
the pain was still there, you know, and like I'm trying to tell my brain, you
know, you can make the pain go away because you're making the pain there
in the first place. So it really, I even spoke with mum about suicide.
November of 93 I sat down and I said to my mother if I'm still in this much
pain by June next year mum, I'll jump, I will jump, I cant, I cant cope with
it any more. No-one's believing me I'm making up the whole story
(Verbatim Transcript, September, 1995).

David explains:

People have told me the pains in my head. I just said look you know, in me
head, trying to tell me its in me head, I just walk away and shake me head,
that's all I do. I say oh you'd know, People have told me its all in me mind.
.A couple of blokes, mates and that have, supposed to be me mates, and ah
me doctor he would never, I said to him one day I said I suppose your sick
of seeing me too are you, he said it to me on two or three occasions and
that, he said oh what makes you think that, I suppose that you'll say that its
all in me mind or something (Verbatim Transcript, September, 1995).

The preceding discussion explored how persistent pain sufferers draw upon the
cultural schemas contrasting an illness of the mind with one of the body in
constructing their narratives and reconstructing their past. Overall, the narratives
typically recount the search for an answer that will help persons make sense of what is happening to them and a justification for their persistent pain experience.

Let us now return to the dilemma of the perceived self and the actual self. Charmaz (1994:234) believes that repercussions to self are threatened or exacerbated when a particular experience, injury and resulting pain, or the realisation that pain will not abate are overwhelming, and the suffering individual is unable to reconcile who they are. The inability to reconcile self is a consequence of living with persistent pain. David’s story suggests, and it is a major theme of all persistent pain stories, that the assimilation of prior with present self may be reinforced or undermined by others who doubt the presence of pain in the suffering individual. Others encompass a gambit of persons from significant others to friends, acquaintances, and health professionals.

David states:

I am not envious of people who don’t have back pain. No, not now, I was at first I wished it on a lot of people. Ah people who’d used to say there’s nothing wrong with you and all of that, you know you look alright. I used to just walk away and say that’s what you think not me. People like Bill Green and a few other fellas just I did do that a few times actually wish it onto people, I always said why me you know, so. It doesn’t worry me now, it does but I’d like to get it out of me, I don’t go saying things like that now, you know as you get older you learn to live with it, I know I’m not gonna get right and that’s all there is to it. That’s how I really feel. Yeah (Verbatim Transcript, September, 1995).

The implications of other’s disbelief about the experience of pain in the suffering individual and the repercussion to the same on David’s life trajectory are significant. David reluctantly signed papers which established his back injury as a Workers’ Compensation claim in order to support his family. He continues:

The person where I hurt meself, I’d worked for him for 15 years shearing you know. I used to go and do his shearing every year. He wouldn’t even talk to me he just defied that I, cause I used his claim for, you know, and when I rang him up, when I first hurt meself I rang him up and said look Dr. Lewis has put me off for a month can I get the, can you send me a form for workers compensation, he said you’ll be right just give it time. I said what am I going to live on, and he said just give it time you’ll be right,
and then I was in bed and Fred, the union organiser, come around, cause some of the boys told him about it, he come round and seen me, and he said have you got the compo going yet? I said no, no, this would have been about a month after that and ah he said what are you living on, I said just a bit of money I had put away, I said I rang him up and he wouldn't give me the papers, wouldn't send me the forms. He said well you give me the phone number and everything and I'll go and see him. He did he drove out the next day and seen him he wouldn't give them to him, but he told him that if he didn't send them within seven days he'd have in, something, they put some court order to send them and I got them in the mail, and from that day that blokes never ever spoken to me.

After the accident he never ever spoke to me, and I'd worked for him for 15 years. And when we were flat out shearing at other people's shed, he'd ring me up and say oh can you, get someone to take your place and come up here and help me do the crutching because the flies were eating them and that. Righto, I'll look around and get another bloke, and I'll slip up there for a couple of days just to help him out. I done everything for him.

He turned dead set against me, never came to see me after I had the operation, never come near me, he just told all his neighbours what happened and they said it got to be settled you know, and all the other people I shore for after the operation. I was walking down the street with me wife one day and this other bloke Billy Green, I said "How are you going Bill" and he just looked at me and I shore for him for about 18 years too, he just looked at me and I could hear him saying he's only going for a back claim, you know, after that I just come home and I said that's it, I'm selling me house I'm getting out of here. I sold me house, put me house on the market, sold me house and bought a place at Bogavilla (Verbatim Transcript, September, 1995).

David's story encapsulates the isolation felt by persistent pain sufferers in this study. Osborn & Smith (1998) undertook an interpretative phenomenological analysis of chronic benign lower back pain sufferers and found that the experience of pain is mediated by its meaning to the sufferer. The meaning to the sufferer is compounded not only by the search for explanation of their pain, but by comparing their actual self with other selves, not being believed by health professionals, friends and significant others; and by withdrawing from others. Studies by Carson & Mitchell (1998), Seers &Friedli (1996), Charmaz (1995), Hitchcock, Ferrell & McCaffery (1994) and Reid, Evans & Lowey (1991) have extrapolated this point to account for the sense of desperation and isolation experiences by those who experience persistent pain which is not verifiable and identifiable. Research relating to spousal adjustment to partners
who experience persistent pain (Block & Boya, 1984; Flor, Turk, & Scholz, 1987; Flor, Kerns & Turk, 1987) supports the view that the persistent pain sufferer often maintains pain-related behaviours and a self-perception as a consequence of reward and reinforcement from significant others. Significantly, Stampler, Wall, Cassini & Davis (1997) found that the more satisfied a spouse, the more physiologically reactive the spouses were when listening to the patient describe pain, and the less reactive when responding to it. David's relationship with his wife evidenced this perspective.

He recounts:

The only thing that's hanging onto me here is you know I've got a fantastic wife and ah. She reckoned my attitude changed completely, I went from a happy bloke to a cranky bloke and she thought I didn't like her and all that sort of thing, the kids actually thought that too. Either of them they didn't realise to go and have a shower and throw myself down on the bed but she was always there when the help was there, if I couldn't get out of bed, she always made sure she was there to get me out of bed and that sort of thing. She always went to the doctors with me but ah we've been pretty good you know, she sort of accepts it now.

Sex life was no good, I was no good down there for a while, still not much better but I'll... but that didn't worry her, I suppose it was worrying me more than her, but ah everything just turned around from being good to being everything just come down on me with one lousy fall. Its hard to explain it sort of thing (Verbatim Transcript, September, 1995).

While David acknowledges the support he needs from his wife he also tells of his withdrawal from friend and family life.

I've worked half me life and then it started that they wouldn't talk to me the other blokes, no matter where I went, people said, I'd never told anyone I had a crook back or anything, but they could see it the way I was getting around, nah, there's nothing wrong with you. You know (Verbatim Transcript, September, 1995).

He continues:

I just got that cranky in the end I started mowing the lawn mower around, my attitude changed, I've been married 25 years, I've a girl 24 and a boy 21 and I've never had a fight with me wife in me life and I'd just sort of bitching to one another, its my fault I'll admit she was A1, she couldn't get over the way I'd changed and everything and um, I thought, I just didn't know what to think any more (Verbatim Transcript, September, 1995).
Vicki states

Yeah, Yeah, I couldn't do anything. It was just devastating. I didn't know why I lost a lot of friends, because I had to rely on friends to do everything for me so they got tired of me, so along the next three months after the accident I lost a lot of friends. In the end I just rang mum, mum was living in Albury at the time and I just said mum I've got to come home I can't do anything here everyone hates me (Verbatim Transcript, September, 1995).

Johnson (1985) asserts that a major part of the social context of living with chronicity revolves around spouses or partners. In long-term marriages, among older couples, loyalty and attachment typically remain unquestioned although spouses may have sharp differences about health monitoring. David and Vince have been in long term marriages: both describe the loyalty and unquestioned support provided by their spouses. David explains:

I wouldn't swap my wife for a million quid. No I wouldn't part with her for the world, but I've been bloody hard on her just being abusive and you know and getting cranky, there was one time I never ever got that, and she'll tell you herself (Verbatim Transcript, September, 1995).

He explains:

She just, like I said she said that all my attitude changed, I never used to swear, never, I never swore in front of a women in me life, but I was swearing and any little thing that went wrong I'd just go off and she got that way she thought I didn't like her any more (Verbatim Transcript, September, 1995).

Vince explains his wife’s reactions to his pain experiences:

I think she knew, because I wouldn't be here if she took notice of what I done, I wouldn't be here. I insulted her to get her out of the house, really insulted her, and she wouldn't go and the lad was living here at the time and his rifle was in that bedroom.

November last year, cause if she would have went out in the yard I insulted her to get out in the yard I would have used the rifle. She wouldn't, she just rang up a doctor to see if I could make an appointment there, and I said I'll go around if I can get in, yeah, so I went to the doctors. He wasn't going to let me out of the surgery, you could see it, he wasn't going to let me out of the surgery and he made me promise I wouldn't do. So he let me go. It was close, yeah, I dunno, cause I didn't wanna go back to the way I was, yeah, but I think that's how my life's been every since. But Lana, she doesn't say anything, but I know she's there (Vince, Verbatim Transcript, September, 1995).
However, Johnson (1985:166) purports that problems generally arose later as the long
term effects of illness emerged. In contrast, support from husbands and boyfriends of
middle-aged and younger women was more tentative throughout the illness. These
men did not take over tasks as readily as wives did, and they abandoned their
relationships emotionally, if not completely, more quickly than women. Joanne
describes her husband as supportive, but as the following transcript indicates, she is
stressed by her inability to perform in the wife role. She calls upon support from her
mother to perform the day-to-day activities of caring for her home and husband. This
is also accordance with Johnson’s (1985:167-8) view that women relied on family for
emotional support and practical assistance. Joanne elaborates:

Wow, the three months before I came in here (pain clinic) they would have
been the worst. They, well those months just consisted of getting up in the
morning and struggling out of bed and having my husband come in and
help me get out of bed. I would walk, we live in a highset house and we
live downstairs, just the bedrooms upstairs and I would finally make my
way down the stairs, and um I would just go straight onto the lounge and
my husband would bring me a coffee and make me breakfast and I would
stay on the lounge.

Then my mother would be over by 10.30 and she would make me morning
tea then she would make me lunch, then she would make me afternoon tea
and she would stay all day and then put dinner on, and do the washing and
the ironing, and the cleaning and the cooking and everything and I would
just stay on that lounge.

I got up to go to the toilet. That was it. It was painful, even lying there
was painful but, and just getting up to go to the toilet, that would stir it up
again and then I would go back and lie down and for the next couple of
hours be in excruciating pain from just getting up and going to the toilet. .I
was taking pain-killers for the pain. Codral Forte, Endone (analgesics) just
drugs that is all. And I did have, occasionally a hot thing on my back. One
of those ones that vibrate with the heat. I had that on occasionally but um
alot of the time it was such a pain because I had to get my husband to turn
it all on before he went so I didn’t end up doing it. But yeah I just lay on
that lounge the whole time, I didn’t move. My mum all she could do was
feel sorry for me.

Um she would have done anything for me. She still will, but I have told
her that she has got to let me do it all myself, I have got to get in and do it.
Um but she was wonderful, absolutely wonderful. She would have done
anything. I feel very guilty about that. The fact that I couldn’t get up there
and do it myself, and here is my mother at 65, and here she was over here looking after me. I felt very guilty.

My husband, he handled it actually while mum was able to come over and cook and everything and have dinner ready for when he gets home, because he doesn’t get home until about 7.00pm at night. He could handle that, he just, he was very short tempered when he had to come home, and for some reason mum hadn’t been over that day or something, then he had to turn around and come home and feed the dog and then cook the dinner and then you know get the coffee and completely look after me when he likes to come home from work and be looked after because he has had a hard day at work. So, yeah some days he would just come home and he had had a hard day and he wasn’t real happy anyway, it would soothe him a bit if dinner was cooked and he just had to dish it out, but there were times when he had to go in and try and think of something for dinner and yeah that did take its toll (Verbatim Transcript, August, 1995).

In the above transcript, Joanne voices the inability to function in the multiplicity of life’s roles. Multiple identities as daughter, wife, and accountant usurp any illness identity and cause her to attempt to persevere beyond bodily limits. Her family’s need for her income also bothers her, especially since her husband has recently ventured into a new car sales business. Joanne states:

My partner was really good most of the time. We had a lot of financial worries. We had one car yard and it went under. He has started another car yard now and it is a big struggle. I tried to help with things, like doing the accountants and cleaning the cars, but its really hard. He gets tired and I think that I am not pulling my weight. It gets me down and then everything just gets worse. I try not to tell him too much. He has got so many things to worry about. I suppose I think that I am just another thing he has to worry about (Joanne, Verbatim Transcript, August, 1995).

Here it is evident that in her attempts to realise the limits of her current illness identity Joanne has been forced to relinquish preconceptions of herself. Previous interview transcripts see Joanne describing herself as a successful, well paid accountant. The above transcript sees Joanne describing herself as a worthless thing with little to offer her husband in terms of emotional and financial support. It should be noted that Joanne provided the means for securing and financing her husband’s business ventures. The emphasis on the words worthless thing and the emotions of guilt and frustration encapsulated in such description is supported by the view of Glassner.
(1988) who believes that perhaps more destructive than the anger is the guilt and shame followed by self-abasement that ill people with falling bodies experience: Guilt because they share cultural standards of ageless bodily perfection and correct appearance. Shame because their existence testifies to a failure to meet these standards. Joanne explains:

I did have some guilty feelings, but also I kept saying to myself he doesn't understand what I am going through. I say that, I used to say that so much, they just don't know what I am going through, yeah. I just felt nobody knows what I am going through (Verbatim Transcript, September, 1995).

Charmaz (1991) and Radley (1991) assert that reactions to living with illness may include ignoring it, minimising it, struggling against it, reconciling self to it, and embracing it. Persistent pain sufferers may choose to ignore and minimise their experience and the consequences of these experiences on their lives, or to control the effects of these experiences. Alternatively, they may also ignore and minimise pain experiences when other goals take precedence, such as keeping a job or to an intimate’s needs. Through ignoring and minimising, the individual may preserve their sense of unity between body and self prior to developing pain. Preserving a sense of unity becomes more difficult when the pain sufferer is constantly struggling against pain—fighting it and the identifications that come with it, as in the case of Vicki. When persistent pain sufferers struggle with their pain, they struggle to keep their bodies functioning and therefore, to keep their lives “normal” to whatever extent possible. Joanne describes the meaning of being normal:

A place where you don’t feel pain, and if I had a problem I would be able to forget. Where I can be a normal person. I suppose a normal person isn’t an exact description is it. Normal is different for different people. Get back to having a life and even just being able to, I mean I got to the stage where I couldn’t do housework. No-one wants to do housework, but I wanted too, just to prove to myself that I could do it. I couldn’t do

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anything, not a damn thing, so normal to me is functioning as a wife, and I wasn’t able to do that and I wasn’t able to look after my husband or myself (Verbatim Transcript, September, 1995).

Joanne goes on to explain her inadequacy in the role of wife and partner:

It was depressing, very depressing. Um pain made me feel very useless. It was because I couldn’t do anything. I was in bed most of the time when my mother would come over and look after the house, and clean and wash and cook and everything for my husband and iron I was just in bed. So it got to the stage where I think I more or less just gave up and thought well this is how I am going to be (Verbatim Transcript, September, 1995).

Vicki also describes the meaning of being “normal”:

Normal to me and I should really smack my hand because I am normal, I am just someone that suffers chronic pain and I know that. But in the short term, normal is just a typical way of saying it, so I will slap my wrist again that’s not right, um, because I need to feel like I am not different, like I’ve always been my own person, don’t get me wrong, and being an individual prior to the accident was great, you know, but having chronic pain is different, if you know what I mean. Yeah and I needed to feel the same as someone else. If I sit in a room, I’ve always said that, if I sit in a room of people that don’t suffer chronic pain, I feel out of place, but if I sit in a room with other people that suffer chronic pain I feel the same and that’s a really good feeling, just to be the same as someone else in that sense, but still be an individual which I’m still fighting to get back. Which is the person I used to be, yeah (Verbatim Transcript, September, 1995).

Vicki goes on to explain her “normal” self:

I loved music, very rarely watched telly, I could tell a joke, I was funny, I was happy, I was tactless that’s a Scorpio I think. Sometimes rude when I had to be, I was loud, I was confident, I loved meeting people, I could talk under water, I could make quiet people feel comfortable, you know those quiet sorts of people that just sit there, I could really make them feel comfortable in a room. Um, I was pretty and loved being the centre of attention, I was caring, helpful, strong willed, open minded, active, spontaneous, lively, very independent, I was a motivator in like my um my circle of friends, I was the one with all the noise, picnics out and ring around to make sure everyone could make it.

I was friendly, I was straight forward I was content, I was in touch with who I was, in touch with what I wanted, I was keen, I wouldn’t really say ambitious, ambitious I look at people that would kick someone else in the back to get higher up in things, I was very keen, I was level headed, I loved being outside, optimistic, um a great attitude towards life, wasn’t afraid of failure and loved trying new things. I was a good person to be around I liked the person yeah (Verbatim Transcript, September, 1995).

On the day of the second interview Vicki describes herself:
I am everything opposite to what I was, everything opposite to what I was, yeah and more, I am very serious person now, I take everything seriously, things that used to be, you know how people say oh you fool, I'd take that to heart now. I am just a person that I don't like to be around and I can't escape being around me, the only escape I get is when I'm asleep, but I'm not awake to enjoy it, you know what I mean (Verbatim Transcript, September, 1995).

Vicki's experience with persistent pain portrays the undermining of self, and of personal identity, which have been taken-for-granted; that is, assumptions relating to possessing a well functioning body and a planned life path. Bury (1982), Gadow (1982), Brody (1987) and Charmaz (1991, 1994, 1995) asseverate that any disturbance to a person's previous sense of wholeness of body and self intrudes upon a person's daily life and undermines self and identity. Thus, it may be contended that the struggle and fight against persistent pain produces a disparity between what the pain sufferer believes about who he or she is, and the person that he or she has become in the present. Likewise, Charmaz (1995:663) asserts that the held idea of self tends to lag behind changes to self incurred as a consequence of rapidly occurring life experience, because in reconciling self to illness, sufferers acknowledge and attempt to adapt, but they neither accept the illness as defining them, nor do they accept others' pronouncements of whom they should now be. This point is made most poignant in the way participants described feeling in relation to being told that pain was part of their daily lives and that they just had to live with it.

That was the lowest point because I went to the doctor again and he just said oh you have just got to live with it. I was really upset about that. It was not the answer I was looking for. had a couple of specialists see me then because I was after an answer of what happened and the same sort of answer from them was "oh well you know its just your old trouble", you will just have to learn to live with it. So um I went home and I tried to live with it and it is just getting worse and worse. I went back to my specialist again and he said exactly the same thing. So I went and got a second opinion, and he was the one that referred me in here. (Joanne, Verbatim Transcript, September, 1995)

Vince accounts for his feelings following surgery to remove his pain:
In the four months here, after the laminectomy we were living in a split level house at that time, the bedrooms were upstairs I had my bed down in the lounge, I slept in the lounge could I couldn't get up the stairs to the bedroom, then I used to go to him there I think after about four months or so there he said you're just one of my failures he said that's something you've just gotta live with, it knocked me for a 6. That's when I couldn't accept it (Verbatim Transcript, September, 1995).

Kahane (1992; Kelly (1992), and Yoshida (1993) believe that when experiencing an altered body people with illnesses note physical changes and diminished bodily functions. The development of concepts of self thus means that persistent pain sufferers begin to define bodily changes or the illness itself as real. This attempt to define persistent pain as real is contorted if there are no visible signs of pain. Hence, all pain sufferers interviewed in this study were able to localise their pain to particular body areas and or parts in order to account for how changes and symptoms affected their daily lives. David explains:

The pain in the lower back's there like a band around there and goes into me groin there and ah as soon as I start doing anything or I, I can bend over and do things, but it's there like a knife into me, and as soon as I get to do anything like if I'm mowing the lawn or anything, within ten minutes, half an hour I've gotta sit down because within ten minutes I start it, like five minutes and I start getting these just flicking, just like electric shocks like that down me legs and into me feet, bottom of me feet just burn and go burn and go sort of tingly. Sometimes you've got to kick your leg to see if it's still there.

I stumble on this leg all the time. It makes you feel useless at times because I used to be able to run and I used play cricket, like back home where I come from I was always in the touch football side and cricket teams that played on Saturdays can't do any of that and if I couldn't go to the races, I'd be playing cricket on a Saturday and Sunday, can't do any of that no more, people just used to say what's wrong with you, how come you don't go out any more. They never said it to me. They'd say it to me wife and that you know, like they'd ring me up do you want to play a game, no, no, no, and they wanna know, half of them I never told anyway, the little town soon tell people don't they, so they all found out. (Verbatim Transcript, September, 1995).

David's narrative reconstruction of a biography disrupted by persistent pain preserves key aspects of his masculinity - his adequacy as husband, father and worker.
Although illness has interfered with his life plan in each domain, David creates a social self that is competent and controlled. This is not a portrait of a man who is denying the severity of his pain, or the sadness of a life disrupted but neither is it a portrait of victimisation and dependency (Garro, 1994:1199). Moreover, David's distressing bodily sensations and impaired function act to disturb feelings about body and self as the unity of prior embodied experience is shaken, because assumptions about body and self have been jolted. Charmaz (1995:664) states that at this point, people with illnesses compare their present body with their past body; they assess the differences between then and now, and they measure the costs and risks of ordinary activities.

Before becoming ill, most people take their bodies for granted as functioning instruments or vehicles subjugated to the self. This taken-for-granted instrument becomes the yardstick against which they compare their altered bodies and subsequently the body, self and persistent pain are transformed from the backdrop of life to the forefront. Charmaz (1994:231) asserts that “whether people define themselves as sick depends upon whether the illness remains in the foreground or in the background of their lives”. Further, an illness that is invisible remains masked not only to the experiencing individual, but to others and therefore intensifies the solitary experience of having pain, particularly pain which has not been defined and legitimated by diagnosis.

The search for a medical diagnosis is paramount in the movement of persistent pain from the backdrop of a life to the forefront. That is, the person acknowledges the occasion when pain becomes a different and significant event moving from absolute
meaningless to full meaning (Morris, 1991:35), recognising the need for help and seeking the same. Vince, then aged forty, describes, in a matter-of-fact way the need to seek medical help and the dismay experienced when interventions did not alleviate his pain.

Well the accident was 1976. I was working for the Council and I had a fall, I didn't fall any distance, say stepping from one plank to the other I landed on my tail bone, in the back and broke the jaw, that was 1976, well then for a month or so I was alright went back to work then 1979 is when the back started to pain then by 1981 I was crying when I go to work (Verbatim Transcript, September, 1995).

David recapitulates his need to seek medical attention:

Five foot, I fell straight on the tail bar and I went to get up and I sort of couldn't get up, and my son was there he raced in and grabbed the sheep off me and I had to go and sit down on a drum, he ended up finishing shearing the sheep and that day I couldn't do any more I was just getting these awful pains down there, like switching the lights, like an electric shock and it was going down my both legs and ah I went back to the huts that night we were camped out, and my daughter was cooking there in the shed and I had a shower, and I never even came out and had tea, I was just laying in bed and all night.

After the accident my wife made me go the doctor. it happened on the Thursday and I come home on the Friday couldn't do any more, I just went to bed, you know, and lay down all weekend, and I just couldn't move and my wife said you'd better go to the doctor, she rang up and made an appointment Monday morning and he said I'll send you to have x-rays up at the hospital, bush hospital. And he said nothing showed up on them, so he looked at me x-rays and said take a month off work and come back and see him. Then the months just went on and on and on he give me some pain killers and it was about it would have been about 3 weeks later I broke out in this bruise from my hip to my shoulder blade, it was just a big maroon sort of a bruise just come out overnight and I went in and showed him, he said Jesus and I think you'd better go and have, he sent me to a doctor in Sydney, St Vincent's, an orthopaedic surgeon, and he went, he said have you had a cat scan and I said no, and he sent me to have a cat scan and then me doctor sent me back to him and he said oh he said, I don't want to touch anything like this that's the words he said, but I'll refer you to a neurosurgeon at St. Vincent's, and when he mentioned that I was a bit frightened I didn't know much about it, you know, anyhow I come back home and I went and seen me doctor again about it, I just laid around for months and that and putting up with the pain then I went and seen him and he said well your booked in to see the neurosurgeon, he said he rang me up and I said oh what does that mean, an operation. I'd never had an operation in me life and he said well you'd better go now and see him, I went down and seen him then he said he wanted to see a myelogram he knew what the trouble was he said I'll take this bit of bone off there and this bit of that, I don't know what the words he used now and he said I'll book you in for a myelogram so anyhow they booked me in for a myelogram on 1st
December, and 1st December was a Wednesday I had the myelogram on
the Thursday, and um he come around on the Friday morning he said we've
found your trouble he said I want to see you up in the clinic at St.
Vincent's there. The operation was on 6/12/93. Two years later, yeah. I
had a laminectomy. (Verbatim Transcript, September, 1995).

Joanne reflects upon the beginning of her pain and the treadmill of finding a cause for
the same:

I was riding and the horse took off and, being my first time on it, I didn’t
know how to hang on very well, and the horse bolted then with me under a
tree and there was a low branch, and I ducked to get away from the branch
and just kept falling.

I just fell flat on my back and um I was taken to the hospital. I more or less
couldn’t move so the ambulance came and took me to hospital and that was
upsetting to because there was an accident there in casualty the same day.
A motor vehicle accident and there was people killed and so I was put to
the back and they were looking after all the people that were dying and all
that sort of thing and um I was left there in pain for hours and hours and
they finally came and cut my clothes off me and gave me a needle and took
me to x-ray. But, they x-rayed the top part of my spine and not the bottom
part and they didn’t pick up the breaks. They said it was just a sprain and
they sent me home. The next day and um three weeks later I had my local
GP out to the house as I wasn’t getting better and he felt it, he said oh yeah
come down for an x-ray. So I went down for an x-ray so I went down for
an x-ray and he could see where the breaks or the fractures were mending
in those little trans something of the bottom down there at the side yeah on
my right hand side, I had broken three of them. Fractured three of them.
Yeah I feel that if I had had treatment from day one I wouldn’t have got to
this stage. I was sent out of hospital, then I had the GP and he said oh
yeah, there is nothing we can do, you will be right. And from a pain that
eventually got better so I could start walking and all this sort of thing, but I
again had terrible back pain every day like.

From back then I tried everybody. I tried chiropractors, acupuncturists, all
this sort of thing because I have all this back pain down the bottom and um
it was, I couldn’t sit. That was the main thing, and I had to sit to type or sit
to do all these things. That is the main reason it hurt so I was going to all
these different doctors trying to get relief, and um it was about 1984 I went
to see the first orthopaedic surgeon because I started limping.

Vikki’s search for a name for her pain differs from the stories of David, Vince and
Joanne. Her story is represented mid-cycle in the chronic pain cycle (See Appendix
Three). We now enter the story about nine months after Vicki’s accident: she has been
evicted from her home, lost friends and continues to experience severe pain. She states:
I still didn’t know what was going on and no-one could give me any answers. All I knew was that I was hurting, yeah, um and still really blinded by the pain, you know, I kept thinking well I’ve just had a major car accident, of course I’m gonna be sore, you know, of course I’m gonna be sore, and like as months went by you know, when it got to a point when I shouldn’t be sore any more you know.

That was probably about the middle of 93, um when Workers’ Compensation. Nine months after the accident, when Workers’ Comp took me off Workers’ Compensation because they couldn’t find anything that’s when I just, that when I was thinking I shouldn’t be sore They can’t find anything that’s causing the pain I shouldn’t be sore, I shouldn’t have this pain, so and denial was quite strong then to, as in I don’t have pain, I don’t have pain, I don’t have pain, oh god, I have pain, you know, I can’t have pain, you know, they can’t find anything, they know what they’re doing, they’re the specialists they’re saying to me that there’s nothing in all these bone scans, so I obviously am doing it to myself, you know, but as time went on, it just wasn’t right, you know.

I’ve got pain, you know and they’re wrong, if they can’t find something that doesn’t mean I don’t have pain, you know, it took maybe 12 months for me to hit that point where I’ve got pain, you know, I don’t care what you say, I’ve got pain you know, and if you can’t find where it’s coming from then that’s not my fault that I’ve got pain. I was upset, really upset, devastated, mad. Yeah, mad, alone um, pushed aside, disbelieved, they made me feel like I was out for the money, I was, and that was what I was doing, I was wasting their time because all I wanted was the money from the compensation, yeah.

Vicki’s estrangement from those significant in her life represents the social context within which her persistent pain story is contrived. Like David and Vince’s reliance on their spouses, when others have negated the authenticity of their experiences Vicki seeks solace from her mother to provide support and nurturance during crisis points in her life. This support is derived from her husband, Bill, later in her pain story, and Bill negotiates the interpretation of her pain, both with her and health professionals. Hallberg & Carlsson (1998) describe the pain benefits from family support and assert that individuals with insecure attachment styles are over represented among patients with chronic pain and it may be these attributes which predispose these individuals to feelings of helplessness and hopelessness. Because bodily feelings affect mind and consciousness it would seem extraordinary to expect the reverse in persistent pain sufferers whose previous attachment styles have not only been challenged by changes
to self, but also to the inevitable changes that this self must force upon others who have to had to adjust and re-consider their own life paths. In these cases, adapting to a body which no longer functions ‘normally’ requires that the embodied person and those significant in their lives, not only explicate but come to terms with the tensions between their now and their previously held beliefs about self. Charmaz (1995:657) states

by adapting, I mean altering life and self to accommodate to physical losses and to reunify body and self accordingly. Adapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways. Bodily limits and social circumstances often force adapting to loss.

Thus, bodies must not be reconfigured to encompass changes associated with only pathological, grief and anxiety issues, but also adjustment in family roles and sexual and marital relationships (Snelling, 1994). Price (1996:276) captures the complexity of these changes, stating that “just as the case notes get fatter, so does the catalogue of experiences, and with each successive passing year the redefinition of what happiness and hope mean”. Hence, it may be postulated that meanings of loss and thus, disconnection from self and the society in which self is formed and consequently alienated, are embedded in assumptions and discourses about the body. Not only do individuals achieve bodily control through rational practices, but they also assume their practices achieve and, quite literally, embody individuality (Shilling, 1993). Kestenbaum (1992:3) observes that illness threatens a person’s sense of integrity of self and body, and of self and the world. People who have serious chronic illnesses find that progressive losses repeatedly threaten their bodily and self integrity. They risk becoming socially identified and self-defined exclusively by their impaired bodies (Bury 1988:92). In this case by their persistent pain. Bleeke & Mulderij (1992:7) assert that in illness the body “loses its silence”, calling attention to itself. Everyday

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habits of ignoring the body are no longer possible, and individuals are forced to manage their physical functions in a way that would seem fussy and strange to healthy counterparts. David explains:

My wife has to drive me around and I have to sit on an air cushion. She has to stop the car every couple of kilometres so that I can get on an stretch my legs. It would be so bad, but living in the country means that everywhere we go is usually over a 100 kms, so we are stopping a lot (Verbatim Transcript, September, 1995).

Joanne recounts:

My mum has to help me out of bed most mornings if my husband isn’t home. And them I have to shower, or even just go to the toilet. It takes me about an hour to get over going to the toilet and some days I just don’t even bother with a shower (Verbatim Transcript, September, 1995).

Cassell (1991) contends that whilst ill individuals long to forget their bodies and be freed from their bondage, they actually absolve themselves and are absolved of blame for their condition because their bodies are placed in the care of others who expect them to want to maintain a quality of life, which is culturally defined and often impossible to meet. Further, modes of living with impairment are embedded in social definitions of "appropriate" attitudes, actions, and activity levels. Such judgments take into account dependency and deviance. Hence, negative definitions result when others view ill people as failing to reveal "correct" feelings or to take the “right” stance, engaging in “too much” or “too little” activity than physically warranted, becoming more independent or dependent than expected, or sinking into depression, drugs, or drunkenness. Some people never adapt to impairment; others refuse to admit that they have suffered losses (see examples in Albrecht 1992; Herzlich 1973; Radley and Green 1995; 1987; Williams 1988). Still others adapt to their impaired bodies only long after suffering losses. Many people, however, must adapt time and again as they experience progressively failing health, whether they slowly decline or
rapidly plummet during acute episodes, crises, or complications. In whatever way people live with impairment, they prefer to have certain future identities rather than others, although their preferences may be wholly unattainable (Charmaz, 1994, 1995).

As David explains:

Just the slightest little thing, anything, anything at all it just made me cranky. If you say something to anyone and they didn't hear you or something you'd just fly off the handle, you couldn't I used to do a lot of welding and all that making things and I couldn't bend over and do that and I go over and try and do something like shoe horses couldn't even slap a shoe on a horse, and you'd see somebody else doing it and they wouldn't do it properly I just used to go off me head and ah, it was just incredible, I've never ever gone like that sort of thing. Me wife I never even hit her or anything, she just got a bit frightened of me, the way I was going on (Verbatim Transcript, September, 1995).

Joanne relates her difficulties in attending to activities of daily living in the following:

They would have been the worst. They, well those months just consisted of getting up in the morning and struggling out of bed and having my husband come in and help me get out of bed. I would walk, we live in a highset house and we live downstairs, just the bedrooms upstairs and I would finally make my way down the stairs and um I would just go straight onto the lounge and my husband would bring me a coffee and make me breakfast and I would stay on the lounge. Then my mother would be over by 10.30 and she would make me morning tea then she would make me lunch, then she would make me afternoon tea and she would stay all day and then put dinner on, and do the washing and the ironing, and the cleaning and the cooking and everything and just stay on that lounge. I got up to go to the toilet. That was it. It was painful, even lying there was painful but, and just getting up to go to the toilet, that would stir it up again and then I would go back and lie down and for the next couple of hours be in excruciating pain from just getting up and going to the toilet (Verbatim Transcript, September, 1995).

In struggling against and with illness, the sufferer tries to take control over their illness and their bodies (Charmaz, 1995; Seers & Friedli, 1996), and through the struggle these individuals are eventually able to integrate new bodily facts into their lives and their self concepts (Charmaz 1991; Corbin and Strauss 1987). Until they define the changes as long term and experience the effects daily, however, people with persistent pain look for recovery and can keep pain, and therefore their bodies, at the margins of their self concept. Subsequently, they continue to objectify their bodies.
and distance themselves from them. Again, as Vrancken (1989:439) suggests the
objectification of lived pain experiences creates pain as the centre of one's life-world.
Everyday life is pushed into the background and the body in pain becomes the
foreground, separated from the life-world. Isolation of the body and interruption of
the inter-subjective contact which goes within it, are the two main features of the pain
experience. The isolated body loses its status of subject of the self-evident, hardly
noticed but indispensable part of inter-subjective life. Pain hits as a breach in the
continuity of existence. The physical pain experience seems a registration of a defect,
and pain seems to reside in the body, but always takes place within the framework of
existence, of the symbolic life-world. Thus, pain is seen as an answer to a certain
situation, an interpretation within the framework of existence. This framework
assembles a human consciousness which is constituted by ideology.

Ideology describes the beliefs, attitudes, and habits of feeling and behaviour that a
society inculcates in order to generate an automatic reproduction of its structuring
premises. Ideology is that which preserves social power through culture in the
absence of direct coercion. This study uses a Marxist interpretation of ideology to
guide the following discussion inasmuch as ideology, within this framework,
maintains a covert alliance with the legitimising position, power, and economic
interests of the ruling class. Here, the expositions contained within the participants’
persistent pain stories may be seen to act as ideological tools, which promote the
imaginary relation to one's material condition of existence, thereby constituting
strategies of containment which seek to prevent a full understanding of the social
totality of the persistent pain experience. Abrams (1993) asserts that despite an
attempt to appear self-evident, literature, and thus persistent pain stories, will always

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illuminate the fissures and contradictions within that which it tries to conceal because it cannot refrain from describing the problems it attempts to resolve. It is in this way that the private folklore of persistent pain is revealed.

6.5 IDEOLOGICAL CONFLICT AND CONTRADICTION

The search for meaning for persistent pain is grounded in the influences of ideology. Waitzkin (1991:12) states that "ideology, while difficult to define simply, is in general, an interlocking set of ideas and doctrines that form the distinctive perspective of a social group. Through such ideas and doctrines, ideology represents—on an imaginary level—individuals' relationship to the real conditions of their existence". Thus, ideology serves as a subtle mechanism which helps win a population's consent to the ways a society is organised. A central feature of classical Marxism, and an over-riding consideration of all theoretical perspectives related to ideology, is the emphasis placed on ideology in maintaining the economic system and other supporting institutions which reproduce a society's dominant ideological patterns (Shilling, 1993; Hahn & Kleinman, 1983).

Nelson (1993) and Wittgenstein (1967) suggest that it is through the influences of ideology that the cultural idioms of persistent pain are formed and maintained to create a reality which can be shared by all. Further, Birch (1989) asserts that understanding meaning is a question of understanding social reality. Marxist's (Eagleton 1988, 1990) define social reality as based in a history of struggles centred upon class and systems of production, reflecting at any given moment a dialectical relationship between history and society and the structures contained within the same.
Interestingly, Shilling (1993), Turner (1984, 1989) and Waitzkin (1991) affirm that the challenge for social theorists has been to clarify how macro-level social structures and micro-level processes affect one another. Here, it is not the intention of the researcher to provide a convoluted discussion relating to the arguments pertaining to structure and agency (Calinicos, 1988), rather to acknowledge that many schools of thought have dealt with this theoretical challenge. The position taken in this discussion is fundamental. That is, while some theorists have argued for the importance of macro-level structures like social class and political power in determining what happens in interpersonal processes at the micro level, others have claimed that micro-level processes are primary, and that macro-level structures emerge only as a reflection (similar terms include “integration”, “aggregation”, “gloss”, “repetition” and “transformation”) of micro-level processes occurring routinely in everyday life. Pappas (1990) asserts that concerns with either perspective, in general, are caught in this dualism of structure and agency, with competing theoretical perspectives leading to opposing reductionist interpretations causing reality, and its institutions, to appear as if they were little more than backdrops against which action is negotiated and meanings formed. Figlio’s (1984) discussion of miner’s nystagmus presents an illustration of negotiated meanings in the historical development of this disease, whereby the social relations of production create backdrop in which work conditions pre-empt the evolution of medico-legal practices which enhance the position of the mode of production.

A compromise position holds that macro-level structures profoundly influence interpersonal processes, but that micro-level processes cumulatively reinforce social structures at the macro level as well. Waitzkin (1991:12) asserts that

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at a macro-level structure of society, ideology impinges on patients and
doctors as part of their social context. At the micro-level of interpersonal
interaction, elements of ideology appear in doctor-patient communication.
What patients and doctors say when they meet reinforces their particular
ideologic conceptions about the social conditions that they experience.

The chronologies of persistent pain sufferers’ stories, provided earlier in this
discussion, represent the social context of living with pain. That is, during interviews
when invited to share significant moments in a life *lived*, participants focussed on
tangible events such as visits to the doctor, diagnostic processes and surgical
intervention as moments to be remembered and reconstructed. Thus, it may be argued
that social context of their experiences were reduced to events and transactions with
health professionals.

It is important to remember that Vicki is a 26 year old mother who can not care for her
child or have sexual relations with her husband. Joanne is 36 years old and is house
bound, relies on her mother to clean and cook for her and is no longer able to maintain
her position as a State accountant. David is in his mid 40s and moved his whole
family to another town in order to deal with the attitudes and prejudices of his fellow
workers. He is no longer able to sustain his family financially or even lift his grand
child. Vince was forced into redundancy in his mid 40s, and like other participants,
had recently attempted to take his life; and Steve is in his mid 30s and lost visitation
rights to his child, had to sell his possessions and moved interstate for pain treatment.
These events could be considered major events in anyone’s life trajectory, but for
participant’s in this research they are glossed over and take secondary place in the
lives *lived*. Waitzkin (1991:15) suggests that this tendency may be attributable to the
over-riding influences of medical ideology. Whereby the medical processing of social
problems invests them with the symbolism of objects, relatively immune from
criticism or change. This same process constrains the level of attention to the disturbed individual, rather than social structures impinging on the individual. For instance, when the organisation of work or tension in the family creates personal distress, expression of that distress in a medical encounter tends to reify the social structural roots of the problem. Under these circumstances, it is the objectified symptom or sign that requires treatment—not the institutional sources of individual distress.

Each society has normalised practices which validate the way in which individuals cope with and ascribe meaning to their pain, and it is through these shared understandings of the “locally shared cultural idiom” that the doctor and patient establish the standardised truths for a local cultural system, as indisputable. Pain is an experience which is subjectively and culturally derived, with individuals exercising local cultural orientations in order to make sense of their embodied pain experience. Similarly, the political nature of pain and pain management is clearly argued in Illich’s *Medical Nemesis* (1976). Here, he discusses the transition of pain as a traditional experience which implies the unique human performance called suffering, to the medicalization of pain into a technical matter, depriving the individual of the pain experience’s inherent personal meaning. The pain experience is posited as a ‘social curse’ which threatens the ideology of Western society, resulting in the need for society providing the masses with medical pain killers. Medical dominance in health care has facilitated widespread acceptance of medical views on illness and the experience of pain. The facilitated widespread acceptance of medical views on illness, and thus the experience of pain, may be ascribed to ideological “hegemony” and reification. That is, institutions such as the medical and health care system inculcate a
system of values, attitudes, beliefs, and morality which covertly predominate. This ideological system supports the established order and the class interests that dominate it. The same ideological forces achieve consent and mute resistance from groups and individuals which learn how and when to act or react in particular circumstances.

Waitzkin (1991:27) states that

> the ideological impact of medicine, would ask to what extent medicine reinforces the dominant ideological system of a society. When doctors convey ideological notions about desirable behaviour, especially as these notions help shape patients' roles in work and the family, medical encounters contribute to the broader hegemonic impact of ideology. In this sense, medicine exerts ideological effects that parallel those of such institutions as schools, churches, and the mass media.

Waitzkin (1991:16) contends that reification involves the transformation of social relations into things or “thing-like” beings that take on their own separate reality in people's consciousness. Shaped by ideology, consciousness focuses on the concrete problems and objects of everyday life, especially economic commodities, rather than on the totality of social relations that lie behind these routine concerns. Through reification, as attention becomes focused on the concrete objects of daily life, the totality of social relations escapes conscious attention. Hence, reification contributes to the impact of medicine in determining the appropriate method for managing persistent pain. And it is for this implicit reason that in medical encounters, technical statements assist in directing persistent pain sufferers’ responses to objectified symptoms, signs, and treatments. I will return to this point later. This reification shifts attention away from the totality of social relations and the social issues that often cause personal troubles, to problems of individual pathophysiology and personality. By reifying the problematic needs of patients, during the medical encounter the health professional is able to encourage individual behaviours in directions that are consistent with a society's dominant ideological patterns. Pappas

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(1990) and Cassell (1991) concur suggesting that medicine as an emissary of social control maintains a health care system which promulgates the dominant ideology of a society, and that the doctor-patient relationship is a major site for this development to occur. Medicine, like the legal system, religion, and politics, reinforces norms, often in an unconscious manner creating pain as a political issue which gives rise on part of anaesthesia consumers for “artificially induced insensitivity, unawareness, and even unconsciousness” (Illich, 1976:126), although Hansen & Gerber (1990) purport that simply administering advanced surgical techniques or potent analgesic agents has not resulted in dramatic reductions in complaints of persistent pain.

In summary, Fagerhaugh & Strauss in their classical text *The Politics of Pain* (1977) assert that the management of pain, whether diagnostic or symptomatic is contingent upon medical ideology and its powerful organisational influences. Therefore, in order to bring understanding of the persistent pain experience and its meaning for the persistent pain sufferer, it is necessary to consider the influence of the ideology of medical encounters and of the reification processes which are implicit within these encounters. The ideology of medical encounters and, in particular, the medical consultation, interview and diagnostic processes must be considered in view of the powerful positioning of the health professional and the concurrent powerlessness of the patient. This situation best illustrates the ideological contradictions inherent in the management and treatment of the persistent pain sufferer.
6.6 RE-INTRODUCING MARXIST CONCEPTS

The following discussion considers the impact of medical ideology and the reification processes of first maintaining the position of biomedicine as the dominant ideology in confronting the persistent pain experience, and second that this process acts to maintain the position of the dominant ideologies of Western society. A Marxist approach will be assumed to illustrate the inherent power relations in the medical encounter and the positioning of the persistent pain sufferer as dependent, and yet isolated in and by a world view fraught with conflict and contradictions. In this instance the term ‘power’ will be used to describe the exploitative nature of the encounter. Although, Pappas (1990:200) provides a laconic description of power in the following comment:

power is an aspect of relationships, as is manifest in the deployment of resources. Domination, then, is the structural asymmetry of resources drawn upon in interactions. To recognise domination is to acknowledge autonomy and dependency in a relationship. Even the most seemingly ‘powerless’ individuals are able to mobilise some types of resources which give them control over aspects of their day-to-day lives or over the lives of others. The helplessly ill patient has power to disrupt or resist, a frequent observation and frustration of health care workers.

In classic Marxist theory, ideology is an important notion. According to the principle of economic determinacy, the events of history emerge chiefly from economic forces and the conflicting relations of social class. From this viewpoint, economic forces affect the ideologies of a specific historical period. Despite the primacy of economic forces, ideology is crucial in sustaining and reproducing the social relations of production, and especially patterns of domination (Pappas, 1990; Waitzkin, 1991; Cheek, Shoebridge, Willis & Zadoroznyj, 1997).
Marxist concepts define the literary qualities of the research interviews. That is, what is the **mode of production**; what is the **product** to be consumed; how are these part of the superstructure; and what is the dialectical relationship with ideology; are there hidden class struggles inherent within the interview transcripts and finally are meanings uncovered within the interview transcripts which need to be discovered within the larger framework of social reality. In order to understand these relationships it is necessary to recapitulate upon the Marxist use of the term **mode of production**. Cheek, Shoebridge, Willis & Zadoroznyj (1997:67-71) assert that contemporary Marxists use the concept of the **mode of production** to encapsulate the notion of particular ways of organising economic and material production which characterise all differing forms of social organisation. More specifically the **mode of production** incorporates: the **forces of production**, which consider the broader historical issues in the development of discourse; the **means of production**, that is, the mechanisms of production; and the **social relations of production**, or the ways in which the labour process is socially organised. The social relations of production of pain are mediated by the search for pain meaning and by the processes of the medical interview.

The medical interview provides the basis for all persistent pain treatment, and it is during this interview and subsequent treatments that ideological contradictions become apparent. Although the researcher did not have primary access to participants’ medical interviews it is still possible to infer the ideological flaws incurred during this process through an examination of interview transcripts in relation to this point. Here, the term ‘text’ is used specifically to denote a written or spoken unit of language that is available for appraisal by one or more observers.
(Waitzkin, 1991:12-4) a definition which assumes that a critical analysis of non-literary, spoken texts is both acceptable and desirable. The texts to be considered, then, are those of spoken medical discourse in actual encounters between persistent pain sufferers and the researcher. Consonant with Seldon's (1989) view, and as the stories of persistent pain sufferers depict, once ideology is worked into a text all ideological contradictions and gaps are exposed. Moreover, it is contended by Macherey (1978:113) and Hahn & Kleinman (1983:315-6) that contradictions within the text may also be exposed by silences within the text because societal ideology makes it impossible to say explicitly. These textual absences, or aporias are symptoms of ideological repression of the text's own unconscious. A text, then, tends to break down at its margins, facing tensions, incompatibilities, and contradictions between itself and its social context. Here, the aim of Marxist criticism is to make these silences 'speak' and to reveal the inherent ideological flaws, stresses and incoherence within stories. Mishler (1984:62) intimates

that it is during interviews that physicians and patients talk to each other in ways that we, as members of the same culture recognise as culturally appropriate. Our sense of appropriateness depends on shared and tacit understandings; on commonly held and often implicit assumptions of how to talk and of what to talk about in this situation.

The medical practitioner, in the case of the diagnostic interview, uses certain means of production technologies to transform the materials of language (pain talk) and pain experience into a determinate product. Borrowing from the works of Althusser (cited in Eagleton, 1989:59) on the conceptualisation of practice, it may be determined that medical practice is the process of transforming a determinate raw material, that is pain experience, into a determinate product, a transformation effected by a determinate human labour, using determinate means (of production). This transformation of determinate raw material, that is the persistent pain experience, has been enhanced by

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ideological representations or metaphorical constructs which conceptualise the body and mind. These metaphors of the body and mind have, in effect, objectified the person, who becomes less an individual than a set of mechanical parts, or chemical processes which must be calibrated and well defined. The means of production, through processes of diagnostic medical testing, maintains the objective image of the person and encourages the use of biological tests as means of classification and as instruments of controls. Nelkin & Tancredi (1989:1) and Wakefield (1995:905) claim that as medical testing has become more refined and accurate, these institutions have placed more reliance on medical judgment to define the boundaries of 'normal' behaviour and thereby to identify competence, deviance, or capacity to work. They state that the prerogative to test has long been recognised as a source of power and social control. Social control refers to mechanisms that achieve people's adherence to norms of appropriate behaviour, and in medicine, ideology and social control are closely related. When doctors transmit ideological messages that reinforce current social patterns at work, in the family and in other areas of life, they help control behaviour in ways that are defined as socially appropriate (Waitzkin, 1991:12).

There was a stage of economic production of the society in which understanding relating to pain experiences emerged, as a particular way of dealing with the associated behaviours and sensation. This formulated varied technologies for the reduction and elimination of pain (forces of production), thereby constituting a set of social relations between health professionals (providers) and pain sufferers (consumers) with which the use of technologies are affiliated. Moreover, the embodied relationship of ideology to health care practices creates the ways in which the pain experience is suffered, understood and given meaning within a particular
context. That is how the persistent pain experience is controlled. Eagleton (1989:60) contends it is this kind of argument which connects modes of production to the expression of pain.

The medical modes of production a society has available is a vital factor in determining the social relations between providers and consumers, in this case, persistent pain sufferers. The social relations between providers and consumers is governed by discourse. Discourse implies integrated practices of speaking, thinking and acting in certain social contexts. Living with pain, pain management and the commodification of pain is a social activity, a form of social and economic production which exists alongside, and interrelates with, other such forms (Eagleton, 1989:59). Eagleton (1989:61) asks what is the position of pain stories within the relations of production, within the time of the story’s telling. It is posited that the telling of pain stories, as an experience within the social relations of production, is dependent upon certain techniques of production and vilification. Thus, the way in which the medical community conceptualises what a ‘pain patient’ is, and how he or she should be treated, exemplifies how the medical community understands pain.

Within medicine, philosophical reflection on pain is uncommon, especially with regard to literature concerning the management of pain and pain syndromes. Vrancken (1989:436-9) asserts that Western medical discourses have developed and utilise techniques of production and vilification which encompass the following modalities for treatment:

- the somato-technical approach; that is, an organic view of pain;
• the dualistic, body oriented approach whereby pain is seen as the result of organic, psychological and possibly also social factors, although physical pathology is the central determinant of the experience;

• the behaviourist approach which constructs pain as an overt behaviour which may be learnt, induced, and reinforced by environmental reward responses. Persistent pain from this perspective is quite a different disease entity, separate from the initial nociceptive stimulus;

• the phenomenological approach which attempts to return people to human life; and,

• the consciousness approach which considers pain as a problem of consciousness.

That is, suffering pain has to do with our being human.

However, whatever the modality for uncovering the cause for pain the main requirement for seeking help remains the establishment of a medical diagnosis, the curative aspect of intervention and motivation on part of the sufferer to get well. In all instances getting well refers to the absence of, or adaptation to pain. Hence, it is during the search for getting well that the techniques used to diagnose and treat the sufferer form the productive forces of pain management. These considerations encompass medical encounters, to the extent that doctor-patient interactions convey ideological messages under the rubric of scientific medicine. From Habermas’ (Arnason, Birchall, & Overend, 1977) perspective, such messages legitimate current patterns in society and further depoliticise issues of social and personal concern to individuals by deflecting critical attention from them to concrete issues which may be addressed in the medical consultation. The consultation thus becomes an instrument which monitors and controls suffering to the extent of the surveillance of the ‘how?’ the ‘when?’ and the ‘whys?’ of pain experience. Persistent pain experience, therefore,
must be managed out of existence or reclassified to conform with the scope and purposes of the dominant ideological influence, medicine. Williams' (1988) discussion of the residual, dominant and emergent effects of ideology provides valuable insight into one of the mechanisms employed by Western medicine to reify the persistent pain experience within the acute-illness model. To recapitulate, the residual is by definition effectively formed in the past, but remains active in the cultural process, not only as an element of the past, but as an effective element of the present allowing certain experiences, meanings, and values which cannot be expressed or substantially verified in terms of the dominant culture to be lived and practised on the basis of the residue of some previous social and cultural institution or formation. A residual cultural element is usually distanced from the effective dominant culture, but parts of it will be incorporated, despite the risk, into the dominant culture if the dominant culture is to make sense. It is for this reason that meaning and values which represent areas of human experience, created and significant in the past, may be either neglected, undervalued, opposed, repressed, or not even recognised until the dominant culture incorporates the actively residual. Incorporation of the actively residual occurs through reinterpretation, dilution, projection, discriminating inclusion and/or exclusion.

Hilbert's (1984) discussion of pain folklore captures a sense of the actively residual. That is, pain folklore is underpinned by the tenets of the acute-illness model. However, when pain fails to comply with this model, sufferers are required to assemble resources extrinsic to accepted pain folklore in order to organise, understand and bring meaning to their pain experience, and in the case of persistent pain sufferers to re-define their role in life and the subsequent continuance of their pain. Here, the
socio-cultural meaning of pain depends on the residual meaning of pain, that is understanding of the concept is largely ascribed to social formations and phrases of the cultural process in which certain real meanings and values are generated; since, the dynamic of pain experience requires an interpretation within a social context which is controlled by dominant ideological forces, the sufferer is required to make sense of their experience within this context. Making sense of the persistent pain experience requires the continuous creation of new meanings, values, practices, relationships in response to the effects of the residual and dominant either through the development of oppositional or alternative perceptions. Consequently, within this perspective the process of production forms a singular social act, and the product is only valued in so far as it is useful to the society with produces it. In this society, therefore, the individual is only valued in relation to fulfilling role obligations within the means of production. The juxtaposition created when the emergent has not kept pace with the dominant constitute, in the words of Eagleton (1989:61), is a society in which the stage is set for revolution because the productive forces and productive relations of society enter into contradiction with each other. The contradiction lies in the belief that the persistent pain sufferer, despite attempting to reconcile the experience in their life, is unable to do so. Cocooned within their persistent pain experience, they have become a commodity which can not be sold, exchanged, or understood.

Macherey (1978:142) contends that an understanding of intrinsic interpretation is located within the larger sites of production of the text, and herein lies the significance of ideology and the significance of language. Kristeva (1980, cited in Birch, 1989:19) argues that the text is a site for the negotiation of meanings and that meanings are expressed by a range of voices. Heath (1989:114) suggests that it is increasingly
apparent that an understanding of the use of everyday language and the social interaction of how individuals express and experience pain needs to be established. This is particularly significant considering that the social interaction between the health professional and the persistent pain sufferer is embedded in diagnostic work which is not only constrained in the ways in which professionals are sensitive to and deal with the suffering of patients, but by the way in which the expression of pain is manifest. The expression of pain is manifest in Western society through medical discourse.

Discourse is the most important concept in Foucault's (1974) work and it is centrally concerned with, although irreducible to, language. In his work on discourse Foucault discusses discursive practices which provide valuable insight into the role of ideology, social control and the rules which govern language, and as a consequence pain talk (MacDonnell:1986). Foucault (1972:117) defines discursive practice as

a body of anonymous, historical rules, always determined in the space and time that have defined a given period, and for a given social, economic, geographical, or linguistic area, the conditions of operation of the enunciative function.

Wittgenstein (1967:89) states that words have no meaning unless they are rule governed. These rules, however, are context specific and govern both linguistic and non-linguistic practices. Appropriate language and behaviour is understood by players of the language-game. Language-games are the basic units of social behaviour, language is socially mediated and shared, and the meaning of a word depends upon the context in which it is uttered and this meaning is implicitly understood by the players of the language-game. Nelson (1993:172) states that "what we do in our language-game always rests on tacit presuppositions. Thus, language games are
situated within the backdrop of the norms of life. That is, the understandings against which persistent pain sufferers, conduct their affairs, enabling and constraining their experience, and reproduced through communication.” It is the pre-understood context that makes understanding possible. Wittgenstein (1967:184) said “you can never get outside it; you must always turn back. There is no air outside; outside you cannot breathe”. Moreover, Wittgenstein (1967, cited in Nelson, 1993:172) suggests that language is part of the shared practices that make up what is termed our ‘forms of life’. These ‘forms of life’ are what we do, they are the social practices that make us human. These ‘forms of life’, the influences of hegemony and the effects of reification give meaning and rules to our language. Thus, as Nelson (1993) argues, pain expression and pain communication are one. There is no gap whereby consciousness filters the pain experienced into an expression. Fabrega & Tyma (1976) affirm that pain has an abstract conceptual dimension; this is to say that people talk about pain and derive theories to explain it. In this sense, pain is similar to any other abstract cultural category which has no visible or material form. Therefore, the diagnosis of pain is complicated by the fact that diagnosis is largely dependent on the patient’s subjective self-report concerning the location, severity, and duration of symptoms (Stoudemire & Jeet, 1987).

The very purpose of language is the communication of meaning, and how this communication changes across time is informed from a cultural standpoint. For example, in the English language the phenomenon of pain, viewed semantically and metaphorically, has also stood for a condition which implicate suffering, punishment, wrongdoing and/or justice. This theme is explicit in the early ‘pain’ forms and implicit in the early ‘ache’ forms fundamental to understandings of pain in the Pre-
Christian and Christian periods. Not linked to the *pain* term, in an explicit sense, was the idea of the specific grounds and sources of this condition. Nettleton (1989:1089) suggests that pain a ‘purely subjective complaint’ which could only be understood as the patient’s personal experience, during the inter-war years, evolved to acquire meaning only within the confines of the body pain. This uni-dimensional perspective, constructed pain as the “logical and necessary result of physiological responses to physical stimuli, having significance and meaning only within the space of the body”.

Nettleton (1989:1089-90) continues, asserting that in the post-war period, pain experience developed as a two dimensional phenomenon which “with its psychological component, achieved meaning because of its location in the patient’s socio-psychological-biochemical ecology. Interestingly, despite this evolution of meaning one is left to speculate as to whether a folk theory of natural or pre-natural causality may have underpinned this theme. At any rate, a physical process or change which can injure and damage (the ‘how’ of pain), which may have connections with individual wrongdoing, and which may reflect chastisement and retribution (the ‘why’ of pain) would seem to be the principal metaphorical sources for the elaboration of the pain experience (Fabrega & Tyma, 1976). Subsequently, pain constitutes a mental experience which the individual locates in his or her body, but which must be conveyed to another in order to be explained, alleviated and understood.

With this in mind let us now turn to the pragmatics of the medical diagnosis and the cycle which begins with the same. The chronic pain cycle depicted below illustrates the central place of the medical fraternity in the decision pathways sought, and taken by the persistent pain sufferer, and the significance of the medical practitioner in
determining the life events of the persistent pain sufferer within this framework for participation.

![The Chronic Pain Cycle Diagram]

Adapted from the Consumer’s Health Forum (1992:2).

Western capitalist economies have a number of structures in place to support the mode of production. The Western medical system is a significant generalising descriptive system which not only exerts influence on culture as a whole, but upholds the mode of production providing the framework for participation in medical encounters.

Foucault (1973, cited in Honkasalo, 1991:252) states that

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medicine has undergone a 'syntactical reorganisation of disease', and it therefore looks at signs and symptoms differently, inasmuch as it 'knows' in a different way how signs and symptoms should cohere. The world in seen in terms of commitments to particular aetiological and pathological accounts. Being visible to the examining eye, sign have become the basis of diagnostics, while intra-subjectively perceived symptoms have come to be regarded as futile.

This view dictates that within the biomedical paradigm there is a sharp distinction between the symptom and the sign, with the objective signs of pain taking precedence over the subjective qualities of symptoms. Symptoms only gain meaning and credence through transformation under the clinical gaze to verifiable events (Honolasko, 1988; Nettleton, 1989). The gaze is a way of seeing; it is through the gaze that things become visible to the health professional and, once seen, become objects formulated as discrete entities which can be observed and analysed.

The communication process provides the understanding of, and meaning for, symptoms, which are made to relate to some difference, some previous experience, belief, or folk concept, in the search for some cause or treatment. Honkasalo (1991:251) contends that the communication process instigated by these questions include negotiations between various explanations. Kleinman (1988) has dealt extensively with relationships between healers and patients focusing on the characteristics of idioms of communication and clinical realities. He purports that the simplest statements made by the patient highlight problems in the doctor-patient interaction as problems of 'translation' (Pappas, 1990:201): that is, in the doctor-patient interaction, with its implicit understanding of power, ideological clashes occur between accepted biomedical truths and those of the patients stories of pain. Furthermore, the problem for the persistent pain sufferer may be that the health professional as diagnostician and care-giver function as the interpreters of symptoms,
often understanding, producing and interpreting different semiotic signs from those of
the sufferer. They define or reconstitute the persistent pain sufferer’s relationship
with society by translating a set of symptoms, i.e. privately experienced signs of
disorder, into a pattern that the patient recognises as belonging to a highly
conventional and, therefore, public discourse. This view is expanded to the conception
of the semiotics of illness (Herzfeld, 1986:108). The semiotics of illness is concerned
with determining what social and personal judgments are entailed and manipulated in
the symptomatology, diagnosis and cure of illness. Hence, illness may be viewed as
an *interpretation* and as such constitutes a *text*, though not a primarily linguistic one,
which is read, and therefore reinterpreted, as the cure. It is this reinterpretation of
expression as texts, linguistic or not, which allows for the social sharing of experience
(Herzfeld, 1986:108-110). Thus, in order to communicate pain the persistent pain
sufferer must take an analytic stance towards their complaint and deliver an
“objective” exposition of their various signs and symptoms. In this exchange the
individual uses persuasive language in order to legitimise their need for assistance from
the doctor or health carer who has a bias in relation to the results of their pain
assessment and the language used by the individual.

Heath (1989:114) contends that the patient is subjected to two almost incompatible
demands during this process. First, to provide reasonable grounds for seeking
professional medical help, and in particular to detail the pain and suffering
experienced, and second she or he is obliged to take an analytic or “objective” stance
towards his or her own difficulties and cooperate with the diagnostic investigations of
the doctor. Heath (1989) and Nelson (1993) aptly describe how the expression of
“unpleasant” physical sensations, pain, is embedded in the social organisation of
participation in face-to-face interaction and the role of language games used to establish the rules of the interaction. Subsequently, ideology and domination appear in the face-to-face interaction of individuals. The expression or experience of actual suffering during the consultation inevitably undermines the patient's ability to deliver an accurate and coherent rendition of the illness and forestalls the possibility of the practitioner producing a diagnostic assessment of the complaint. Indeed, where patients are overcome by pain and suffering, practitioners unfortunately rely on witnesses to provide the necessary information to formulate an appropriate diagnosis and treatment. The delivery of health care in general practice and in other forms of medical consultation relies on a clientele which is able to manage the expression of personal suffering for the purposes of diagnostic inquiry and treatment.

The patient adopts an observer's perspective on his or her subjective experience, indicating both the source of the difficulty and where it hurts. The patient imbues the talk with the expression of pain, and it is the reply rather than the actual suffering which assumes immediate, sequential significance. The doctor disregards the actual experience of the pain and uses the patient's reply as the basis for further diagnostic enquires into the problem at hand (Mishler, 1984; Heath, 1989, Wakefield, 1995). In fact, within this framework for participation the practitioner withholds his or her gaze from the patient during the cry of pain, to avoid inadvertently encouraging the patient to display further, or to describe his or her actual subjective experience. Furthermore, medicine's ideological impact becomes much more apparent in encounters with patients when doctors interpret personal problems as pathological signs, and encourage individual behaviours in directions that are consistent with a society's dominant ideological patterns. Waitzkin (1984:139) asserts that how medical...
encounters convey ideological messages, and how they invoke social control, sometimes involves doctors' explicit pronouncements about what patients should or should not do. These pronouncements are synonymous with implicit contemporary definitions of health. Waitzkin (1991:) argues that the doctor-patient interaction reinforces a definition of health as the ability to work. In certain encounters with patients, doctors communicate explicitly or subtly a message that work is preferable to idleness; and during their routine talk with patients, doctors inevitably convey some attitude about work, usually to encourage patients' continued performance on the job. In these instances and many others, the impact of the doctors' words is to define health as the capacity to work productively. Within the social relations of production there is an assumption that individuals are motivated to, and actively seek help in order to return to work. However, participants, in this research, expressed concerns in relation to being unable to work. David explains:

I was earning between 30 and 35 a year, shearing, I was working it out in that three years I've virtually done a $100,000. They offered me a $120 to take the common law and I was out the door and no more that's it you're finished. Nothing coming in you know. If a bloke had of been fit and thought he could have gone back to work well a man might have took it. I had a good seven maybe 12 years of working and I loved me job, that's all there is to it, so.

I would never have been compensated for what I lost anyway, especially if I had lost me wife over it you know, but she stuck it out, she's good, we're good now you know, we're, I've learnt to settle down a bit with her. I just know, I can tell when enough is enough and that's it you know. She bought me to this understanding, she pulled me aside one day and said we'll try and work as a team (Verbatim Transcript, September, 1995).

Joanne states:

I was not working when I was retrenched. I was State Accountant for Natwest Bank. It was a good job. Hmmm it was great. I was retrenched because of my back I was only making it to work two, maybe two - three days a week and always going home sick in pain. So it got to the stage where I just couldn't handle work and they retrenched me. I wasn't happy at the time to be retrenched, but looking back, it was the only thing because
I wasn’t functioning. It was upsetting (Verbatim Transcript, September, 1995).

Steve describes the difficulty of paying maintenance for his child owing to loss of income:

I was paying $20/week when I was paying $50 and sometimes you know she’d ring up and say Kirby needs this and needs that and I’d say how much money do you want, she’d tell me and I’d just go to the bank and put it in, it wasn’t a problem you know, but when I got hurt I was alright for a little while, then they dropped me pay right down I rang her and I said listen, I’m really, really sorry I’m gonna have to work something out later, I just haven’t got any money. I said can’t pay me phone bill, I can’t pay me rent I can’t even live, and I was still in the hospital paying rent and trying to get everything organised while all this was going on- and she said that’s not good enough, you’ve gotta think of your kid, and I said have you ever thought of me, I said no-one gives a stuff I said I’m just a piece of shit, I’m just a meal ticket for you and Kirby. Kirby’s missing out on everything cause she’s not even seeing me and she says who cares, so I said look I cannot afford to pay it. Anyway it went on and on and on, a weak bastard I suppose I am, worrying more about me daughter than anything now I was giving them $50 here and $50 there and when I like got a bit of money, I kept selling things like you know, like me motor bikes I had two beautiful Harleys they’re gone, just to pay bills and she just wants, wants you know and I said look I haven’t got any more. This was about 6 weeks ago and I said I haven’t got any more. I said look you’ve reached the bottom of the barrel, she said sell your car, I said what and walk, she said buy yourself a wheel chair you useless prick (Verbatim Transcript, September, 1995).

A Marxist perspective leads to questions about how elements of ideology in medical encounters relate to economic behaviour. Ideological conceptions of work, as they are transmitted in doctor-patient interaction, reflect more general ideological notions about economic activities in a given society. When they are spoken in medical encounters, these notions reinforce a society’s dominant ideological conceptions about the nature of work and of economic production, both of which are constructed from a materialist perspective (Waitzkin, 1991; Pappas, 1990). Marx (1964) described a materialistic perspective as the starting point for the study of humanity: the view that as humans we have certain physical (material) needs that must be satisfied in order for other aspects (existential) of our existence to operate effectively. Marx (1964) also postulated that the material needs of the individual can only be met by the personal
efforts of the individual. Subsequently, Marx argued that the most fundamental aspect of human existence is the absolute necessity to produce the means for subsistence. Put simply, we all need to sell our labour for money in order to exist. Moreover, in order to produce the means for subsistence the individual entered into a dialectical relationship with the self and the environment. This relationship, during the twentieth century, has emphasised an interpretation of health as the ability to work. Hence, it is evident that contemporary ideas related to work and health cannot be understood in isolation from people’s lived, material circumstances. Here, medicine acts as an agent of social control by defining health as the ability to work, thereby supporting our system of production. Again, this happens without the full consciousness of the actors and without the explicit intention of supporting exploitative relations in society. Instead, medicine controls by perpetuating, re-enacting and supporting an ideology which makes society as it is, thus implicating the essence of being in pain (Pappas, 1990: 199-201). That is, by responding in limited ways to some of patients’ non-technical problems, medical practitioners tend to shift the focus of attention from societal issues to the troubles of individuals. Waitzkin (1991:224) and Wakefield (1995) suggest that it is also likely that ideology and social control emerge from what doctors and patients exclude from their talk, and how it comes to be excluded. Again, the following participant transcripts illustrate this point. Joanne explains her despair following failed surgery:

That was the lowest point because I went to the doctor again and he just said oh you have just got to live with it. It is just scarring tissue that left from the other operation and no more can be done, surgery wise so it will um what did he say, just the nerves would get better sooner or later, but it hadn’t been long enough. My nerves would just shut down and then I would stop feeling pain. I was really upset about that. It was not the answer I was looking for. I wanted my old life back. I wanted to look after my husband, I wanted to work and I wanted to have children. But the doctor said the surgery had been a success. But how could it have been. I was still in pain, but he didn’t want to hear that. He just said I was
depressed and that I had to lose weight. That I wasn’t helping myself. But, Joyce what could I do? (Verbatim Transcript, September, 1995).

Vince recounts:

In 1981 I think before the operation I think I was off work, like, that’s right I left the council then I started working for another building firm, doing schools, I think I was off work for two or three months and then I went back to work so then they give me a lighter job, fitting windows or something in the school so there was no heavy lifting involved, they give me a lighter job, well even then I think after a few weeks I couldn’t stand it, so I went off again so then I think I was off on compo then until the operation, so I decided to do the operation the specialist made it sound so good. He said that the operation would take away the pain and that after a few months I would be able to go back to work. I had the op cause I believed him. Well I could go back to work. I was only 42 years old and they pensioned me off. I had worked hard all my life and I owned me house, but that’s all. He never asked me what I was going to do. What could I do. I just laid around the house. I am cranky and me children moved out. They still don’t come around much, but that’s mostly my fault I didn’t make life easy for them.

Joanne and Vince express some of the central concerns about living a life of persistent pain. However, both are adamant that neither of their doctors or specialists were interested with hearing or discussing how persistent pain had interrupted their lives.

Mishler (1984) has described how medical discourse cuts off contextual issues and redirects the focus of the medical interview to technical concerns. He describes two "voices" that compete with each other. The “voice of medicine” involves the technical concern of doctors in their professional work, while the “voice of the lifeworld” comprises the everyday, largely non-technical problems that patients carry with them into the medical encounter. Persistent pain sufferers often try to raise contextual issues through the voice of the lifeworld. However, the medical processing of social problems invests them with the symbolism of objects, relatively immune from criticism or change. This same process constricts the level of attention to the disturbed individual, rather than social structures impinging on the individual. For instance, as eluded to in the above transcripts, when the organisation of work or tension in the family creates personal distress, expression of that distress in a medical
encounter tends to reify the social structural roots of the problem. Under these circumstances, it is the objectified symptom or sign which requires treatment, not the institutional sources of individual distress. In diverting critical attention away from the lifeworld, doctors subtly reinforce the ideas that pattern the lifeworld and help win acquiescence to those features of the lifeworld that patients find most disconcerting. Mishler's (1984) delineation of the two voices of medicine and lifeworld posits that the voice of medicine tends to suppress the voice of the lifeworld, thereby, reinforcing the orderliness of the lifeworld in its present form (Bendelow & Williams, 1995:149). Waitzkin (1991:22-25) particularises this point, claiming that doctors do not simply exclude, overlook or suppress patients’ contextual concerns, but that this exclusion of social context from critical attention is a fundamental feature of medical language, a feature that is linked with ideology and social control. As a micro-level process, doctor-patient communication reflects macro-level patterns in a given society and helps to reproduce those patterns. Pappas (1990:201) asserts that a social reality is created which is not only separate from the lives of individual members of a society, but is also dominant over them. The consequence of this social reality is significantly illustrated by participants’ discussion of life events which reflect the particularisation of their stories. That is, all participants were able to accurately recall the exact events of their persistent pain experiences, as these experiences related to the search for medical meaning and treatment. This is in keeping with Heath’s (1989:122) assertion that pain cries, like certain other forms of physical and emotional expression, achieve their significance, their factual status, by momentarily revealing the “natural” feelings and subjective experiences of the individual. Yet, even at moments of severe physical or emotional suffering, this revelation of difficulty is context-sensitive and socially organised.
At this point, one should reflect on the paradoxical position of the health professional. That is to say that the health professional is also trapped within the influences of ideology and, therefore, does not consciously seek to exclude the persistent pain sufferer’s lifeworld. Rather, when faced with a situation which does not respond to accepted methods of treatment, health professionals feel ill-equipped to deal with such issues and, therefore, repeatedly return to the voice of medicine. For instance, when Joanne raises the issue of repeated failed surgical intervention she is told that the surgery is a success and that she needs to lose weight. She states:

He (the specialist) was good but I just had a feeling that he really didn’t know what pain I was going through. He was a good doctor, well I suppose he was a good doctor, he was a nice person, but I just didn’t feel that he knew how much pain I was going through and how debilitating it was and I just couldn’t do anything. He kept saying that the surgery had been a success, but how could it have been. It was supposed to relieve my pain and it didn’t. He said that I needed to lose weight, but I couldn’t. I tried to say I am trying to diet and all this sort of thing I wasn’t having any luck and I was sort of telling him yeah I am trying to do the things you are suggesting but um I would just say I can’t, I can’t do it and he would just say, but this is what you have got to do to get better. This is the only thing you can do to get better. It was more or less stalemate I was saying I can’t but he was saying but you have got too (Verbatim Transcript, September, 1995).

Here, Joanne is attempting to raise personal troubles which do not pertain to technical problems, although they are related to technical problems which are not amenable to technical solutions. The raising of her personal troubles leads to discomfort not only for herself, but also for the health professional. A position highlighted by Szasz (1975:xx) and Seers & Friedli (1996:1162) who state that the doctor experiences a sense of failure and guilt when faced with patients whose pain experiences do not conform to accepted regimes of treatment. Under these circumstances the health professional reverts to the clinical gaze and the voice of medicine. This has a multifarious consequence for the doctor-patient interaction. The most significance of
which relates to confusion in communication during this interaction, because the persistent pain sufferer is unable to express their subjective pain experience. Moreover, the persistent pain sufferer is given no alternative but to persist in an effort to obtain medical validation and relief for their pain. The physician, on the other hand, who has applied his or her expertise and technical skill in a genuine attempt to treat the problem feels betrayed by the patient. Hansen & Gerber (1990) contend that the physician may even have objective evidence that the surgical procedure worked as planned. Yet the patient does not keep his or her end of the implicit agreement by reporting improvement in symptoms.

This point is illustrated in the following:

I could hardly go to work in the end, and they just said, they believed for my own sake I should have had time off to try and get my back better but I just had no where to go to get it better. I just didn’t know what to do. I have had two operations, and I was still in all this pain. I asked my surgeon what was wrong and he kept saying that surgery was a success and that my spine had healed really well. I couldn’t understand how surgery could have been a success when it was supposed to take my pain away, it didn’t. I was still in lots of pain. I just didn’t know what to do, where to go I just lived as much as I could (Joanne, Verbatim Transcript, September, 1995).

Vince not only describes his dismay at being told that surgery was a success, despite continued persistent pain, but this portion of the transcript represents the way in which critical attention is removed from the persistent pain sufferer’s lifeworld.

In 1982, I went off on Compensation and had the laminectomy, and he said 4 months after the operation I’d be back at work but 4 months later I couldn’t even walk upstairs ah. 12 months after the operation they said, the specialist said it’s something I’ve gotta live with, so um, where’d I go to from there, about in 1985 they pensioned me off, an elderly pension because every time I used to do something I’d collapse. I could be down the yard, I could be upstairs I used to collapse and they thought it was heart attacks and things like that and then they said that it was all in my head. I was in the Gold Coast Hospital then, they sent me to the psychiatrist, they turned to me and they said if you accept the way you are the better you’d be, I couldn’t accept it, so I used to have these tension build ups and I used to pass out, and they thought heart attacks for a while, but it was just tension, but I still don’t understand how the doc keeps saying the operation...
was a success when I still keep having pain all the time (Verbatim Transcript, September, 1995).

Hansen & Gerber (1990: 35) state that repeated failures often result in a widening of the gap between patient and physician, since there is a tendency for both patient and physician to attribute blame to the other. The patient, who is seeking medical solutions, has placed total responsibility on the physician. The physician has willingly assumed this responsibility but has not kept the implicit agreement to make the patient well again. Consequently, the patient may feel betrayed and blame the physician for being incompetent.

While conversely, the physician blames the patient for not getting well. The bipartite attribution of blame may be explained by Habermas’ concept of distorted communication. Habermas (1981a) argues that distorted communication arises in both the macro-level realm of politics and the micro-level realm of interpersonal relationships. Simply, the framework for participation is formed by the pervasive effects of ideological representations which further estrange the persistent pain sufferer not only from the means of production and a consciousness which permits maximisation of human potential by giving the impression of a unified explanation of reality which maintains the dominant ideology. This operates through a means of interpellation which requires the individual to acquire pre-established subject positions which, in all cases, serve the interests of the ruling class. Hence, this mode of being produces alienation, an existential vacuum in which the persistent pain sufferer is cut off from the outer world and thrown into an obsession with the body in itself. In Vrancken’s (1989; 439) words

The pain sufferer falls out of the symbolic order and falls back into a dual relationship with the body… (Persistent) pain inevitably creates a split within the individual himself (sic). Immediately a dichotomy is brought about, the very dividing line between that which is hurting on the one hand, and that which is submerged in pain, dealing with pain and trying to control it, on the other.
The control of pain rests with the health professional, and as such the persistent pain sufferer unconsciously and passively accepts the terms which lead to their subjugation. This passive acceptance draws attention to the struggle between doctors and patients, and to the elemental nature of power within this relationship. An issue to be later discussed. Moreover, Waitzkin (1991:225) and the findings from the Chronic Pain Forum (1992) indicate that within the current system of health care, patients appear as victims of the system lacking any control over their circumstances. Pappas (1990:200) expands this point stating that “power relations in medicine can be understood in terms of an imbalance in autonomy and dependency”. This imbalance creates distortion in communication, and enhances the conditions under which domination exists. Domination is attributable to the structural asymmetry of resources drawn upon in doctor-patient interactions, with implications consequent to patient ratings of global treatment satisfaction and effects of treatment, and doctor ratings of patient satisfaction with treatment (McCracken, Klock, Mingay, Ashbury & Sinclair, 1997). Here, the health professional produces the valued curing, caring and relief of pain while simultaneously reproducing the thrust, authority, and control of the entire structure of domination, through which the persistent pain experience is constructed. Although, Szasz (1975:xvii-xviii) contends that the standard therapeutic methods of medicine fail, in principle, in two types of situations. The first, by the individual who is physically healthy but, nevertheless, complains of pain. The second is in situations which reflect the severely depressed and agitated person who complains of annoying bodily feelings, such as lack of appetite, insomnia and backache. Hence, it is in these situations that the problem of the control of pain is placed in its proper perspective. Unless we wish to restrict our attention to purely medical and surgical considerations, we cannot even speak here of the “treatment: of pain, for “treatment” implies that pain
resides in a particular person, the patient, and can be influenced by altering the anatomy or chemistry of his or her body. This understanding, however, does not consider those patients whose pain is not of this kind. The experiences of these individuals and their relations to others, especially members of their family and the medical fraternity alienate persistent pain sufferers from the milieu of their constructed experience. Waddie (1996:869) states

the (pain) response is made as a reaction to socialisation and through culture of the individual. Therefore, the term pain is the name of a simple object; deputising for that object, assuming the significance of that object.

Interestingly, despite McCaffery’s (1983:906) claim that pain is, whatever the experiencing person says it is, existing whenever she/he says it does and McGuire & Yarbro’s (1987) contention that pain is a complex and subjective phenomenon involving physiological variables, in Western discourse pain is condensed to medicalized phenomena. In order to discern the whole complexity of the lived experience of pain and to arrive at a position which incorporates this complexity, again one needs to move beyond the reality of the experience to reconsider the contemporary rhetoric of the actual experience and the repercussions to the experiencing self. Bendelow (1993, 1995) believes that there is a need to extend the construct of pain from the Cartesian proposition which inevitably acts to divorce mental from physical states and tends to attribute single reasons or causes for the pain experience, to the notion that pain is an everyday experience linking the subjective sense of self to the perceived ‘objective’ reality of the world and other people, thereby allowing discussion of feelings and emotions. Melzack & Wall (1988:3) concur asserting that pain is a highly personal experience, dependent on cultural learning, the meaning of the situation and other factors which are unique to the individual. It is, as a communicative process, steeped in the problem of semantics with wide variation in interpretation and meaning and

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scientific verification. Pain as a communicative process, condensed in meaning and interpretation, creates a conceptually void backdrop, which fails to distinguish physical events and consciously derived experiences which have socially constructed significance. Shorter (1994:1) embellishes this view stating that “the patients’ problems are determined by their life stories and social situations, not just by disorders in the physical fibre of their bodies” and “at the level of perception and sensation, the cognitive dimension of our cultural life, the evidence of disease seems to those afflicted to be so undeniable”. Moreover, social or cultural mores are significant to the way a person discerns, reacts to and expresses pain. Hence, it may be postulated that contemporary understandings relating to the origins and truth of, and fear of persistent pain are not located in the anatomy but in social relationships, and while it is acknowledged that cultural categories confer specific meanings on illness, it is also recognised that illness meanings and the experiencing of illness in daily life are not static but are produced in ongoing social interaction (Nettleton, 1989, Anderson, 1991). Accordingly, if the stories told are interpreted exclusively as the symptoms of underlying pathology, then epistemologically the persistent pain experience is considered as one variable and the social context in which the experience occurs as the other.

Vicki illustrates this situation by describing her inability to function in the role of mother. Her own mother has moved into Vicki’s home to help. I spoke to Vicki the day after a facet injection into the spine to alleviate pain. During the interview her husband Bill lent moral support:

I haven't coped being a mum in the last month, I can't change his nappy. Joyce cause I'm having one of those days when I can't get it together. Bill
and mum have taken over in the last month. I feel bad about this. I cried a lot, I cried a lot because I can’t participate in like all. All I can do is lie down and watch him play, and watch Bill play with him, you know if he needs his nappy changed I’ve gotta go mum he needs a nappy change, you know, Bill he needs a nappy change, you know. I can handle hold him for long. I held him this morning for about five minutes - that’s it, that’s it as you can see my walk changed after I passed him over to mum because my, the pain in my back got worse and that was only a few minutes I was holding him I just can’t, that’s why I gave him to mum, that’s how it’s been ever since I had that 3rd injection and the 3rd injection was right down in the lower part and whatever he touched has made my soft tissue worse, if that makes any sense at all.

Bill said that he put the needle in and then he said just hang on I’m gonna try something and he pushed the needle in a little bit more and that’s when he hit something in there and I’ve just let out an almighty scream like it was just and gee the pain, and like it hurt it really hurt and from then I’ve been down hill (Verbatim Transcript, September, 1995).

Further, it may be contended that actions which constitute proper behaviour for people, or what constitutes legitimate pain, subsequently, alter individuals’ perceptions of their bodies and patterns of illness. History illustrates ways in which culture may suggest individuals into illness (Shorter, 1994; Walding, 1991). Quintner’s (1995:258) analysis of the social commentary relating to the implications of medical stereotyping with chronic cervico-brachial syndrome (RSI) provides valuable insight into the effects of such commentary on women and recipients of compensation payments. He states

[The twin stigmata of malingering and mental illness were recognised as being very real dangers for those who reported their symptoms (RSI). The patients I see are best described as demoralised and dejected. They are also, to some extent, rejected by their employees or by insurance companies, and many of them have had to abandon sports and other social activities and their lives have become gradually more restricted and reclusive.

Cognate features may be found in research relating to fibromyalgia, chronic fatigue syndrome, attention deficit syndrome, endometriosis, pre-menstrual pain, menopause and tempromandibular pain disorder to name but a few. Furthermore, Anderson (1991:710) contends that an individual’s subjective experience is not random, but is generated by an objective organisation of social reality: The discourse of medicine

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provides the reality for illness experience and the legitimation of the present world view lies ultimately in contemporary science which offers core notions of individual identity, responsibility and action. Therefore, it may be postulated that in all societies illness is experienced through an expressive system, which encodes local assumptions related to the maintenance of social order, because as suggested by Honkasalo (1991:252), the physician, as diagnostician, still functions as sign producer and interpreter of illness. Thus, despite the manifestation and behaviours associated with a particular illness, uniformity and conformity is maintained through legitimisation of that which is deemed to be ‘acceptable’ within the experience of pain. Moreover, whilst serious illness “is an event that challenges meaning in this world … medical beliefs and practices organise the event into an episode which gives form and meaning” (Young 1989:151), and as Good & Good (1981:179) attest “the power of an illness reality is derived from its ability to evoke deeply felt social responses as well as intense personal affects”. This obligation to order abnormality is likely to increase when it is manifest primarily through unusual behaviour. The person whose behaviour is seen as being unpredictable or unusual not only becomes an object of fear; she or he may be endowed with a potentiality for a perverse sort of power (Littlewood & Lipsedge, 1985:290). Further, Littlewood & Lipsedge (1985:290-1) assert that the patient’s power lies in the unstated assumption that it is society which will be ultimately responsible for how the sufferer should experience the illness, that is pain. An important feature of this sick role is that it applies only to acute, time-limited conditions, and once people become well, they are expected to return to their normal activities and responsibilities. The implicit assumption is that if “patients ‘do their job’, that is, be willing and cooperative, doctors will ‘do their job’ and cure the pain” (Hansen & Gerber, 1990:23). Interestingly, Morris (1991:290) argues that “it is
inappropriate to expect doctors to manage a condition such as chronic pain that stretches far beyond the borders of medical practice". Thus, the need to maintain social order, or experience cure, requires that the patient desires to become well and returns to their pre-pain status, and anything short of this is rejected. The consequence of these subliminal cultural artefacts causes the persistent pain sufferer to seek relief for pain in conventional pain relieving methods, and precipitates their spiral into a physiological world in which there is *no fit!*

Certainly, Fordyce (1994:51) suggests that gains of the *sick* role (or pain) can act as reinforcers such as greater attention, alleviation of an intolerable situation, or avoidance of unpleasant consequences. If this reinforcement of pain behaviours occurs the probability of that particular type of behaviour being displayed in the future increases. Hence, the experiencing of an altered body means, for Joanne, that persistent pain is correlated with physical changes and diminished bodily functions (Yoshida 1993; Charmaz 1991; Kahane 1992; Kelly 1992) which may be supported by significant others in her life. Here, the experiencing of an altered body means more than having, or acquiring one. It means that Joanne has begun to define her bodily changes, or the illness itself as real, and to account for how changes and symptoms affect her daily life. Olesen, Schatzman, Hatton & Chico (1990) suggest that distressing bodily sensations and impaired functions pre-empt disquieting feelings about body and self as the unity of prior embodied experiences are shaken; and assumptions about body and self have been jolted. At this point, people with illnesses compare their present body with their past body; they assess the differences between then and now, and they measure the costs and risks of ordinary activities. Before becoming ill, most people take their bodies for granted as functioning instruments or
vehicles subjugated to the self. This taken-for-granted instrument becomes the yardstick against which they compare their altered bodies.

I am 26, I should be healthy and my body should not have let me down. You know when you’re 26 hell you think you can do anything. I used to play netball and squash and I always had people saying how lucky I was. You know cause I am slim and have long blond hair, but now no-one looks at me. I am really lucky to have Bill. He tells me I am pretty, but I don’t believe him (Vicki, Verbatim Transcript, September, 1995).

Vicki’s description of her feelings represents a radical disruption of body and self. She felt her body as alien and expresses the desperation of experiencing multiple bodily losses and intensified feelings of estrangement from her past familiar body and sense of self. Her persistent pain, which cannot be traced to a pathology renders Vicki to the world of the pain career patient, a term first described by Freud (1893-95). Here, Szasz (1975:xix) states that “Freud reminds us in plain but persuasive language, that playing the sick role may, for some people, some time, be the most gratifying pursuit open to them”. However, this term helps neither patients nor doctors. The humanistic physician must try to understand persons and see their life from their perspective. To choose pain, suffering and doctoring as a career means attending to the dysfunctions of the body and their repair. Vicki, Joanne, David, Vince and Steve have previously described their lives as fulfilling and satisfying. All have also stated that when their became chronic and “unbearable,” this experience re-occupied and demanded their complete attention. In contrast to Freudian contention (1961), however, participants did not continually burden others with stories of their pain. Steve explains:

Me mother would ring up and I'd go ooooh christ me back's aching, I can't walk, I've got a headache you know, the dog got run over, the cat got stolen everything's going wrong, it sounds horrible doesn't it.
Doesn't help me pain in the back. makes it worse cause I'm thinking about it more and like we sat through a class here the first or second week we were here you know and told all about it you know, you are not allowed to talk about your back, like the way I put it now, if my back's aching I say my back's not aching or something. You can have a laugh about it, we all have a laugh about it, like I'd say that to her at home, she'll say how are you feeling Oh me back's not aching and she'll look at me and say yeah I know it's not, I'm fine, I'm perfect and I walk outside and crack and carry on like you know. I've seen the way you jump around your flexible like the way I used to be like (Verbatim Transcript, September, 1995).

David said:

I didn't talk to people about my pain. I just kept it, the most I ever spoke about me pain is in here (during the interview), and all these other fellows sort of realised that, about it, I did mention it a couple of times to people at home and they just said nah, it's all in your mind go to a chiropractor (Verbatim Transcript, September, 1995).

David continues:

I felt shocking after the operation, I just thought everything's starting again, you know, I felt real, I never even told me wife cause I thought jeez I've had a gut full of this listening to it and she could see it in me the way I was going on again, she knew something was wrong and when I told her, she was a bit upset about it all and that and she was, she was that one time there she was thinking of leaving me and we had a bit of a blue about it and I said well that's the way it is you know. I was that cranky I didn't care, I said well that's the way it might have to be then. I felt bad about her saying that, real bad, that's one of the times I felt like just going down and getting it over and done with you know. Real bad I felt (Verbatim Transcript, September, 1995).

To sum up, pain experience fundamentally heralds underlying pathology and is an expression which alerts the recipient to seek assistance to alleviate their suffering. However, pain is also an artefact, a product of social consciousness in a world governed by implicit ideological rules and functions. The effects of ideological practices form the ways in which the pain sufferer organises and seeks relief for their pain. If relief from pain is gained and the sufferer resumes a productive life then pain treatment, and the effects of ideology and discourse remain concealed and therefore unchallenged. The challenge to ideological influences and the dominance of representative discourse, however, is revealed and subsequently challenged when

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individual’s experience persistent pain with is not alleviated by conventional methods of treatment, or when the sufferers search for meaning, and validation of experiences is not forthcoming. These individuals are forced to enter the chronic pain cycle, and in most cases have their experiences negated by those who are unwilling to acknowledge that Western medicine has failed in attempts to bring understanding to their search for validation. Fundamentally, these ideological influences sustain two types of sick people, those who suffer from pains due to bodily lesions, and those who suffer from pains due to mental lesions. The latter have pains which are imagined, hallucinated, or pretended- call them what we may-are not the signs of bodily diseases, just as actors pretending to be corpses are not the signs of ordinary crimes; and as mock-murders have no victims, so mock-pain sufferers have no pain. Ultimately, in an effort to conform to the rules of the dominant discourse, during the medical interview health professionals, label unexplained, persistent pain experiences under the pellicle, ‘psychogenic disorder’. Notably, Foucault saw the medical examination as a strategy of political domination, a means of “normalisation.” In *Discipline and Punishment* (1987) he described the examination as a “normalising gaze” that “introduces the constraints of conformity and compares, differentiates, hierarchises, homogenises, excludes” (Nelkin & Tancredi 1989:8). Similarly it has been argued that it seems

ludicrous when a biomedical diagnosis is not possible to the exclusion of all else as is the case for individuals who are experiencing persistent pain, especially if it cannot be traced to a medical cause that the unifying aspect for all these sufferers is that at some time the authenticity of their pain will be questioned (Bendelow, 1993:276).
This point was alluded to in David’s last transcript, and is captured by Vicki in the following:

People don’t believe that I suffer pain, specialists because I had the accident on my way to work, specialists seem to treat you like dirt. Um I was really blinded at that time to what was going on because I denied my own pain, I was trying to do things like a normal person would do, but I wasn’t coping, the pain was excruciating. I was snapping and yelling and screaming at anything and everything. And well I thought...

People say that your mind controls everything, - you know like, people that have cancer they change their thoughts and they change their way of life and change their eating habits and the cancer, in very rare cases, and I thought I could do the same thing because they could not find any cause for my pain so I thought they must be right. It’s my fault that I have pain, so if I deny that I have the pain then I won’t feel it, but that doesn’t work. But I thought I don’t want pain, I don’t want it there so if I can deny it’s there it will go away. Yeah (Verbatim Transcript, September, 1995).

Vicki is expressing her attempts to control her body through manipulation of her mind. That is, if others do not accept or believe her pain, then her pain must not be real: it may be controlled by simple denial of its existence, of course, an activity which is itself flawed. As Denzin (1985:224) explains, the body is both the vehicle for movement forward and the structure that radiates and expresses the feelings that one feels. Embodied experience is situated, circular, temporal and dialectical, for it turns back upon itself, affirming, denying and elaborating what is and is not felt. Thus, Vicki’s felt attachment to the situation is a moving, unfolding process that turns back upon itself, trapping her within emotional feelings that are both desired and not desired. As a process, embodied experience reaches outward to carry the subject into the field of experience that attaches him or her to others.

For persistent pain sufferers without a consensual medical diagnosis this attachment, is fraught with disappointment and frustration by the very nature of the sufferer’s own non-attachment to the world and the suffering pursuant to this state. Rawlinson

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(1986:40) asserts that suffering is both evidence and experience of a failure on the part of the individual soul to assume its proper position in the harmony of an ideal order. Hypothetically the ideal order would encompass abolition of sensations and feelings of pain and return to the workforce. However, suffering is an emotional state triggered by anticipation of threat to one’s self or identity, an identity configured prior to the development of pain and the acknowledgment its longevity. In essence, any human situation presents an opportunity for suffering. We open a place for suffering wherever we own some purpose as our own: purposes which may be frustrated, ends that we may fail to meet, or possibilities that may never be realised. For participants in this study the consequences of the inauthentication of their suffered pain further distances and alienates them for the social context in which they live. Moreover, Kleinman & Kleinman (1987:227) contend that situations which cause sufferers to lose their world, denies the defeats and victories, and the desperation and aspiration of individuals that could perhaps be more humanly rendered not as representation of some other reality, but rather as an evocation of individuals whose experience stands for itself.

6.7 SUFFERING PAIN

Rawlinson (1986) asserts that Western medical discourse fails to locate suffering with respect to the purposive activity of a human subject, identifying it instead with distance or alienation from an ideal order. Vickers (1969:20) states “medicine as a science detaches the disease from the man (sic) who suffers it and in consequence, to use Polanyi’s phrase, our knowledge of both dissolves”. Biomedical interpretations of illness have properly been criticised for leaving the experience of suffering out of assessment of disease and, in fact, health professionals’ attempts to exclude the
emotional and social contexts from patients' complaints of pain attest to this. Vrancken (1989:436) asserts that the ideal doctor-patient interaction is when the duration of the patient's complaints are brief, especially so because the risk of secondary psychological pain components developing increases with time. Moreover, Heath (1989:113) contends that the practitioner's sympathetic alignment towards the patient's suffering derives from the readily available diagnosis of the complaint and the practitioner's analytic orientation towards the suffering of the patient.

Freud (1961:24) asserts that suffering may visit the individual from a number of directions: from their own body; in relations with others, or in the theatre of inter-subjective life; and with respect to personal powers of self-possession, self-regulation, and production vis-a-vis the external world; or in the arena of the will. Rawlinson (1986:47) asserts that a fourth dimension may exist which comprehends the economic relationships among the other three orders: that is, the effect of suffering upon the overall organisation and unity of the subject's purposive activity. Here, suffering in the sphere of universal alteration, presents as an attack upon the fundamental coherence of the sufferer's world. Let us now consider suffering in the realm of embodied action.

6.8 SUFFERING IN THE REALM OF EMBODIED ACTION

The body in pain may obstruct access to the world by occluding or constricting ordinary horizons available in the human domain. When this occurs, we suffer. Bakan (1968:55, 71,88) states
on a brittle quality. One finds plans disrupted and possibilities withheld, as experiences that one does not own or intend obtrude. In illness one discovers one's embodied self as an obstacle in one's own project of encountering and shaping the world. Illness necessarily involves the suffering of alienation, of being set against one's self in falling prey to possibilities one does not own.

The definition of suffering is expansive and, within the framework of living with persistent pain may be explained as the torment of increased dependence on others and the opprobrious contraction of human autonomy. Vicki explains:

My pain causes my depression because I used to be a really independent person. Now I lack independence, with lack of independence comes invasion of privacy, um inability to do things, too scared to do things because pain might intervene um, I'm not the person I used to be and I believe the person that I used to be and hating the person I am now (Verbatim Transcript, September, 1995).

She continues:

I am everything opposite to what I was, everything opposite to what I was, yeah and more, I am very serious person now, I take everything seriously, things that used to be, you know how people say oh you fool, I'd take that to heart now. I am just a person that I don't like to be around and I can't escape being around me, the only escape I get is when I'm asleep, but I'm not awake to enjoy it, you know what I mean (Verbatim Transcript, September).

Joanne describes similar restrictions to her life:

I just wanted to get away, just be by myself, just sleep and feel no pain. To a place where you don't feel pain and I have a problem I would forget. Where I can be a normal person, I suppose a normal person isn't an exact description is it. Normal is different for different people. Get back to having a life and even just being able to I mean I got to the stage where I couldn't do housework. No-one wants to do housework, but I wanted to just to prove to myself that I could do it. I couldn't do anything, not a damn thing, so normal to me was functioning as a wife and I wasn't able to do that and I wasn't able to look after my husband or myself (Verbatim Transcript, September, 1995).

Both Vicki and Joanne are effected by the abashment of limits imposed by their persistent pain and the purposes with which they identify themselves. This confusion lies at the core of suffering in the realm of embodied action and alienates the persistent pain sufferer from self, others and humanity. Western medical discourse has been posited as the manager of the conflict between the self and embodied Pain: a Biographical analysis
distress, weakness, and unreliability of their pain. However, in reality the conflicts and contradictions inherent in this discourse require that it plays a policing function in order to cure and return the pain sufferer to normalcy within the existing dominant order (Szasz, 1975; Foucault, 1972; Illich, 1976). Interestingly, Cassell (1976:89) and Rawlinson (1986:45) expand this point, purporting that although the health practitioner and the patient represent and articulate different value systems or horizons, the health practitioner must not only know what the symptoms are, in order to treat the patient, but also what they mean to the patient. Thus, while the role of the health practitioner may be to arbitrate, it is not to determine what experiences or meanings derived from the persistent pain experience are of value. Rather, the health professional should be the one who tries to understand his or her patient as a valuing and proposing individual in order to aid in the restoration of their bodily connectedness to the world.

6.9 SUFFERING IN THE THEATRE OF INTERSUBJECTIVE LIFE

Human identities emerge and take determinate shape only as positions within complex systems of exchange (Rawlinson, 1986). Kleinman & Kleinman (1987:277) state that

the intersubjective medium of social transactions in local moral worlds is the outcome of cultural categories and social structures interacting with psycho-physiological processes such that a mediating world is constituted. Experience is the felt flow of that intersubjective medium from which habitus is structured and where shared mental and bodily states in turn structure social interactions.

Thus, it may be argued that the persistent pain sufferer is in the dynamic of reciprocal self formation with others. Furthermore, Rawlinson (1986:44) contends that “the human subject does not so much project an already well-formed self into his (sic) relations with others, (but) finds his identity emerging there before him”.

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Being-with-others is an essential feature of human life and constitutes a complex array of possibilities within which each individual take a definitive position. It is within this theatre of life that the persistent pain sufferer has been able to define who they are and their reason for being. Thus, as Freud (1961:) suggests, suffering that comes to one in their relations with others is perhaps more painful to the sufferer than any other. Joanne explains the way in which she withdrew from family and friends:

Before the operation I believe it (the pain) affected my self esteem. I wasn’t as outgoing and as fun loving and joking around. I became very withdrawn and very quiet and a lot of the time suffering the pain. I didn’t want to tell everybody about it so I more or less suffered in silence. Yeah it is hard, you don’t want to burden it on anybody and you feel as if it is better off for everybody if you don’t tell them. Family members knew what I was going through but it was very lonely, very lonely (Verbatim Transcript, September, 1995).

Vince recollects:

I didn’t tell people I was in pain. Well they couldn’t help me, I mean it’s something you just keep to yourself. I think Lana new what was happening. Yeah, anybody could tell, I think they might even knew at work too but I didn’t tell em (Verbatim Transcript, September, 1995)

David explains:

I’ve worked half me life and then it started that they wouldn’t talk to me the other blokes, no matter where I went, people said, I’d never told anyone I had a crook back or anything, but they could see it the way I was getting around, nah, there’s nothing wrong with you 9Verbatim Transcript, September, 1995).

David continues:

My friends They just, they never even used to come around to see me. I just, they had to ring up and look for work cause I done all that I used to ring em up Sunday night saying we’re going to such and such a place, there’s so many ewes and lambs to do out there we’ll finish that on such and such a date and start another shed on Monday the following week and they never even used to come near me much you know, even then sorta thing, But were friends with them, after that they just got work with other people.

So even the guys I used to shear with, they were the ones that actually stopped talking to me. Oh they’d talk to me, but they never ever went out of their road to come round to see me or anything. I felt mad about that. Mad, because 2 blokes used to come and see me a fair bit, you know, I just
thought what's wrong with me you know and ah people never used to see me out or anything I used to walk up to the physiotherapy and people would stop and look at you and you'd feel that you were some sort of a germ or something, that's the way I used to get.

Yeah. I heard one of the cockies call me a bludger talking to all his mates there, he said oh he's only going for compo claim. I was gonna say anything to him, but me wife was with me and she said don't say anything you know. Otherwise I would have turned around and said if you think that you know, I'll give you my back and you give me yours. That's the way it is with you I would have said, but I didn't think he was ever like that. So.

I worked with him for 18 years. Funny thing but when I was out there shearing all their sheep you know, he used to ring me up every night telling me how many we all done for the day and real pleased with me, you know, and we used to finish, he said you should finish around here, you finished 2 days earlier than I thought you would and that's good, cause we used to buckle down and work hard you know. We used to save them money, yeah, a lot of money (Verbatim Transcript, September, 1995).

Isolation from others also means divorce within ourselves, and a recasting of our roles so that we may be forced into parts we never intended to play. Persistent pain isolates and alienates a person from the social roles through which their position in the community or system of discourse is realised. This disconnectedness itself establishes a critical feature of personal suffering.

6.10 SUFFERING IN THE ARENA OF THE WILL

The will achieves the unity of a life-history through a labour of recollection, in which it comes to know itself by reworking the past in which it has displayed itself (Rawlinson, 1986:46). The will is significant in that it allows the individual to conceive a future which brings confirmation of self. However, if the will is challenged by a disruption to self, the will may undergo spectres of regret, fragmentation and self-alienation. This aspect is significant to the will, and thus self, when the persistent pain sufferer is presented with being unable to work, as it is through work that one is able to inscribe oneself in the world and shape it into familiar habitation. Moreover, if one is unable to sustain the role of worker and producer then
one falls prey to it, one suffers feelings of ineffectuality, failure, and loss of self-esteem. Thus, it is in the arena of work and production that the persistent pain sufferer without a consensual medical diagnosis is confronted with the ideal of mastery and accomplishment, and the impotency of their actions. Thus, the persistent pain suffer without a consensual medical diagnosis faces contradictions between his or her responses to pain and regulative principles which are recognised as binding.

6.11 SUFFERING AND THE SPHERE OF UNIVERSAL ALTERATION

The human subject longs to belong to the community of humankind, to some final purpose or image of the whole. Thus, universe altering events, such as the development of persistent pain, calls into question both the individual’s capacity to maintain its self as a whole and the idea of the whole according to which that organisation takes place. The individual becomes both alienated from that purposive activity which distinguishes him or her, and disconnected from the idea of the whole that resolves the fragmentation of his or her life. There no longer seems to be any purpose with respect to which all things can be measured and valued (Rawlinson, 1986:47-8). Ontological suffering is distinguished by the way in which it assails the overarching purpose and meaning of life. The shattering explanations of life seem no longer commensurate with envisaged lived experience, or the persistent pain sufferer’s envisaged lived experience is seen in the image of Hell, and they become a hopelessly eternal exile from order or world in which they should belong. Rawlinson (1986:48) asserts that the order of the world is constructed within an ideological framework which defines not only the meaning of life experiences, but a world inscribed by horizons of value. These horizons determine the formation of possibilities invested
with concern or taken as ends. Kleinman & Kleinman (1987:276) augment this view claiming that

the interpretation of some person's suffering as a reproduction of oppressive relationships of production, or the symbolisation of dynamic conflicts in the interior of the self, or as resistance to authority, is a transformation of everyday experience of the same order as those pathologising reconstructions within Biomedicine. What is lost in biomedical renditions - the complexity, uncertainty and ordinariness of some man or woman's unified world of experience - is also missing when illness is reinterpreted as social role, social strategy, or social symbol anything but human experience.

Thus, within this sphere the persistent pain sufferer without a consensual medical diagnosis is vulnerable to a rupture between his or her condition and the image of the whole by which he or she is bound to life and the world.

To sum up, suffering names the experience of, and alienation from, or disruption in one's own ends of purposive activity and an inability to maintain the ordered wholeness of one's world. Rawlinson (1986) and Shneidman (1995) concur that the one who is unable to suffer stands at the limits of this experience, or relief is gained through disowning life.

Within the confines of Freud's discussion of suffering, it is evident that the persistent pain stories presented in this study illustrate the complexities of a multidimensional concept. The importance of this concept for persistent pain sufferers, particularly when considered within the ideological influences of Western discourse, is twofold. First, this ideological system constructs self worth as the undertaking of some purposive activity; and second medicine as an apparatus of this system, constructs health as the ability to work or to partake in purposive activity. Thus, no matter in what order of meaning suffering registers, it never remains contained. Suffering tends
to reverberate throughout all orders of meaning, obstructing and warping the horizon of value inscribed there. Inside each of the orders of meaning, suffering erupts as rupture within the participants themselves, a rupture between his or her situation and those ends that he or she take as their own. Joanne describes her suffering in the following:

I feel so down and useless. At that time Umm I felt I wasn’t any good to anyone, myself as well. The pain was just so intense that I just wouldn’t do anything. Some times I just didn’t want to live. It just didn’t seem worth living because I had no life (crying).

One time I was so low that I had sleeping tablets and I wasn’t me and I just wanted to be pain free. I just took a handful of them. There was about ten or twelve or something. It only worked for an hour (laughing) and I was awake again. It didn’t work for very long. I didn’t really want to do anything that would really hurt I just wanted to get away, just be by myself just sleep and feel no pain. To a place where you don’t feel pain and if I have a problem I would forget (Verbatim Transcript, September, 1995).

David explains his suffering:

I’ve tried to go back to work. But no luck. I was on cement for two days, the first day wasn’t too bad, the second day I had a job to get out of bed and I had to go and take pain killers, I was pumping them into me all day I don’t know why I was taking pills because I hate it, so in the end I just said I can’t handle it and that he went to pay me and that and I said don’t worry about it, keep it for yourself.

Then I had a go at truck driving I only, it was too rough for me truck driving and tractor driving I spent a night, two nights in hospital after I done a days truck driving, and ah I have just been doing nothing, I’ve been doing painting at home and when I get crook I just go and lay down and I suppose there was a time when I thought of just going down to my room and pulling a gun out and shooting meself, I wasn’t game enough. I’ve felt like that half a dozen times, before I had the operation and after I had the operation.

When I felt like shooin myself the pain and just getting neglected by people I’d worked for, for so long and I had one of the best names around that area for a Shearer (Verbatim Transcript, September, 1995).

Vince recollects a time when a simple action caused a precipitation of severe pain:

I picked this water melon out of the fridge and your pain comes back. It was a bad pain worse than before. Lana, I think she knew, because I wouldn’t be here if she took notice of what I done, I wouldn’t be here.
insulted her to get her out of the house, really insulted her, and she wouldn't go and the lad was living here at the time and his rifle was in that bedroom. I insulted her to get out in the yard I would have used the rifle. She wouldn't, so she just rang up a doctor to see if I could make an appointment there, and I said I'll go around if I can get in, yeah, so I went to the doctors there he wasn't going to let me out of the surgery, you could see it, he wasn't going to let me out of the surgery and made me promise I wouldn't do anything so he let me go. It was close, yeah, I dunno, cause I didn't wanna go back to the way I was, yeah, but I think that's how my life's been every since (Verbatim Transcript, September, 1995).

David, Joanne and Vince have experienced suffering, at times to a point where they have contemplated suicide. They have described periods of intense depression following the development of their pain and have experience serious ruptures in their horizons of value (Rawlinson, 1986:46-8). Rigatti-Luchini, Fracca & Merskey (1998) examined the interrelationship between suicidal ideation, suicide attempts, depression and chronic abdominal pain and have found that the lifetime prevalence of Suicidality was much increased in those with chronic pain to those without pain. Further, rates of thoughts about death, wishing to die, suicide ideation and suicide attempts were two-to-three times more frequent in those with chronic pain compared to those without pain.

Shneidman (1995:169), using a psychological perspective, provides an apt description of suicide as a ‘drama in the mind’, a drama caused by a kind of pain, a psychological pain or ‘psychache’. Moreover, it is ‘a conscious act’ best understood as a multidimensional malaise in a needful individual who defines an issue for which suicide is perceived as the best solution. This is the position of the persistent pain sufferer who contemplates a quick and easy death as relief from pain.
Lum (1997:64) asserts

pain distorts one’s perception of reality and makes living - or wanting to live - difficult. Whether I’m actively in pain or not, there’s the dread of being in pain. That tempers how I feel about life and whether I want to continue living. When I think about living I don’t have pleasant images or feelings. Instead I picture the persistent vibrating of pain moving up and down my spine.

Since usually I am in some sort of pain, thinking about death seems justified: I have more of a reason to want to die because it is a sure a solution.

Kosky, Salimi & Kneebone (1992:97) appropriately combined both perspective by describing

suicide behaviour as a manifestation of distress associated with loss or abandonment, a release from despair an expression of hostility a revenge, an appeal for help, a wish to tempt fate or to be reunited with a loved one and or a response to the disordered thinking of psychotic illness or drug reaction.

These views indicate the multidimensional nature of suicide and imply that attempting to pinpoint an exact cause for a suicide event can become particularly complex. Raphael (1993:68) asserts that while social factors influence suicide there is an increased risk for those who are socially disadvantaged and facing high levels of life stress such as the unemployed and those suffering ill health. Christine describes her husband’s suicide after a long and tumultuous life with chronic pain, following an injury at work:

The pain had completely taken over his body as well as his personality. His self esteem was low and he was depressed. Talk of suicide was always in a joking manner. John said he was “too chicken”. On April 11, 1989, four days before his 44th birthday he ended his suffering

She continues:

chronic pain is unfair and destroys lives, but suicide is not the answer. Suicide is a very selfish act that leaves a path of destruction behind suicide is not linked in the literature with chronic pain as a result of an accident or an injury.
Gullickson’s (1993) phrase *my death nearing its future* provides a valuable analogy with the wishes of those persistent pain sufferers who have contemplated suicide. It is contended that the experience of chronicity accentuates the individual struggle to keep at bay the possibility of their own death, which has been constructed as the end point of a linear time sequence. This is analogous with pain - that is that it will end. Pain, as death has and is not been viewed as a potentiality or as a possibility, therefore humanity is afraid of death and similarly seeks to obliterate the human existence of pain. Death, if conceived as an actual event requires that each person wait passively for that event to occur. If death is seen as a possibility then the person may be active and anticipate the event. Gullickson (1993:1390) states:

> It is through the understanding of death nearing its future that new possibilities emerge for living. Every or even a linear event, new possibilities emerge that provide meaningful insight into how one chooses to be. Creating and re-creating a future of possibilities requires reciprocity.

The capacity to create and create a life of reciprocity requires that the persistent pain sufferer has hope. Dufault & Martocchio (1985:380) suggest that hope is a multidimensional dynamic life force characterised by a confident, yet uncertain expectation of achieving a future good, which to the hoping person, is realistically possible and personally significant. Hope is a process, a set of a complex of many thoughts, feelings and actions that change with time. Schneider (1980:12) claims that hope is an illusion which has a reviving effect and a survival function. In effect it is the antithesis of despair.

The spheres of hope encapsulate two broad dimensions: generalised hope protects against despair when a person is deprived of particular hopes, and preserves or restores the meaningfulness of life - past, present and future. It is an underlying
sensation and belief that functions as a foundation for dealing with the process of living (Schneider, 1980:12; Dufault & Martocchio, 1985:380). Particularised hope, on the other hand, is concerned with a particularly valued outcome or state of being. Here, hope is conceptualised as an object, which may include a goal, solution, relief, a relationship or anything significant to the person (Stephenson, 1991:1458). This aspect of hope is significant to persistent pain sufferers without a consensual diagnosis because it allows the sufferer’s hopes to include product focussed wants. That is, that their pain can be improved and that they can have a pain free life. Importantly, it provides the possibility of that which is valued in the present being part of thehoping person’s future.

Here, it may be noted that the hoping person clarifies, priorities and affirms that which they perceive is most important in life. Moreover, Default & Martocchio (1985) contend that some particular hopes serve as a diversion or respite from stress generated threats to generalised hope, or other particularised hopes. In some circumstances, it is as though generalised hope provides the climate for developing particular hopes and later rescues the hoping person when particular hope no longer seems realistic.

Default & Martocchio (1985) outline six dimensions of hope: affective, cognitive, behavioural, affilative, temporal and contextual. The temporal dimension is particularly applicable to the persistent pain sufferer in that this dimension focuses upon the hoping person’s experience of time, that is past, present and future, in relation to hopes and hoping. Hope is directed at a future good, but incorporates the past and present predicament of the individual. Hickey (1986:134) asserts that hope is like an anchor, stabilising our lives in the present and giving life meaning, direction
and optimism. Steve describes his hope when he felt someone understood his predicament. He says:

I felt that he understood what I was going through and I thought this is so strange I couldn't believe it, I thought there might be hope for me yet and um he said to me that he had a pain clinic here in Brisbane (Verbatim Transcript, September, 1995).

David defines his feelings about the future after spending five weeks in the Pain Clinic:

um I still have me sheep dogs and that they are only pets now, they’re the only things that have been keep me, I just. I don't go out anywhere I cant mix with people I just get too irritable and that, me wife she wants to go out, I just say, go on go for your life, she wants me to come you know and I'm just not up to it and so hopefully when I finish here there might be a bit of difference.

David explains his hopes prior to his injury:

I'd hope d my life would be to get out of shearing by the time I was 50, cause most blokes do because they're pretty well wore out by 54, not many shearsers make it right through. I was one of the ones that could have gone a bit further, I never drank and knocked meself about like some blokes did, and always had good tucker, some of the blokes would just drink all weekend and, and I have never done that, I treated it as a business because I was contracting meself and um that's all I had 11 months run of the year I had 9 blokes working for me (Verbatim Transcript, September, 1995)

Keeping hopes non-specific serves as a protective device; the persistent sufferer is protected from disappointment when a hope is not realised within a specific time frame. Non-specific hopes also expand the possible, extend opportunities for positively affecting the hope, and delay the need for further reality surveillance. However, when the persistent pain sufferer recalls situations from the past that were painful or precipitated an exacerbation of pain, memories of previously hoped for unfulfilled hopes renew the sense of disappointment that accompanies abandonment of hope, and increase their personal sense of alienation.
Vince explains his relief and hope to be back at work:

I say possibly he was relieved when they said they’d found something in the myelogram, cause he said 4 months after the operation he said you’ll be back at work, it gave me a lot of hope a lot of promise, but I think at that time I was only 40, I wanted to get back to work. I felt that the surgery would be a success (Verbatim Transcript, September, 1995).

He continues by acknowledging that when pain relief is not possible he would resort to any measure to find relief:

You try anything, if anyone says go out there and hang by your feet up on that branch there for two hours or something, I reckon I would have tried to do it, if I knew it was going, there was some hope that it was gonna help me. But when you try something and it seems like its gonna work and then you turn around or reach for a magazine and BANG its back. Well you just felt like shit. Alone and Lana says its ok and you try to sound cheerful, but you know its not ok. Your just alone again. Awake at night, sometimes sitting up all night, mostly lying in bed all days and the world just keeps going around you (Verbatim Transcript, September, 1995).

The contextual dimension of hope brings hope to the forefront of awareness and experience within the context of life as interspersed by the hoping person (Default & Martocchio, 1985:388). Furthermore, the contextual dimension focuses upon those life situations which surround, influence, and are part of a person’s hope. For the persistent pain sufferer without a consensual medical diagnosis, the continuance of pain which can not be secured to a definitive diagnosis expedites the source of grief which leads to the situation where the experience of being registers as a life loss. Loss may be considered in light of physical well-being; functional ability and independence; ability to participate in the aesthetic, recreational and intellectual activities of life; ability to fulfil expectations, meaningful relationships; and financial security. All participants in this study have experienced these losses. Vicki explains:

I’m the only one who thinks I am not worth it to Bill. Its just that I’m a burden, I look at myself as a burden. I’ve always been really independent and um the loss of independency like as I said before, you lose your privacy, you know, you lose your self esteem, you lose your confidence um you lose your whole being you know, who you are, you lose everything you know, the things that you stood for before it just not things that you can
stand for now, you know you've gotta find other directions in life and as well as coping with the devastation of the lifestyle and the ... anyone that suffers chronic pain you know it's a cruel world to have to live in until you get your shit together you know getting your shit together takes a lot of hard work you know and when you come up against doctors that treat you like shit they make it worse for you, you know and you don't need those brick walls because of what you have to cope with alone is enough without having to come across medical practitioners that are brick walls, you know, they have no idea, and you walk in and you say I have no diagnosis, that's just like, that just make it even worse you know (Verbatim Transcript, October, 1995).

Gadow (1982:87-9) argues that illness results in loss of the original unity of body and self and provides the means of recovering it at a new level. However, what unity means can only be defined subjectively. Further, with each new and often unsuspected bodily impairment, people with chronic illnesses repeatedly experience loss of whatever unity between body and self they had previously defined or accepted. Thus, at each point when the persistent pain sufferer suffers loss, identity questions and identity changes are evidenced. Steve no longer believes he is able to dance or to ride his motorcycle. These limitations have severely altered his perception of self. David is no longer able to shear. His ability to shear 200 sheep in a day signified his sense of personal worth and his standing within the local community. Joanne’s weight gain and inability to sustain employment and care for her husband led to feeling of worthlessness and depression and Vicki believed herself to be unstoppable, but experienced the increasing inability to walk without a limp or to carry and nurture her child. In essence each participant endures life as the inability control certain events or situations which relate to personal identity and to the life they mapped for themselves. Notably, Bury (1987) and Fuchs (1987) assert that powerlessness is a resultant state in which an individual perceives a lack of control over certain events or situations. Moreover, it is the expectancy or probability held by an individual that his or her own behaviour cannot determine the outcomes he or she seeks. Averill (1973:286) described personal control in the following ways; behavioural control is
the availability of a response that can influence the event; cognitive control is the way in which a potentially harmful event is interpreted; and decisional control as the opportunity availed an individual to choose between alternatives. A number of studies attest to the positive consequences of the mere possibility of personal control in relation to the proportion of helplessness and hopelessness experienced by suffering individuals (Seers & Friedli, 1996; Walding 1991; Fuchs, 1987; Cohen, 1980). Conversely, Brackney & Westman (1992) stress that the lack of personal control is associated with a lessened sense of hope (Walding, 1991). Seligman (1975) and Schneider (1980) contend that helplessness is being in a situation in which responses occur not as a result of actions by the person in the situation, but apparently uncontrollably from his or her standpoint. Hopelessness is an emotional state displaying the sense of impossibility, the feeling that life is too much too handle, and apathy. The individual involved becomes passive and cannot foresee ever being in a different situation (Schneider, 1980:15). Price (1996:276) contends that chronically ill individuals experience stressors as distressors, and that life, instead of seeming a challenge, increasingly seems to involve 'pervasive' helplessness. The extant position here suggests that when placed in this space, continuously these individuals reach a state of disequilibrium which preface the labelling of these individuals as non-compliant, withdrawn or depressed.

The Foucauldian concept of "discourse" provides insight into the ways in which the 'pervasive helplessness' of persistent pain sufferer may be sustained. To recapitulate, discourses are sets of rules which define particular realities. When coupled with the influences of ideology, power is exercised through the creation and sustenance of social norms, practices and institutions which support those who define the rules of a particular reality. Discourses exist in related groups of controlling practices, or in discursive fields. The discursive fields of Western medicine, when applied to the
persistent pain experience, consigns the persistent pain sufferer to a world in which micro-level human experiences, such as persistent pain, become the object of intense discursive analysis, resulting in their re-configuration within a paradigm of truth and knowledge which, despite its efficacy, attempts to absorb all the particulars of subjective and inter-subjective experiences (Banarjee, 1995). Szasz (1975:xxi) encapsulates the sentiments of paradigmatic truth in the following

'[T]he persuader is not a man (sic) who must find solutions for problems, but one who must construct problems to fit pre-existing solutions." As pain constitutes the career of l'homme douloureux, so its diagnosis and relief constitute the career of many physicians. The passion of patients trying to persuade physicians to engage in this or that pain-relieving intervention is matched only by the passion of physicians recommending this or that pain-allaying treatment. Just as the seriousness of the patient's devotion to suffering is measured by his resistance to relinquishing his (sic) chosen career, so the seriousness of the physician's devotion to relieving pain is measured by his (sic) resistance to admitting defeat in his (sic) struggle against pain.

The excerpt to follow illustrates the reconfiguration of a lived persistent pain event into an objective attempt to alleviate pain and the resistance of both parties to accept the persistence of pain. We enter Vicki's story the day after her visit to a general practitioner who has commenced her on intramuscular analgesia. The ludicrousness of this attempt to alleviate persistent pain, is best explained by the general practitioner's choice of analgesic. That is, Pethidine (Intramuscular, 100 milligrams) which has a short acting effect of approximately two to three hours. This necessitates the frequent repeat of the drug and the subsequent labelling of Vicki as drug dependent:

She poked and prodded the lump and as she was poking and prodding the lump, I was saying to her that I am going to be in extreme pain after you do this and she ignored me as though I said nothing at all, but I knew because I was probably taking Doxopin and I had changed over to Voltarin on my own general practitioner's advice, gave me nothing to get home at all I left there in more pain than what I was when I got there because she poked and like I'd get mad at myself because I allowed her to poke and prod that lump knowing that it's going to cause me pain because no-ones listens to me, no-one listens that in five minutes time I'm going to be in
excruciating pain because I'm allowing you to do this and they don't listen she just disregarded me and then left the room, see you in a fortnight, get back on Doxopin stop taking Voltarin, see you in a fortnight and walked out of the room, left Bill and I in there on our own. Those fucken (sic) tablets. Joyce you know I don't, I need someone to pin-point what it is that's causing the pain so I can physically work at getting other areas in to substitute for the area that's damaged so I can live better, you know, physio wise, strength wise you know what I mean, so I'm not lying down as much as what I am. I'm just sick and tired of. I don't leave the house now you know other than doctors appointments, don't even get out into the yard, you know this is it, this is my world.

Hell. Hell. The last month Absolute hell um, I might have to get Bill to help me to talk about this. It started with the third injections on 4th, here we go, 5th October I got three local injections in the right side of my back the third injection which was in my lower back um you should actually read this to see how I've actually gone in the last month. Ever since that third injection I've been in double the amount of pain that I normally suffer and I've had to go on to Pethidine injections in the bum which was found out because I'm sensitive in that area it's easing the pain at the time I get the injection but the actual injection is aggravating um the soft tissue damage that I have. I've just been backed up against a wall and didn't really know, when did we go and see Dr W.? Tuesday 24th and that's when he realised that no more injections in the bum cause it's aggravating the pain that's when he gave me one in the leg and as you can see, I knew my muscle was tense when he gave it to me, he just gave it to me the wrong way. (Vicki has got a good tennis ball size bruise on her left thigh that she's showing me, looks really sore, it's going down now).

I haven't at all. I haven't coped being a mum in the last month, I can't change his nappy, you don't mind him. I need him today Joyce cause I'm having one of those days when I can't get it together. BILL SITS DOWN AT TABLE. Bill and mum have taken over in the last month. I feel bad about this. I cried a lot, I cried a lot because I can't participate in like all I can do is lie down and watch him play and watch Bill play with him, you know if he needs his nappy changed I've gotta go mum he needs a nappy change, you know, Bill he needs a nappy change, you know, how long I held him for this morning that's it, that's it as you can see my walk changed after I passed him over to mum because my the pain in my back got worse and that was only a few minutes I was holding him I just can't, that's why I gave him to mum, that's how it's been ever since I had that third injection and the third injection was right down in the lower part and whatever he touched has made my soft tissue worse if that makes any sense at all, with just one. Bill said that he put the needle in and then he said just hang on I'm gonna try something and he pushed the needle in a little bit more and that's when he hit something in there and I've just let out an almighty scream like it was just and gee the pain, and like it hurt it really hurt and from then I've been down hill. These suicidal, even to the point where I'm, I got to a point of what I was gonna write in the letters that I left behind for everybody and people say that you can't Vicki you know, you've got Bill and you've got Callum and you've got your mum and it. In the last month I've, they can survive without me, they'll get by, sure it will be hard but they'll get by without me it's got to that point you know, and um like I don't think like that now but I'm still in that down, if you know what I mean, I'm still that down even though, one day there I said to Bill I wish I had a gun and I'd use it, I would use it and the last time I saw Craig H. my psychologist he asked how I was going and he said you know how bad it is suicidal

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thoughts and I said well I've pictured myself sitting down with a gun in my hand and like not knowing whether I would use it or not, like that's a pretty scary thought not being able to say no. I'm not gonna, I won't use it if you know which I've always said, you know I've had suicidal thoughts for months and months and months on end but I have always said I won't do it, but in the last month it's got to the point where I've really had to say to Craig if I had a gun and it was in my hand I don't know whether I would use it you know and the run around with doctors and tablets and just the extent of pain that I now suffer since those injections which were local injections, a double the pain and it's like I couldn't cope with what I was in feeling before and now that it's double it's am I coping with it at all, see I'm, I've just live minute by minute and as the minutes go by I forget like this morning I got up but I couldn't tell you what I did between when I got up this morning and when you arrived you know I'm blank.

It is like this most days, most days, so I'm not, you know what I mean, it doesn't, I can't understand why I'm blanking it out or if it's doing itself or is my mind coped with that much that it's doing it for it's own sake you know, you just don't know you just blank out like, gees did I have a shower today you know just with everything I'm just down on everything, no-one, nothings going for me all I'm getting is medication that's bombing me out I don't want to be bombed out I want to have a life, I want to be on minimal medication and have a life you know, even if it just, even if I just lie down three times a day you know and I'm up, but at the moment I'm down a lot too much aren't I. (B. Most of the day). 90% of the day I'm lying down now either through fatigue or through pain and like pretending is just fighting I don't know where it come from and you know mum said with the amount of tiredness that I suffer it she's, it's like chronic fatigue mum said you know, the amount of tiredness, you know and I haven't got the energy to do this and I can't be bothered doing that and there just, you know, I can't be bothered if I have put a drink down on the table and then I go and lie down I can't be bothered getting up, it's an effort to get up to get that drink so I would lie there and go without and have a dry mouth because of the effort it is to actually get up, you know, like that's all new to me as well. I'm normally a fighter Joyce you know and like I'll fight to the bitter end but it's getting the better of me now and three doctors, like my own doctor, plus Dr. W. and Dr K.L. and they're not communicating with each other and I'm, it comes back on me because they're not communicating and I can't, I'm not coping with that you know it's I've just, I don't think I've given up I just don't want I need time out you know and I'm not getting it, and I don't know, I just need time out and giving me tablets to knock me out isn't time out because I'm not awake to enjoy the time out I'm sleeping you know what I mean, so that's not time out for me, time out is being awake and being aware of the time out and the break and I'm not getting it, I'm just simply fighting all the time.

Myself and doctors you know, I don't want more medication I don't, I know I need medication Joyce, you know that's obvious (B. Being shuffled around from doctor to doctor). To doctor. (B. Go to one doctor alright I think we can help yah put you onto somebody else and it starts over and over again every doctor you go to you've got to tell them the whole lot right from where you started it's just wearing her down, it's destroying her). We were over the moon last time you were over the moon with what Dr. W. had said and what he had promised. Then he put us onto another doctor, which then started again (Verbatim Transcript, October, 1995).

Foucault (1977: 227) summarises the consequence of this ensnarement, asserting that:

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the obedient subject, the individual subjected to habits, rules, orders; an authority that is exercised continually around him (sic) and upon him and which he must allow to function automatically in him.

From the above excerpt it is clear that Vicki’s experience reflects not only the helplessness and despair of living with pain, but Vicki’s firm belief that her pain should be dealt with by another, or through some kind of intervening event or medication. The objectification of her pain to the soft tissue in her back allows others, particularly those in the position of power of dispensation of treatment, to seem powerful. However, what also becomes evident in this excerpt is that all individuals concerned with the persistent pain event, and the event’s subsequent by-products, are significant and, therefore, powerful in constructing the event and the event’s sequelae.

Douglas (1973:72) asserts that the social body constrains how the physical body is perceived and experienced. These perceptions and experiences themselves sustain a particular view of society, but when collapsed together the risk of reducing the ways in which people live, experience and perceive their bodies - into the positions and categories made available by the social body is significant. Moreover, Foucault’s (1980) analysis of power suggests that power is not monopolised by any one subject through its control of a predominant discourse; the discursive field comprises multiple subjects who manipulate various discourses to some extent. For Foucault, the issue is not the origin of discourses, but the implications of their power effects and the types of knowledge they produce and institutionalise. Since power originates in discourses, it has no unitary source. It is heterogeneous and pluralistic, coming from everywhere and being everywhere creating and validating a social network of normative power which disciplines and constrains the individual at the micro-level.
Banarjee (1995:25) asserts that the disciplinary techniques of modern society employ the normalising hegemony of rationality to construct docile and useful subjects and, in relation to power, Pratt (1986:7) states

by the virtue of the fact of its universality, power is able to encircle the body; by virtue of the fact of its positivity it is able to incite, exhort and produce bodies that will be useful. The net result is that there is no standing outside of power, no-one escapes, no-one is allowed to give up, whatever one’s handicap, disability, crime, disorder and so on.

Thus, living with persistent pain may be viewed as a complex process and implies a balance between the demands of the situations presented to the sufferer and their ability to respond to the demands (Pollock, Christian & Sands, 1990). As posited earlier, this balance requires that the responsibility of the health professional is to return the suffering individual to work, or to ensure that the sufferer adapts to their altered self in a way which absolves the existing discourse from failure to relieve persistent pain. Adapting leads to taking responsibility for self and maintains the persistent pain sufferer without a consensual medical diagnosis, within the confines of a discourse which attempts to either control or disqualify their lived experiences. Vicki describes her discussion with Sue, who is also a persistent pain sufferer and provides strength and acceptance of Vicki’s descriptions of pain. She says:

Sue said, you know your own body, you know when you’ve had it for that long you know and you get frustrated with doctors because they treat you like you are an imbecile and they know and, in actual fact, they don’t know - you know, sure they do know but when it comes to your own pain and when you hurt and how you hurt and what makes you hurt they don’t listen to that you know I don’t care if, how if pressing on that lump causes pain, I don’t care if that’s unethical or it doesn’t make sense I don’t give a shit, that’s what happens, you know and they don’t listen to you, you know, if they took the time to sit down and listen to me maybe they could pin-point it a lot better and everyone has a different injury you know and people have to find that injury to acknowledge it, maybe I’m one of these people that have a got an injury that isn’t known you know and they have to find out what it is before they can help anyone else that has the same sort of injury you know, maybe I’m one of those people but that’s not reason to disregard me that’s no reason to give me these tablets to bomb me out to get me out of their office, that’s no reason for them to treat me like a liar, treat me like shit, treat me like a number you know, nobody deserves to be treated like that and not only with chronic pain but anything, you know and I’m just mad at them because they’re not listening to you you know, their the doctors they will know like, like we said at the pain group they think they’re god you know and you get to the point where they, I think, like this lady at the pain group, sure she knows about pain but she doesn’t know about chronic pain, she has no idea about chronic pain at all as far as I’m concerned the way that she’s been treating me especially yesterday you know, that’s
supposed to be a happy day for me you know how you have your birthday
(Verbatim Transcript, October, 1995).

Foucault (1977:301) states

the carceral network does not cast the unassimilable into a confused hell;
there is no outside. It takes back with one hand what it seems to exclude
with the other. It saves everything including what it punishes. It is
unwilling to waste even what it has decided to disqualify.

Here, power does not operate only through the disqualification of persistent pain,
but through the discursive creation of pain and painful beings. Moreover,
Foucault (1978:140) coined the term "bio-power" to describe the process of
politicisation and disciplining which encompasses both human anatomy and larger
society. Although, it would seem that Foucault provides little assurance for the
persistent pain sufferer to transcend the obdurate circumstances of living with
pain, Best & Kellner (1991:54-7) contend that Foucault's theorising is grounded in
the belief that knowledge can be transformative: hence, the importance of
recognising the evolution of modern subjectifying discourses and practices. For
instance, in The History of Sexuality (1978), Foucault questions notions of sexual
liberation by demonstrating that modern concepts of sexuality originate in early
Christian culture and are expressed through disciplinary techniques that confine
individuals within totalising discourses and identities (Best & Kellner, 1991).
Attempts to achieve liberation by liberating sexuality do not escape the
normalising discourse. In order to escape the principle of sex and sexuality, which
are accompanied by social mechanisms of sexual control, one needs to claim
multiple pleasures for individual bodies: “The rallying point for the counterattack
against the deployment of sexuality ought not to be sex-desire, but bodies and
pleasures” (Foucault 1978:157). At the same time, although discourses reinforce
power, they also provide potential for resistance, whereby the disenfranchised can
extend oppositional discourses and demand legitimacy, frequently by
appropriating institutional categories. For example, also in The History of
Sexuality (1978), Foucault points out that while the discourse of “perversity”
intensified social control mechanisms against social acts such as sodomy, it also
created “a ‘reverse’ discourse” of homosexuality, which rejected institutional
classifications and demanded validation (Foucault 1978:101). The creation of a
reverse or oppositional discourse which legitimates persistent pain, without a consensual medical diagnosis, allows persistent pain sufferers to glean meaning from their experiences and thus end the search for traditional and conventional forms of relief.

6.12 POWER AND RESISTANCE

Power is inseparable from resistance. Banarjee (1995:29) asserts that even though Foucault's discussion of political tactics is slight, it represents a break with earlier revolutionary strategies and posits a postmodern politics. Foucault (1978:57) urges a multiplicity of resistances, a micro-politics of local and autonomous struggles battling diffused and decentralised sites of power. It is the contradiction of contesting hegemonic forms and practices which provide the basis for resistance. Thus, it may be purported that it is the degree of opposition within a space that potentially subordinates persistent pain sufferers from a merely theoretical resistance to embodied challenge, from unconscious and unintentional to deliberate and collective resistance. Resistance may occur in two ways: when marginalised groups contest hegemonic normalisation discourses to liberate differences; or, when, individuals resist disciplinary powers by reinventing the body through new modalities, thus subverting the construction of normalised identities and forms of consciousness (Best & Kellner, 1991:55-8).

The application of the concept of resistance has far-reaching implications for the development of new ways of understanding persistent pain, for the sufferer, and for the discovery of meanings of such pain in order to create a life of future possibilities; in particular the feminist interpretation of the Foucauldian construct of resistance is useful. Diamond and Quinby (1988) contend that there is a vital convergence between feminism and Foucauldian inquiry. According to them, both perspectives recognise the body as the site of power relations; both focus on localised power effects as opposed to those of macrostructures such as the state; both highlight the critical role of discourse in creating and sustaining hegemonic power relations that espouse universalistic rationalism; and, both call for resistance through marginalised discourses. Martin (1988) suggests that Foucault's deconstruction of power, knowledge and sexuality provides exciting
alternatives to traditional Marxist macroconceptions of sexuality and power grounded in economic essentialism. Soper (1993:30-2) states that Foucault's most significant contribution to feminism is his idea that sexuality is a historical and socio-cultural construct with accompanying power effects, thus strengthening the opposition of feminists to the notion of sexuality as natural or innate. Sawicki (1991) demonstrates that Foucauldian analyses of sexuality, power and freedom resolve the problems of radical and liberal feminisms, which rely on essential, ahistoric and naturalistic arguments. It also suggests that Foucault's emphasis on difference can be utilised by feminism to proliferate resistances. Further, Diamond and Quinby (1988) and Soper (1993) purport that a crucial Foucauldian contribution to feminism is the power/knowledge relationship. Foucault demonstrates that knowledge and power are inseparable, and that knowledge is produced through an intricate network of prescriptive technologies and disciplines, such as medicine and psychology, which constitute regimes of truth and normalise underlying power mechanisms. Fundamentally, the persistent pain sufferer exists within a mode of technologies and disciplinary forces which support the discourse of medicine and it is through the deconstruction of this discourse that they are able to see its contradictions and, therefore, act to remedy their alienation from it. Similarly, Foucault's deconstruction of the subject is also highly pertinent to understanding the dilemma confronting persistent pain sufferers. Foucault demonstrates that any discussion of a subject carries within it the underlying assumptions of the established normative order. The idea of the subject signifies a unitary and deterministic entity which does not consider the diffused and decentralised applications of power, and the multiperspectival resistance required by the effects of such power (Soper, 1993:30). The subject also implies an essential human self which holds the key to empowerment and liberation and the foreground of alternative existences. Again, let us return to Pappas (1990:200) who purports that, as in other social systems, power relations in medicine can be understood in terms of autonomy and dependency. However imbalanced in terms of power, individuals in subordinate positions are never wholly dependent. They are able to convert whatever resources they possess into some degree of control over their conditions.
Vicki, Steve, David, Joanne and Vince are in the process of redeveloping personal identities which embrace their *pained* bodies. The embracement of their *pained* bodies, and the influences upon their personal life trajectories require that they conceive a life which acknowledges their pain and validates their experiences. Charmaz (1994:238) writes that once an individual learns to listen to their body, they are able to abandon those perceptions held of self, before illness forced them to adopt other priorities in life. When the persistent pain sufferer is able to do this they cease to measure their body against past perfection, or past hopes of perfecting it, and begin to live with it. This disidentification with their previous self represents the beginning of an alternative discourse, a resistance to the dominant ideologies of pain. The *pained* body becomes familiar and comfortable. The persistent pain sufferer may feel that he or she is beginning to unify the altered body and the self. Ramazanoglu (1993) contends that the resistance to dominant modes of power develops through the production of new discourses which produce new truths, and counter discourses which appropriate categories of existing truths to claim legitimacy. Pappas (1990:200) claims

To recognise domination is to acknowledge autonomy and dependency in a relationship. Even the most seemingly “powerless” individuals are able to mobilise some types of resources which give them control over aspects of their day-to-day lives or over the lives of others. The helplessly ill patient has power to disrupt or resist, a frequent observation and frustration of health care worker.

Gotfrit’s (1991) account of resistance in the article *Women Dancing Back* is applicable to understanding the situation of persistent pain sufferers. It is asserted that dancing is a site where dominant ideologies are both reproduced and resisted through women's accessing the powers of desire and appropriating of pleasure and space for themselves. Thus, living with persistent pain is also juxtaposed with dominant ideologies of pain and the actual lived body. In order to understand how loss and recovery of body-self unity occurs we must understand ill people’s meanings of their bodily experiences and the social contexts in which they occur (Fordyce, 1994:51) Such meanings arise in dialectical relation to their biographies.

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(Bury, 1982 1988; Bendlelow, 1995) and are mediated by their interpretation of ongoing experiences, but arguably under the guise of dominant ideological forces. Thus, the type of self emerging from the persistent pain experience depends on the type and degree of pain, the meaning of the experience of pain, the timing and the sequencing of pain, and the individual's expectation of and for the self.

If persistent pain sufferers continue to exist within these confines, then in Turner's (1992:31-43) words the mind, and consciousness, is itself disembodied; and there is no sense of the mind's location within an active human body. Bodies are produced, but their own powers of production, where they have any, are limited to those invested in them by discourse. As such, the body is dissolved as a causal phenomenon into the determining power of discourse, and it becomes extremely difficult to conceive of the body as a material component of social action. If the mind is ignored then the immediacy of personal sensuous experience of embodiment which is involved in the notion of my body receives scant attention. My authority, possession and occupation of a personalised body through sensuous experience are minimised in favour of an emphasis on the regulatory controls which are exercised from outside (Turner, 1984: 245).

Moreover, the alienation of the phenomenology of the pained body tends to weaken the bonds of the dominant cultural dialectic, polarising the individual and social spheres. Kleinman (1988:5-11) asserts that not only does illness pose a very real threat to the sick individual, but it does the same for his or her social nexus and may even become a threat for the entire social community. The very values and sense of order inherent to society may be called into question by illness, as may be the forms of social stability and control. Healing, especially in its traditional guise, might be interpreted as restructuring this dialectic, operating at both poles to strengthen and support the bonds linking the individual and social experiences of illness.
Notably, Gotfrit (1991) views culture as not a product but a practice within a field of signification and ideology, and offers a way to understand popular culture as a set of signifying practices, where representations continually vie for ascendancy. Thus, the process of signification, of attaching meaning to forms and practices is an ideological one. Who creates culture, knowledge, and history, what is valued as culture, and how and with whom it is shared are dependent on the social and power relations that exist (Wexler, 1982). Moreover, Frank (1991:87) contends that bodies, and thus individuals, are inextricably related to social forces and social relationships and develops the idea of the body as a corporeal phenomenon which itself affects how people experience their bodies. Frank recognises bodies do not emerge out of discourses and institutions; they emerge out of other bodies. Bodies provide people with the means of acting, but they also place constraints on action. His discussion of the communicative body represents a paradigmatic revolution when applied to the persistent pain sufferer without a consensual medical diagnosis, as the communicative body emphasises the importance of shared narratives and communal rituals. In light of the way the social and power relations that exist within society, as a consequence of ideological forces, the liberation and transformation of persistent pain sufferers may be found in the sharing of understandings, narratives and communal rituals related to living with persistent pain. These together would represent the private folklore of living with persistent pain and evince a life of future possibilities. Garro (1994:777) believes that it is often a relief for persons to discover that others have similar problems, and lessens feelings of isolation. These individuals feel that only someone who has suffered long term pain or dysfunction could truly understand what they have
undergone, but that those who are healthy simply do not understand how draining pain is, and what a long-term issue pain is. Thus, participation in support group meetings and personal interactions with other individuals are important in lessening the sense of isolation felt by persistent pain sufferers, and in validating experience and feelings. Steve recounts:

A girlfriend and me got together earlier this year, I was with her before and then we got back together, she's been fantastic she's been more supportive to me than anyone has been and she is a chronic pain sufferer as well, and I'd say if it wasn't for her I wouldn't be here today really, cause like (Verbatim Transcript, September, 1995).

Joanne says:

A place like this (Pain Clinic). It really makes the difference when you have got a group of people who are in the same situation, like all our class and I have formed such a strong bond more or less. We all know we have been through the mill and you come to a place like this, and we don’t, most of us don’t talk about what we have all been through. We all know that we have had a problem but there is a lot of encouragement here from not only from the lecturers, or whatever but from the other members in your group. You know you have a bad day an off day and they seem to know what you are going through and you just keep each other company. Just the support you get here and then you have got all the lecturers. I think they are fantastic, you get so much support from them to. I know that they know you are hurting and they don’t let you give up and that’s what I reckon I needed back in 1991. After I had had the second operation I just couldn’t recover from it. If I had had a place like this back then I don’t think I would have gone to any of the lows that I have been at (Verbatim Transcript, September, 1995).

Vicki declares:

I feel alone. Alone in the sense of being in a room and feeling the same as someone else, I needed to be with someone else that suffered chronic pain that sort of alone, but support wise and talking to you know, I have mum and Bill but the understanding and the comprehension where I could sit down and I could say something and they say yep, I know exactly what you mean, rather than with mum and Bill I have to try and explain in a normal circumstance the way that I’m feeling, which is sometimes really hard to try and grasp how your feeling and then turn it around to a normal situation, so they can get some sort of idea of how I’m feeling. Whereas with another chronic pain person, you don’t have to do that you just say it and they know, and they go YES! I know what you mean (Verbatim Transcript, September, 1995).
It is through communication and interaction with others that Steve, Joanne and Vicki have been able to locate themselves in a space where they a beginning to find unity of self. The communicative body is the body which provides for individual future possibilities, its contingency is not a problem but a series of possibilities, and its essential quality is that it is a body in the process of creating itself through constructive interaction with others. The communicative body produces the need to develop and sustain relations with others (Shilling, 1993:97). The communicative body is also related to itself, being comfortable in rather than alienated from itself. Thus, communicative bodies are about the “capacity for recognition which is enhanced through the sharing of narratives which are fully embodied” (Frank, 1991:89).

Individuals living their material relations to the dominant ideologies discover the contradictions between individual subjectivities and reality as presented. Foucault (1980:58) in his discussion of the histories of bodies argues that central to this history is a concern with mapping the relations which exist between ‘the body and the effects of power on it’. We struggle against being tied to identities of self that subject us to domination and exploitation. As subjects we have multiple relationships to the dominant ideology. The self is constantly being reorganised, reconstituted within larger social relations. We make sense of our experiences in ways that attempt to resolve the contradictions of the self that are created and lived within dominant forms. An individual’s inscription into the culture becomes a process of negotiated consent, not coercion, marked by moments of refusal. In other words, as Apple (1982:159) writes that
the formation of ideologies is not a simple act of imposition. It is produced by concrete actors and embodied in lived experiences that may resist, alter, or mediate these social messages.

Thus, the definition and construction of reality, that is, how knowledge and meaning are created and organised, are always being challenged and struggled over. There is always struggle by, and resistance from, those who are subjected to rule: hence, ideological hegemony is not monolithic and static, fully achieved and finished, but constantly negotiated (Alonso 1988). The terrain of ideological struggle is often that of popular culture, as a contextualised, dynamic interrelationship, an arena of exchange and negotiated meaning between dominant and subordinate groups. Resistance and consent are not dichotomies, but occur together, in the struggle over finding meaning from life (Banarjee, 1995). However, the struggle for finding meaning in life may require a surrender of past beliefs and expectations of self. For example, living with persistent pain may require that the sufferer surrender to a life of persistent pain.

To surrender means to stop pushing bodily limits, to stop fighting the episode or the entire illness, with the quest for control over illness being superseded by the flow with bodily experiences (Charmaz, 1995: 672). Denzin’s (1987) work, *The Alcoholic Self* encapsulates the awareness of bodily ills and a willingness and relief to flow with it. Furthermore, Charmaz (1995:672-674) states that when a person ceases to struggle against illness and against a failing body, through surrendering the person anchors bodily feelings in self. No longer does he or she ignore, gloss over, or deny these feelings and view the ill body as apart from self.
The narratives contained herein represent the restructuring of persons’ lives as they struggle to meet the challenges and limitations of their afflicted bodies, although each participant is at different stage of the chronic pain cycle. All participants felt that the quality and substance of their lives had changed considerably, such that their persistent pain experience represents the foreground of their lives, and in consequence continually force an awareness of the body as separate from the self. While participants described the usefulness and effects of support from like sufferers in validating their pain experiences they were at the time of interviews unable to surrender to their persistent pain experience. They were unable to relinquish their quest for control over their body; unable to give up notions of victory over their pain; or affirm, however implicitly, that they, themselves are tied to their pain-filled bodies. Moreover, participants remain within the culturally based dichotomy between mind and body, and sustained the view of the body both as an object, in need of being fixed, and as an obstacle that constrains and opposes their sense of self. Pain alleviating treatment remains the means through which the body is controlled and the narratives centre around the search diagnosis for an effective therapy, and the failure to find it. Universe altering events, such as the persistence of pain call into question both the individual’s very capacity to maintain itself as a whole and the idea of the whole according to which that organisation takes place. Here “the centre does not hold”: the individual becomes both alienated from that purposive activity that distinguishes him or her from others and disconnected from the idea of the whole that resolves the fragmentations of life. There no longer seems to be any purpose with respect to which all things can be measured and valued (Rawlinson, 1986:47-8). Charmaz (1987; 1995) explains that chronically ill persons frequently experience a crumbling away of their former self-images without simultaneous development of equally valued new
ones. The experiences and meanings upon which these ill persons had built former positive self-images are no longer available to them. Vicki illustrates this point:

Depends on the pain, yeah, depends on the pain, plus it depends on things that happen in my life but yesterday I went to Brisbane to see a um Dr who it looks like he's actually found, he hasn't pin-pointed a diagnosis, but he's like he manipulated my back and like he found one leg short, my right leg is shorter than my left leg, like he manipulated my back, and like he pushed this way and pushed that way and by the end of it he sat me up again and rubbed my ankle bones together and he's the first doctor I have ever left in less pain than what I was when I got there, so like that's positive for me. So today I'm positive because I've actually found a doctor that and he saw it on the x-rays, you know, for 3 years people have been saying well nothing showing up on x-rays, bone scans and cat scans and you know so where is this pain coming from, but he saw it on the x-ray itself (Verbatim Transcript, September, 1995).

Steve describes his willingness to accept any regime of treatment to assuage is pain.

He states:

Wouldn't worry me in the slightest, if I had $50,000 I'd go have another operation. To be well I'd give everything, if it takes the pain away, I can go back and do what I want to do not a problem and I can run out of here and do what I wanna do, go back to work and I'd go, fair enough if I can go back and drive a truck for 6 - 12 months or something like that. I want me off on top which it wouldn't take long to do just go and work around the plot for 6 months and then come home, if I was out of the pain I'd pay for it, it wouldn't worry me, and that's sort of kept me going (Verbatim Transcript, September, 1995).

Though Steve also believes that he has reached a comfortable place with his pain in the following:

At the moment there's still a light at the end of the tunnel, I'm still alive and like one thing I know after coming here is that I'm not gonna be in a wheelchair like I'm gonna deteriorate we all are, I mean you get old that's the thing. I'm never gonna be out of pain I can live with that now, there's gonna be days when I feel like getting out with an axe and go and rip peoples head off, but what do you do, do you sit there with a mournful look on your face, like I didn't realise until I come here how much boring people sound sitting there talking about how their back aches.

David took a more resigned approach to his life with pain. He says:

It's time I stopped worrying about people and my pain and just get on with it. That's what I wanna do, that's why I'm here aren't I? I know, I know I've gotta make it, now I've just gotta get over it and get home, I'm gonna give everything that they've told me a go. I'm gonna give everything a go. And most importantly I am only gonna worry about things that I can control.

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Me body’s in pain, but I wanna life, maybe it won’t be the same life, but it’s a life and I will just have to live it (Verbatim Transcript, October, 1995).

Vince also eludes to the acceptance of pain in his life. He relates:

It took me two years to accept it. You know the way I was. Which was in pain, and that’s something I’ve gotta live with (Verbatim Transcript, September, 1995).

Vince, David and Steve seem to be forming a personal outlook based on a synthesis or harmony between mind and body. Rather than seeking control over their bodies, there is rudimentary acceptance of the pain they are experiencing which serves as sources of guidance, knowledge and values for living their lives. Surrendering differs from being overtaken by illness, resigning oneself to it, or giving in (Charmaz 1991; Radley & Green 1987). Being overtaken occurs without choice; surrendering is an active, intentional process. Surrender to pain, however silently and tacitly, represents an epiphany in the lives of persistent pain sufferers. When surrender is complete, the person may experience a new unity between body and self, and this surrender to pain in one’s life forms the basis for a private folklore of persistent pain. This folklore is consistent with, and in contradiction to, personal schemata developed prior to the acceptance of persistent pain in the sufferer’s life, but simultaneously enhances the reclaiming of life’s possibilities and futures. Kidel (1988:18) advocates “reclaiming our illnesses [may be] expressions of our own being” to gain authenticity. Frank (1991:1) views illness as “an opportunity, but a dangerous one” which risks opening “ourselves to the full and unpredictable impact of the unknown”. Hence, persistent pain sufferers may define their experiences as newly authentic when they realise that having a pained body is part of living, and they accepts the experience of it. Moreover, Rawlinson (1986:41) asserts that the ‘lived body’ is unlike any other object.
in the world; rather, it is a domain of delimited access to and power for shaping the world.

While literature (Cassell, 1991; Frank, 1991; Garro, 1994) suggests that surrender to illness may be a transformative process, and that this process is inherent once the individual is able to reconstruct personal pain experiences within the communicative body, participants in this study have been unable to fully surrender their bodies to living with pain. In this regard, Bakan (1968: 59, 71, 88) writes

that pain and physiologies of illness tell us very little about the suffering of bodily affliction, for they do not explicate the effect of illness within the life-world of the subject. Illness constricts time and space by filling it with the pains and concerns of illness. The future, either short-term or long-range, takes on a brittle quality. One finds plans disrupted and possibilities withheld, as experiences that one does not own or intend obtrude. In illness one discovers one’s embodied self as an obstacle in one’s own project of encountering and shaping the world.

As such David, Steve, Vince, Vicki and Joanne remain isolated in their worlds. Rawlinson (1986:42) contends that illness necessarily involves the suffering of alienation, of being set against one’s self in falling prey to possibilities one does not own. Participants at the time of interviews resisted surrender as a means of holding on to past identities. They continue to struggle against persistent pain and try to impose order upon their experiences and their lives. They continue to hope and believe that sustained effort would force change to occur and victory to prevail over their pained bodies. Yet no amount of effort has changed the fact of their pain experiences, and the influences of these experiences on their life trajectories is significant and detrimental to their embodied selves.
Typically, participants believed that they already suffered beyond tolerable limits. Vicki states:

My pain has caused me to change my whole thinking about life. I think I have suffered enough. But every time I think things can't be worse, things do. I don’t think anyone needs to suffer, but I keep asking myself why me? Why not someone else. How come I have to have pain every day, I can't even walk or even lie down some days. I can’t carry Callum or love Bill. It’s not fair and I’d do anything, take anything to stop having to live this way (Verbatim Transcript, October, 1995).

These findings contrast to the works of Charmaz (1980, 1991, 1994, 1995) and Garro (1994) who concluded that those who suffer chronicity eventually arrive at a space where they are able to adapt to a life confronting them. A chronic pain sufferer interviewed by Charmaz (1994:231) describes the meaning of acceptance and surrender to chronic illness:

defeated on all fronts, I had to lean how to surrender and accept what I had become, what I did not want to be. Learning to surrender and accept what I had not chosen gave me knowledge of a new kind of change and a new kind of experience which I had not anticipated. It was a paradoxical change. When I stopped struggling, working to change, and found means of accepting what I had already become, I discovered that defeat changed me. Rather than feeling disabled and inadequate as I anticipated that I would, I felt whole again. I experienced a sense of well being and a fullness I had not known before. I felt at one not only with myself but with the universe.

For this persistent pain sufferer, surrender meant stripping away the fantasy of recovery, and the wish for recovering a former wholeness of self. Surrender allowed for being in the flow of the moment rather than wishing and waiting for a mythical future. No longer could pressing symptoms, marked disability, and progressive illness be ignored or denied. When surrendering, illness merges with subjectivity; it becomes subjectivity. Surrendering to illness opens the possibility of transforming the self. By re-centring the present anew and flowing with it, ill people gain fresh views of their resolves and their situations. External social mandates melt away as the person gains
a new and different voice within the folklore of pain and a new sense of wholeness of
self emerges. Moreover, because of physical losses, they reassess who they are and
who they can become, and they form identity goals as they try to reconstruct normal
lives to whatever extent possible.

6.13 CONCLUSION

This chapter has discussed and analysed the persistent pain stories of David, Vince,
Steve, Vicki and Joanne. These stories are unique and unfolding, having their
beginning points on the day each participant recognised that their pain, the result of an
injury, was not going to stop, and an end point which coincided with the date of
interview with the researcher.

The biographical detail contained within each story set the framework for listening to
stories as interlocking patterns of cultural-historical, individual-biographical, and
interpersonal-relational threads, woven through the multiple strands of the subject’s
life. Turning point moments or epiphanies, which collated with significant life events
were identified in light of Marxist literary theory; in particular, the concepts of
alienation and the influences of ideology were used to deconstruct the plight of living
with persistent pain. Foucault’s discussion of power was also used to provide an
alternative way for understanding persistent pain stories, in that it was postulated that
persistent pain sufferers could re-construct embodied pain experiences once they
surrendered their bodies to the experience. It was also postulated that Frank’s (1991)
concept of the communicative body provided valuable insight for the surrender to the
persistent pain sufferer to embodied experience. The concept of resistance was used
to connect personal stories to the prevailing communal folklore of pain and to signify
the possible emergence of a private folklore of pain through the unfolding of distinct identities which sustained each participant in their present evolving life. However, it was found that while David, Steve and Vince had begun to accept the place of pain in their lives, Vicki and Joanne had not. All participants continue to view their pain objectively and have not been able to develop alternative or new identities which encapsulated the phenomenology of the lived body. The following chapter will provide a summary of the thesis and identify new areas for research.
CHAPTER SEVEN

CONCLUSION

7.0 INTRODUCTION
This chapter revisits the methodology, the methods used in the collection of data, the key concepts illuminated the study and makes recommendations for future research.

7.1 PREAMBLE
Research relating to the topic of pain is extensive. Pain has also been conceptualised from many philosophical perspectives over past decades. Five major approaches to the conceptualisation of pain and ‘chronic’ pain have been delineated by Vrancken (1989). These include the somato-technical approach, the dualistic, body-oriented approach; the behaviourist approach, the phenomenological approach; and the consciousness approach. The development of these approaches are chronological but, by far, the technical and the dualistic body oriented approaches have been most significant to the contemporary understanding of pain, although a phenomenological approach to pain which constructs the experience from a humanistic perspective has come to the foreground. This approach to pain harmonises with the consciousness approaches to pain, which views it as consciousness in form and content. This approach, also considers that pain is to do with being human and with states of consciousness. That is, in pain, the pained part of the body enters immediate awareness forcing the sufferer into a dualist stance with the body, drawing a dividing line between that which is hurting on the one hand, and on the other that which is submerged in pain, dealing with pain and trying to control. It is only when the pain sufferer is able to integrate the experience of pain in life, and thus shift personal
priorities back to the world, instead of the body, that a complete reunion with the
world occurs and the pain experience is given meaning.

This study expands from this perspective to consider the context of pain in the life
trajectory of the persistent pain sufferer. Methods based in the interpretive
biographical approach (Denzin, 1989a) were used to develop a deeper and new
standpoint on the private folklore of the persistent pain sufferer because prevailing
discourses of persistent pain render an inability of the persistent pain sufferer to
normalise their experience within communal folklore, particularly by those who do
not have a consensual medical diagnosis. Thus, the pain sufferer is casts into an
isolated and alienated world because usually accepted methods of dealing with pain
are ineffectual in bringing relief.

The development of knowledge related to the sub culture of the persistent pain
sufferer and of the private folklore which is used to bond such individuals, and
consequently exclude non-sufferers, required that the acultural dimensions of
persistent pain be illuminated. Illumination of these dimensions provides a place for
persistent pain sufferers in culture, and an appreciation that the persistent pain
experience fundamentally alters the entire experience of living, and the sufferer’s
conception of their affliction and their self.

An understanding of pain as it is experienced by the persistent pain sufferer was made
possible by the use of interpretive approaches to biographical analysis. This study
uses Dolby-Stahl’s (1985) literary folkloristic methodology for a micro-analysis and
interpretation of David, Vince, Steve, Joanne and Vicki’s persistent pain stories. The
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interpretation of these stories provided the means to uncover the private folklore of the persistent pain sub-culture; an experience which is selectively shared and creates a sense of intimacy between sufferers. It is this private perspective that the biographical method illuminates.

At the same time, communal folklore referred to the collective traditions shared by a wide segment of the population, and it is this type of folklore that Denzin's Interpretive strategies (1989a) uncovered through a macro cultural analysis of the persistent pain sufferer's stories. Thompson (1978) postulates that all aspects of the lived life be represented in research, since individual lives contain multiple narratives and that no self story contains all the stories that can, or could, be told about a single life. Thus, a cross-multiple narrative drawn from the self stories of individuals ensured that history, structure, and persistent pain sufferers received a fair and thorough consideration in the undertaken study.

Dolby Stahl's (1985:17-19) understanding of communal and private folklore, and Denzin's work (1989a, 1989b, 1989c) are grounded in similar philosophies and provided the mechanism through which understandings relating to pain were generated by considering pain through ways which made good sense and were intuitive and holistic. Listening to people talk and encouraging them to use their own words and frames of reference about what had been significant in their lives; and the development and transitions which occur in their lives as a consequence of their pain experiences enriched their stories and transcended the limited range of understandings made possible from preconceived psychometric scales, survey methods or contrived experiments (Josselson & Lieblich, 1993). Through the use of interpretive
biographical methods the focus of the study remained upon the life that is being lived and the story that was told by real people, in the real world because I believed that persistent pain sufferers need the acknowledgment of their pain as real and to be dealt with as whole people, who experience pain. This aspect was re-enforced by the request of participants for their real identities and names to be used for the purposes of this study.

The interpretive process and more significantly ‘Interpretive Biography’, as described by Denzin (1989a, 1989b, 1989c), enabled an understanding of the essence of the persistent pain experience and the significance of this experience to the life trajectory of the persistent pain sufferer by encouraging an independence of thought in the researcher as well as in the interpretation of the data. Further, it provided the persistent pain sufferer with a voice in telling their own story as it unfolded through events in time. As Brown (1985:573) claims that it is through the narrative provided that the “the essential features of human existence are expressed through specific events”.

7.2 OUTLINE OF THE METHODOLOGY

An understanding of pain, and the life stories of pain sufferers, presupposes that the sufferer is able to use a language which is shared and understood by all. Pain, an inner sensation and a perception, is always described in the language of experience. Language is a complex, learned and culturally determined behaviour which reflects the dominant discourse, and therefore articulates an understanding of pain which is shaped by the distinction between pain as a sensation and as a behaviour. Sensation which may only be authenticated through, and by the use of language. The form of
language used by the pain sufferer translates their personal meanings of pain into a textual medium which is translated by the reader and the listener. Language as a social medium is established within the discursive elements of the dominant culture, and therefore by creating its understanding, legitimates pain as a cultural and personal experience. Despite Steve, David, Vice, Vicki and Joanne’s verbal complaints of pain, their lack of a consensual medical diagnosis and the continuance of pain has not sanctioned and given legitimacy to their pain stories because participant’s pain stories are embedded in medicine’s history and the culture in which it has been shaped. Western cultural influences exhort that the amount and quality of pain experienced by a person is dependent upon detectable physical and physiological antecedents, despite recent claims that the pain one feels is the consequence of personal experiences and the ability to understand and reference the pain episode in and on one's life. An inability by participants to do this necessitated that they abandon previous selves and life plans, and attempt to formulate a self and life plan with persistent pain as the centrepiece.

The recognition of the longevity of pain, in participants’ lives, marked a turning point moment, or an epiphany, as this acknowledgment precipitated the consideration of future prospects. Thus, the interpretation of pain and subsequent action taken in relation to this interpretation formed the fabric of the pain sufferer’s life. Hence, an event which was at one time dismissed as insignificant in the course of daily life, became over time subject to reinterpretation. Through retrospection, the event dropped its original air of meaningless and at last exposed the origin of an unseen chain of events with an insignificant pain finally turning scandalous and terrifying, forcing unwanted transformation in the life of the sufferer.
It may be seen from the above discussion that an understanding of the role played by pain in the life of the persistent pain sufferer is best known through a methodology which highlights the essence of the pain experience and the significance of this experience to the life trajectory of the sufferer. The interpretive process and more significantly Interpretive Biography, as described by Denzin (1989a, 1989b, 1989c), are such methodologies, and illuminated an understanding of pain as a personal and cultural phenomena.

The following will provide an overview of the biographical method and the chosen biographical strategy used to provide a contextualised narrative of the life experiences of the persistent pain sufferer.

7.3 THE BIOGRAPHICAL METHOD

The biographical method presents the experiences and definitions held by one person, one group, or one organisation as this person, group or organisation interprets those experiences. Biographical materials include any record or document which illuminates the subjective behaviour of individuals. A thorough transcription of an interview is one form of biography. This study used the interpretive biographical method to contextualise and represent the life of the persistent pain sufferer whose pain does not conform to the existing discursive view of pain.

The interpretive biographical method entailed the collection and analysis of personal-life stories which illustrated turning point moments in a participant’s life, and are set in the lives of ordinary people. These turning point moments coincided with
chronologically significant events as participants remained within a paradigm which had at the time of interview not surpassed the need to find conventional and traditional relief for pain. While their pain stories were told within the broader historical, institutional and cultural arenas of life, when asked to pinpoint significant moments in their lives of pain all were only accurately able to provide dates of when their pain began and interventions related to same.

Simply, biographical methods are conventionalised, narrative expressions of life experiences which are written in a double perspective- that of the teller and that of the writer, with the perspective of the 'other' directing the pen of the writer. Moreover, the biographer makes sense of the teller's life in relation to the notion that biographical texts are ideological statements which reflect or defend the position of the writer. Further, the biographer uses family beginnings and objective life markers to commence the biography as the family represents the zero point of origins in the teller's life and objective life markers reflect key critical points in the life of the teller which may become turning point experiences. In this research the biographer uses the recognition of the pain experience by the sufferer to mark the zero point of origin of the pain experience. Biographical method incorporates the exposition and understanding by which “real” appearances of “real” people are created. Moreover, the biographical method is a literary technique for inscribing a body of experiences connected to the life of a given individual (Denzin, 1989a; Plummer, 1983:13). A life infers the biographical experience of a named person, and a person is created and named in culture. Biographies are built around the core experiences of the named person, namely those which have a significant and permanent effect on the life of the named person, bringing about a transformation or change in perception and or
behaviour. Denzin (1989c:40) terms this the epiphany of a life. Epiphanies form the basis of personal experience stories. They occur in problematic situations, such as the developing of persistent unrelieved pain, which need reconstruction and interpretation in order to glean understanding of the personal nature of culturally determined experiences. Hence, a focus on the epiphany attempts to unravel the complexities between the universal and the personal, because no individual is singular, rather they are representative of universal social experiences and social processes grounded in the historical moment which surrounds the person's life experiences. These experiences and their attributable meanings form the stories of an individual's life in a flexible, interactive and dynamic way. They represent the ability of the human being “to endure, to prevail, and to triumph over the forces that threaten at any moment to annihilate all of us” (Denzin, 1989a:83).

The subject matter of the biographical method is thus, the life experiences of a person. This method relies on the verbal and written expressions of meaning, with these expressions providing the key to the inner world of the persistent pain sufferer. It is acknowledged that in biographical language, as in all language, the teller of the story only represents that which maintains their sense of self to others. Language is only a tool for creating texts and no final reading of the text is possible. This issue was of particular significance to this study because in research relating to pain the researcher is only able to interpret and understand the pain of the sufferer in relation to personal referents and a standpoint shaped by the discursive practices of dominant ideologies.
7.4 THE INTERPRETIVE PROCESS

The fundamental assumption which underpins this process rests on the significance of interpretation and understanding as key determinants in social life. Social life is comprised through individuals making interpretations and judgements about personal and other's behaviours and experiences. Thus, the subjective nature of interpretation and judgement often results in misinterpretation of behaviour and therefore erroneous understanding or more confusingly behaviour which does not conform to accepted judgements of interpretation, when another's experience are not your own, or your own is not another's experience. Hence, processes set in place to facilitate a particular understanding of one's experience is not appropriate to deal with the individual undergoing the experience. The interpretive process seeks to uncover each individual's experience of their life and to bring understanding of their life experience as a result.

Self stories, one variation of the biographical method, are told by an individual in the context of a specific set of experiences. Self stories positioned the persistent pain sufferer centrally to the story given. Self stories build on the premise that each individual is a storyteller of their own experience, an oral historian of their own life. Self stories are oral histories because they are concerned with factual accuracy focusing on events, processes, causes and effects rather than on the individual, whose recollections furnish oral history with its raw data. Thus, the pain self stories, contained within this study, are personal narratives and take the from of that referred to by Dolby Stahl (1985) and Denzin (1989a) as personal experience narratives. Personal experience narratives are stories which people tell about their experiences.
and may be related to the traditional folklore of a group. Personal histories are the reconstructions of life based on interviews and conversations.

The narrative draws on everyday experiences and identifies core, shared values of the narrator and the listener with these being then placed among broader cultural and ideological themes (Dolby Stahl, 1985). It uniquely creates an intimacy between the teller and the listener. Dolby Stahl contends that the teller and the listener connect selves in a context of shared and sharable experience. The story of the persistent pain sufferer is a story which shared a sequence of events that were significant for the persistent pain sufferer.

This study used the self story or personal experience to glean an appreciation of the contextual understanding of pain in the life of the persistent pain sufferer. The appropriateness of this method rests in the development of pain in the suffer, the recognition of pain as detrimental to daily life, and their subsequent and ongoing attempt to find meaning for this pain; and finally to realisation that their pain is persistent and unable to be located within diagnostic reasoning; and finally, to the potential of acknowledgment that their pain is their life. That is, to surrender their bodies to pain. Participants, in this study were unable to arrive at the surrender point in the sequelae. The persistent pain experienced by the pain sufferer becomes the biographically meaningful event, with experience occurring at the surface level and at a deep level. Deep level experiences effected the persistent pain sufferer to the inner core leaving lasting marks upon them. The experiencing, defining and intimacy of these deep level experiences for the life of the individual became the focus of this study.
7.5 LITERARY FOLKLORISTIC METHODOLOGY

In keeping with Dolby Stahl’s (1985) folkloristic methodology this study complied with the following prerequisites. First, the persistent pain stories be analysed were part of a life story or a personal experience narrative. The method involved the researcher in its entirety. Second, I undertook the responsibility for hearing, listening to and interpreting the persistent pain stories told. Third, I shared the persistent pain sufferer’s point of view. I saw the world and its problems as they were seen by the persistent pain sufferers living inside them. Fourth, I became knowledgeable in literary theory and critique in order to situate and deconstruct the story being told. Last, I took full responsibility for the document interpreted. These prerequisites were meet by undertaking the following steps.

Step One: - The locating of the subject within a given social category

Step Two: - The identification of the salient themes and experiences in the participant’s life

This step entailed a process whereby participants’ stories of suffering persistent pain were listened to and recorded for interpretation in a mutually conducive atmosphere. Semi-structured interviews provided biographical data for analysis and interpretation with participants undertaking two interviews. Open-ended questions were used to record the personal experience and self stories of participants. Interviews occurred at the discretion of participants. Generally, interviews were weekly and lasted approximately of two hours depending on the psycho-biological condition of the participant. Interview transcripts created the data for the persistent pain sufferer’s self
story, with the second interview focussing on expanding key points illuminated from the first interview.

**Step Three:** - Connecting the subjects life history and life story to larger social meanings, including communal and private folklore

Persistent pain sufferers’ stories exist in the cultural texts of biomedicine and in the shared histories with others who experience pain generally, and more particularly with those who are like themselves. Denzin (1989a:72) asserts that to understand a life, and thus its epiphanies, and subsequent self stories one must penetrate and understand the larger structures, as they provide the fabric from which the story is shaped and told.

**Step Four:** - Understanding that the subjects life story reflects a set of meaningful experiences which, when told create an emotional bond between the teller and the listener.

**Step Five:** - Realising that the private, inner meanings of these experiences to the subject can never fully be illuminated.

**Step Six:** - Interpreting the materials by sharing in the world of the experience of the subject.

**Step Seven** - Bring the interpretive approaches literary theory and criticism to bear on the life story materials.

Dolby Stahl (1985) asserts that the biographical method must use strategies for literary interpretation and critique. This included an understanding of hermeneutical inquiry,
semiotics, feminist theory, deconstructive analysis, Marxist literary theory and Foucault's construction or power and resistance to enable a sharing in the experiences of participants, and thereby creating an interpretation which was both grounded in the personal and the cultural.

**Step Eight:** The researcher creates the document that is interpreted.

Significantly, the method advocated by Dolby Stahl (1985) for biographical analysis is not primarily concerned with the issues of reliability and validity of data contained in persistent pain self stories. This study did not seek to generate theory. It simply accepts the self stories of participants, and the records of these stories as material for interpretation. The study assumes that the meanings embedded in biographies are best given by the individual experiencing them. Thus, the life of the persistent pain sufferer is always foremost in the account, with structure and interpretation being blended with lived experience. The researcher's preoccupation with method and theoretical relevance is set aside in favour of a concern for meaning and interpretation of the text (Plummer, 1983). Denzin (1989a, 1989c:39) asserts that one must work back and forth between a concern for process and the analysis of the specific lives that are being studied.

7.6 **FINDINGS**

David, Steve, Vicki, Vince and Joanne are persistent pain sufferers. Their pain stories reflect a life in turmoil and attempts to bring order to this turmoil. Their turmoil is compounded by their search for a medical diagnosis and justification for the pain that they are experiencing. It has been contended that the way in which the medical
community, a representation of dominant ideological forces, which seeks to return the individual to some worthwhile activity, conceptualises who a pain patient is and how this individual should be treated. In short, how health professionals understand pain provides the framework for the understanding and treatment of pain.

This study has used Marxist literary theory, and in particular the contemporary sociological interpretation of alienation and ideology, to deconstruct the stories of participants, believing that often what is left unsaid tells the true story which frames understandings of how pain is suffered. It was found that the persistence of pain in participants' lives influenced the potential for the development of a new self in which pain, although acknowledged, remained in the background of their lives and that in this instance, through processes of surrender participants would be able to move forward to futures filled with possibilities. However, this study revealed that participants remained largely confined within a dualistic stance of body and mind, relying on others to find a reason for their pain and thus cure it. The inability to form a new self kept participants bound to prior images of self and life paths which realistically could no longer be maintained. Thus, they remained isolated and alienated from not only themselves, but wider society. Despite articulating the positive benefits of finding like sufferers who really understood their experience, and thus beginning to identify a private pain folklore in which they could partake, this was at the time of interviews not considered as an alternative understanding for suffering pain.

It was also found that the communal folklore of pain remains underpinned by dominant ideological forces and discursive practices with assist in maintaining the
situation explained above. Through the quest for meaning and cure of pain the persistent pain sufferer is rendered powerless through medical technologies including the medical interview. These technologies subliminally support dominant ideological practices in order to sustain and maintain the discourse of Western medicine. Through language the sensation and perception of pain is understood and translated in such a way as to create a situation in which the persistent pain sufferer is caused to question the validity of their experience while simultaneously accepting blame for the persistence of their pain and the need to have their pain stop. This contradiction re-affirms the powerlessness of persistent pain sufferers and although Foucault's construction of power necessitates the oppositional requirement for resistance, the positive influences of resistance are not clearly evidenced in the stories of persistent pain sufferers. It was postulated that resistance provides the mechanism through which persistent pain sufferers are able to surrender previously held notions of self to alternate identities which encapsulate the embodied experience of pain. The ensnarement of this experience permits the sufferer to move beyond accepted paradigms of pain to a position where their persistent pain experience is validated. This has not been the case for participants of this study. The diagram below represents a framework for resistance and surrender to a *pained* body.
This framework illustrates the interplay of key concepts identified in this study. Interestingly, the concepts identified as epiphany events by the researcher in this study are supported by the works of Bendelow (1995), Charmaz (1994, 1995) and Seers & Friedli (1996), although participants in this study have not managed to find meaning of their persistent pain, and thus their suffering.

7.7 AREAS FOR FURTHER RESEARCH

This study has illuminated the need to continue research into the event of persistent pain for the sufferer. Clearly, participants have pain, their pain is real and needs to be understood within a framework which has the sufferer at its centre. Similarly, a longitudinal approach to this study and interviews which encompass the significant others in persistent pain sufferer’s lives would provide a richer tapestry for understanding what it would be like to awaken everyday with pain, to live that day in pain, to attempt to sleep in pain and then to get out of bed the next day and to be exactly where you were the day before. To experience a sense of *deja vu*.

This study acknowledges at its beginning point, the need for persistent pain sufferers to have a voice. A voice which is theirs and not the distorted reflection of those in care of them, or those who share their lives. This is a self help document which acknowledges that only those caught in the matrix of persistent pain have a right to talk about it. While humanity has an obligation to hear the voice(s) of those in persistent pain and to behave in ways which concede to the persistent pain sufferer the entitlement to be understood as
individuals who have pain which is real. In this way Vicki, David, Steve, Vince and Joanne become ‘whole people, who experience pain’. As such this study is only the beginning point for health professionals who seek to deliver health care which is meaningful and context specific.
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APPENDICES

Appendix One
PLAIN LANGUAGE STATEMENT

My name is Joyce Hendricks and I am a registered nurse and a Lecturer in Nursing. I am currently undertaking a higher degree through the School of Nursing at Deakin University, Geelong. During the time between September, 1995 and December, 1996, I will be undertaking a research project which seeks to understand the role played by pain in the life of a person experiencing persistent and the significance of this contextualised experience for the pain sufferer's life.

To undertake this research I need assistance from people who are willing to share their experience of persistent, unrelieved pain for which a medical reason can not be determined and are willing to be interviewed on a one to one basis.

We would meet weekly for no more than 2 hours over a two week period in a place we mutually agree to. Our meeting would be audio-taped, but you will have the right to switch off the recorder if you so wish. You will also have the opportunity to read, seek clarification of, and amend interview transcripts if you feel that your experiences have not been addressed. As interviews will be transcribed by a person not related to the research, confidentiality will be maintained through the use of pseudonyms (unless you wish to use your own name) and then only I will know your identity. All keys to pseudonyms used, all consent forms, and all recorded date will be stored in a secure place to which only I have access.

If you would like to become involved and then decide to withdraw from the research, you may do so at any time.

If you would like to participate in this research and/or you would like further details please do not hesitate to contact me at the Environmental Health Unit on 55769005 and leave a message for me to contact you or you can call me directly on 019 472968.

Thank you.
Joyce Hendricks.
Supervisor: Dr. C.A. Holmes
Appendix Two

CONSENT FORM:

I, of

Hereby consent to be a subject of a human research study to be undertaken Joyce Hendricks and I understand that the purpose of the research, as described in the Plain Language Statement and discussed with me by the researcher, which seeks to understand the role played by pain in the life of a person experiencing persistent unrelieved pain and the significance of this contextualised experience for the pain sufferer.

I understand that the final work will be prepared as a thesis, and that parts or sections of the work will appear in books, journals, conference proceedings and that I will be offered the opportunity to receive a summary of the thesis.

I acknowledge

1. That the aims, methods, and anticipated benefits, and possible hazards of the research study, have been explained to me.

2. That I voluntarily and freely give my consent to my participation in such research study.

3. I understand that aggregated results will be used for research purposes and may be reported in scientific and academic journals.

4. Individual results will not be released to any person except at my request and on my authorisation.

5. That I am free to withdraw my consent at any time during the study, in which event my participation in the research study will immediately cease and any information obtained from me will not be used.

Signature: __________________________ Date: ________________
Reseacher: __________________________ Date: ________________
Appendix Three

CERTIFICATE OF ORIGINALITY

I certify that the substance of this project has not already been submitted for any degree and is not currently being submitted for any other degree.

I certify that any help received in preparing this thesis, and all sources used, have been acknowledged in this thesis.

Signature:

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