CHAPTER 1 – HUNTINGTON DISEASE: SOLUTIONS AND CHALLENGES

1.1 Introduction

In 1998 in Sydney, NSW, the members of a recently established Huntington Disease Outreach team expressed serious concerns for the situation of the resident with Huntington Disease living in an aged care facility. Therefore, due to a convergence of circumstances and opportunities, a decision was made to embark on nursing research in the area of HD resulting in the birth of the investigation being reported in this thesis. The problem to be studied is described by Frank Gardham (an HD nurse from the UK):

What is the nurse’s attitude to HC? (Huntington’s Chorea/Huntington Disease/HD) The patient has now become an embarrassment to the skills of the nursing staff, who may turn to the things that they know best, concentrating on the care of the other patients on the ward to whom their routine is geared. The regime of the ward may be directed towards a predominantly long-stay schizophrenic or perhaps psycho-geriatric population. The chances are that the HC patient may be the only one on the ward with this illness, and that although receiving attention to basic needs, this “cuckoo in the nest” may always be on the periphery of events and never at the centre (Gardham, 1982).

A clinical nurse consultant in HD, the writer, undertook the investigation described in this thesis. It was motivated by observations that caring for people with HD
in the standard aged care facility could be very difficult for the nurses and frustrating for the residents and their families. This occurred in spite of the fact that the institutions were chosen carefully, and their staffs were dedicated and caring. It was also in spite of the fact that ongoing education and support was provided by the HD specialist team.

1.2 Demography, Pathology and Natural history of HD

Huntington Disease can be defined as an autosomal, dominantly inherited, neuromuscular, degenerative disease with age of onset typically between 35 and 45.5 years (Kovach & Stearns, 1993; The NSW Huntington Disease Service, 2001). The median length of illness is 21.4 years (Foroud, Gray, Ivashina, & Conneally, 1999), and its prevalence in NSW is 6.3/100 000 of the population. The estimated number of affected people in NSW is 380 (McCusker, Casse, Graham, Williams, & Lazarus, 2000), and the estimated number of people “at risk” in NSW is 1520 (based on the inheritance risk rates of 50%). The gene does not “skip” a generation, is not gender linked and, if present, will inevitably lead to disease which affects the neuromuscular systems of the body causing serious disability prior to premature death. Accurate knowledge of the genetic origins is recent with the discovery of the gene dating back to 1993 and the Predictive test only being available since 1996.

Included in the category of Movement Disorders, and acknowledged as a complex condition, a multidisciplinary approach to the provision of care to those affected by HD has been proposed as being an effective model (Klimek, Rohs, Young, Suchowersky, and Trew, 1997). On the other hand, this utilises many health and welfare resources.

Social implications of the disease include the observation that families with a member suffering from Huntington Disease have the potential to become dysfunctional,
resulting in low self-esteem and economic hardship for the members. In addition, because of the relatively early age of onset, the caring burden usually affects young families with other dependent members as well as the person with HD.

This social scenario predisposes towards the use of permanent institutional care at a relatively early stage of the disease. Residential care options include some specialist accommodation for small numbers, but typically, the majority of sufferers are cared for in aged care facilities. Aged care facilities in NSW are designed to provide accommodation for people over the age of 65 years who require full time nursing care. They are not hospitals, and are expected to meet all the needs of their residents in a home-like environment. Residents with Huntington Disease are usually significantly younger than the majority of the other residents. The particular characteristics of the disease place different demands on the staff if the residents' needs are to be met. In order more fully to understand these demands, information on the pathology and natural history of the condition is now given.

The underlying pathological changes which give rise to the scenario described previously include both genetic, cerebral, biochemical and metabolic changes. These are now briefly described.

An increased number of CAG repeats is found on chromosome four. Values above about 35 will result in signs and symptoms of the disease, and a diagnosis will be given. Later age onset HD is associated with a smaller CAG repeat length than when signs are seen earlier (Williams, 2001). By a process not yet fully understood, this alteration of the DNA components results in an expanded polyglutamine fragment of the protein huntingtin, which is linked to brain cell destruction, or apoptosis (Turner & McCusker, 1997). This occurs in two major areas of the brain, the frontal lobe of the
cortex, and the subcortical basal ganglia, especially the caudate nucleus. Whilst it is known that the protein *huntingtin* is essential for life, its precise function is yet to be fully understood. The typical CT scan of a person with Huntington Disease shows an increase in the size of the lateral ventricles associated with loss of adjacent tissue. This cerebral cell loss is the major causative factor producing the signs and symptoms of HD. Current research aims at increasing understanding of this process. It is one of several areas of intensive scientific investigation in an effort fully to understand the pathology of HD and thereby open up avenues for curative treatments. The picture looks more promising each year (NSW HD Service, 2001). The genetic changes also result in altered cellular metabolism in the form of an increased rate of energy utilisation, once again by a mechanism not yet fully understood. Biochemical changes, including altered levels of some neurotransmitters in the brain, are also involved in the underlying changes in HD (Harper, 1996; Williams, 2001).

Diagnosis is made on the basis of a family history, neurological assessment, radiological investigations such as CT scans, and/or a diagnostic gene test. A predictive gene test is available to the at-risk family members, because for each child of an affected parent, there is a 50% chance of inheriting the abnormal gene.

Although scientific advances in understanding the condition are occurring rapidly at this time, there is no current treatment to prevent or cure the disease. Therefore the medical management is symptomatic and palliative. In line with other incurable conditions, the management of Huntington Disease has as the guiding principle, the maintenance or improvement in quality of life (Chiu, 1990; Hardy, 1989; Kovach & Stearns, 1993). From the nursing perspective, this involves both the monitoring of the condition of the patient and the effectiveness of the medical interventions, as well as the
provision of vital education and support of the patient and their informal and professional carers. The disease typically runs its course over 20–25 years (Kovach & Stearns, 1993), and because the age of onset is usually 35–55 years, it causes a significantly shortened life span compared to the norm (Thompson, 1982). Whilst general wasting and increasing frailty are a feature of the end stage condition, death, according to Haines and Conneally (1986), is commonly caused by respiratory infections (42%) which occur due to progressive dysphagia resulting in some unavoidable aspiration. Cardiovascular disease (33%) is another significant cause of death (Haines & Conneally, 1986).

1.3 Clinical background

Against this background, information is now given of the triad of major signs and symptoms of Huntington Disease and some nursing interventions which have been found to be effective in overcoming or reducing the problems.

- Physical problems

Firstly, the presence of involuntary movements (including chorea), of varying amplitude, require risk assessment and risk reduction strategies to prevent injury to both patient and carer. Then there is the unco-ordination and gait disorder which require increased monitoring and modification to the environment. Dietary advice to overcome the weight loss previously mentioned, includes a substantial increase in caloric intake, sometimes even as high as twice the normal (Chiu, 1990). Finally, the swallowing and speech disorders are responsible for increased frustration levels and aggressive outbursts as well as increasing the potential for respiratory infections. Management is usually by
modified texture diet, skilled and time-consuming assistance with feeding, alternative communication strategies, and sometimes the consideration of alternative nutritional support methods. An intervention such as this last requires informed consent, which can raise complex ethical considerations and can require input from several team members.

- Emotional problems

If present, these often include irritability, depression and mood swings which can be helped greatly by timely and appropriate medication, patience, and increased support from familiar staff. The emotional component also can include apathy and a lack of initiative resulting in self-neglect and an impoverished lifestyle. Advocacy for appropriate services, direct intervention to provide for basic needs and the active involvement of carers are vital strategies here.

- Cognitive problems

Firstly there is a lack of insight, also known as organic unawareness (Rosenblatt, Ranen, Nance, & Paulsen, 1999), which is often associated with disinhibited behaviour, difficulties relating to others, lack of compliance and conflict with carers. On the part of the carer, this requires communication which is clear and direct, and stresses the advantages to the patient of compliance with a proposed course of action. Secondly, the executive functioning deficit, due to a reduced ability to process complex information and learn new material, has profound and far reaching personal and social effects such as the need for the appointment of a surrogate decision-maker. This deficit translates into difficulties in making self-interested decisions due to the patient’s inability to take into account several aspects of a situation simultaneously. The person’s thinking becomes distorted and rigid and they appear stubborn, single-minded, and very impatient. The
Assistant Executive Director, Patient Services, Runnymede Chronic Care Hospital, Toronto, Canada, Elaine Hardy (Hardy, 1989 p. 7) further elaborates as she describes their experiences:

We have since observed a behaviour pattern which seems to apply only to Huntington’s patients—I refer to the need for immediate response when they make a request. We wonder if there is an alteration to their perception of time, and we have seen a significant decrease in aggressive behaviours when we respond promptly to such requests.

Dr Ed Chiu, pioneering HD psychiatrist in Victoria, Australia, discusses this characteristic as part of personality changes associated with HD (Chiu, 1989). He calls it primary gratification and associates it with a reactive type of anxiety stemming from anticipated loss of control. On reflection, it may be possible to infer that to deliver effective nursing care to someone with this deficit, insight into the characteristic, and an ability to think like the patient thinks, should be cultivated. The work of Seidman-Carlson and Wells (1998) includes research-based understanding of the affective communication deficits involved and also lists “ability-enhancing” or “ability-compensating” nursing interventions. These include the avoidance of the use of abstract concepts during conversation, the allowance for increased mental processing time, and the exaggeration of the emotional components of speech by spelling out clearly what one is feeling rather than expecting the person to understand by subtle references. Having outlined some of the specific clinical problems associated with HD, details of care provision in NSW are now described.
1.4 HD Care provision in NSW

Broadly relating to the stage of the disease, namely later and earlier, care provision will be discussed under the two main headings of Residential and then Community Care.

- Residential care

About half way through the illness, full time nursing care, usually in an institution, is the norm (Jolley, 1990). Because of the lack of sufficient specialist facilities, this is typically in the aged care sector, and often at an early age (Gelbart, 1998). Therefore, although accommodation in an HD specific setting may be considered ideal, for most sufferers this is not an option. These observations are known by experience to apply equally to NSW.

Kapp (1985 p. 4) provides an historical perspective when she says:

...care of the person with advanced symptoms of Huntington’s Disease was not based on an understanding of the effects of the condition and the needs of the person and their family but on expediency. The perception of the family members was that Huntington’s Disease was “the skeleton in the cupboard.” Families were shunned by the community and by professionals. Huntington’s Disease was regarded by many as “a living death”; there was no way to relieve the symptoms; it was progressive, degenerative, and incurable.

Kapp also described the accommodation as usually being in a mental institution or nursing home with many children of a person with HD having unpleasant childhood memories of visiting their parents and seeing them in strait jackets or sharing rooms with disturbed old people. By contrast the proceedings for the 8th Workshop and Conference of the International Huntington Association (Richards and Kapp, 1989), reports the opening of the specialist HD inpatient unit, known as The Huntington’s Disease Unit, at Lidcombe
Chapter 1 – Huntington Disease: Solutions and Challenges

Hospital, NSW, the previous year. For the HD affected families in NSW this was wonderful news, described indeed as a “dream come true” and “a prayer answered” (Kapp 1987, p.40).

- Community services

In 1995, HD services were relocated to the Western Sydney Area Health Service and based at Lottie Stewart and Westmead Hospitals. In addition to the 16 permanent beds, the residential unit also had two respite beds for specific purpose short admissions. One of these could be used as a subacute bed paid for by the NSW state government whereas the others were funded as nursing home beds using federal government funding. In conjunction with the move, an HD multidisciplinary outreach service was established. Believed to be the first of its kind in the world with respect to comprehensiveness and scope, this service was expected to offer improved outcomes for the HD sufferers in NSW. Figure 1.1 on the next page, provides a graphic representation of the components of the NSW Huntington Disease Service It also includes the other organisations which provide care for the HD population of NSW.
FIGURE 1-1 SERVICE PROVISION FOR PEOPLE WITH HD IN NSW
As the major community provider of specialist HD care, the Outreach service will now be discussed in more detail. Underpinning all activities, the goal of Outreach service provision was stated as follows:

We (the staff), aim to enable people with HD to achieve the quality of life they desire. This will take into account the disability resulting from the illness and will include using creative strategies and all available resources to enable the physical, social, cognitive, and emotional deficits experienced by patients and their families, to be minimised. With this in mind, we have chosen a flower emblem, “Salvia Huntington’s Red” as our service logo.

The salvia (or sage) is a herb representing *Health*.

As far as staffing was concerned, the outreach team consisted of two part-time nurses who jointly provided six days of service a week. The rest of the team consisted of two fulltime social workers, a fulltime speech pathologist, and a part time diversional therapist, physiotherapist, occupational therapist, and dietician. The medical director of the service, a part time neurologist, and staff specialist at Westmead Hospital, held a weekly HD Outpatient Clinic, which included psychiatry and neuropsychology services. As far as the Outreach nursing component was concerned, the nurses’ contribution was underpinned by an understanding of nursing as a profession which sought to accompany its patients, their formal and informal carers and the rest of the community, in a quest for health and healing in its broadest sense (McMahon, 1986; McWilliam, 1996).
The nurses were responsible for the establishment of the respite program, the coordination of the outreach clubs, the rural outreach service and most of the formal education provision. It was also to the outreach office, the nurses’ base that most general enquiries came. In addition, a large component of their work included follow-up of residents in aged care hostels and nursing homes, often in response to requests for assistance by nursing staff there. Following consultation with HD experienced staff, the need to provide education on Huntington Disease became a clear priority. The clinical nurse consultant (the writer), developed a problem-based in-service education session in case study format. It was supported by appropriate reference material, which has been gathered, or written (Appendix A) over the time of the program. Written evaluations indicated that a high level of learning occurred with consequent improved care for the residents. This finding is supported by the work of Feldt and Ryan (1992), and Pearson, Hocking, Mott, and Riggs (1992a, 1993a) regarding the value of in-service education sessions in the provision of institutional aged care.

This chapter has provided information on the existing HD services in NSW. Background clinical information on the natural history of HD and the ensuing individual changes has also been briefly stated. The challenges in providing care to meet these needs either by informal or professional nurse carers have also been mentioned and will now be amplified.

In particular, the difficulties experienced by aged care nurses in providing for the needs of much younger residents with a slowly progressive, incurable illness with signs and symptoms which are not always well understood and for which there are few effective treatments, is now described. As a consequence of the pathology, these residents have little insight into their disease and especially into the impact it has on those around them.
Due to the hereditary nature of the disease, they were often raised in socially disadvantaged families and were themselves not able to provide adequate parenting to their children. Therefore, they tend to have few close or enduring relationships and no private financial resources with which to enrich the time remaining to them. Medical supervision is usually by doctors with little knowledge of, or experience in HD, and the HD medical specialists are few and far between and based in metropolitan or regional centres. The history of scientific progress in understanding the condition is a short one with most progress related to the field of genetics. Therefore, few written nursing resources are likely to be available to those providing care. Finally, due to the relative rarity of the condition, HD experienced nurses who could disseminate what expertise does exist, would also be expected to be scarce.

1.5 Summary

Introductory information about various aspects of HD and some aspects of providing treatment and care to modify its impact have been provided. The remaining chapters of this thesis will focus on presenting firstly the background and then the detail of the conduct of an exploratory investigation into HD residential care provision in NSW from a nursing perspective. This will include a literature review, a description of the methodology, an account of the results and the discussion of the whole process, with recommendations for both practice and further research.

The next chapter, therefore, provides a review of the pertinent literature in addressing the clinical problem of the “cuckoo in the nest.”
CHAPTER 2 – THE LITERATURE REVIEW

2.1 Introduction

The recurring and urgent problems noted in aged care facilities generated a problem statement that:

*Caring for people with HD in the standard aged care facility can be very difficult for the nurses and frustrating for the residents and their families.*

To further the process of investigating this problem, a literature search was undertaken to identify work already completed on the issue and concomitant gaps in knowledge on the topic. Using a mind mapping approach, various topics such as “The care of a person with HD/ young disabled/ chronically sick/ dementia sufferer,” and “Aged care facilities/ specialist facility/ service provision/ long term care”, were included in the search. Both electronic databases, and the resources of the Australian Huntington Disease Association (NSW) Inc. were used to locate relevant published and unpublished reports and documents that might assist in the search. The latter, non-peer reviewed sources, were included in order to fully contextualise the origins and potential importance of the findings of the study. This refers particularly to the organisations representing the HD affected people and their families.

This initial search did not reveal any research into nursing aspects of the care of people with HD in residential aged care facilities. Indeed, there appeared to be little research interest into care provision, as against treatments, for those with HD, let alone into residential care provision. Related work from a medical perspective (Barczak, Pedlar, Hunter & Betts, 1987 and Nance & Sanders, 1996), and by some nurses ( Kanu-
Oti, 1993, and Skirton & Glendinning, 1997), had some application to the problem statement above.

The search for either research-based or comprehensive anecdotal explanations for the difficulties being recounted was elusive. The need for an inaugural nursing study was apparent, but the exact focus required was not yet clear. This was advanced during the search by maintaining the problem statement constantly in the background. The fruits of this search are now presented, commencing with a discussion of work concerned with the issue of achieving best practice in HD. The remainder of the chapter presents work covering the following topics:

- Models of care in HD
- The influence of institutional care provision parameters, and
- Deviance and allied concepts

A discussion of concepts and questions that emerged from the literature search precedes a final summary.

2.2 HD best practice

The first major theme to be discussed relates to those studies or papers dealing with statements of assumed best practice in HD, and barriers to achieving such goals. These would illuminate, for example, whether the HD problems observed could be reduced with changes in therapies employed, referral to other specialists or whether care in nursing homes has already been shown to be untenable. Most work is noted to be practice based rather than research or evidence based. HD nursing practice recommendations for management of signs and symptoms are reported from specialist centres in Melbourne, Australia, and a series of centres in the USA (Ball, 1982; Chiu &
Teltscher, 1985; Tinney, 1983). Their application to HD affected residents of aged care facilities is not highlighted, nor is there much reference to strategies to assist nurses in these settings. The reality of the lives of the majority of sufferers with advanced disease appears to have been overlooked. By contrast it is noted that two of the 2002 editions of the AHDA (NSW) publication Gateway, (July / Aug and Nov / Dec) contained condemnatory statements regarding the practice of caring for young HD sufferers in the aged care system. On the other hand, Smith (1998), a U.K. nurse, reports on a series of visits to care facilities in the USA with the goal of seeking best practice information particularly with regard to nutrition, communication and mobility. He notes great variation in managing the signs of HD, which he ascribes to nursing attitudes, input of allied health therapists and specialist HD knowledge. As a well-written article with descriptive evidence to back up observations, it provided pointers to salient aspects of care needing further investigation.

With respect to HD: the importance of accurate nursing assessment (Fillingham, 1998); a nursing process approach (Castledine, 1993; van der Weyden, 1994); the role of nursing leadership in promoting effective care planning and problem solving (Jolley, 1990); and descriptions of a therapeutic nurse-patient relationship (Plane, 1996) are all discussed in articles of a case study/anecdotal nature. They provided some interesting insights into issues that have motivated nurses to publish on HD.

Other case studies or articles based on personal experience include those by France (1993) Gardham (1982), Geoghegan (1982), McDonald (1993), Sheaff (1990), and Warriner (1990). The tone of many of these indicates a desire to dispel ignorance concerning the disease and to reduce the sense of despair and hopelessness surrounding it. Whilst it is clear that they are also intended to encourage best practice, they include little
evidence of systematic reflection or critical thinking. This is not to say that they have no value to the practitioner, but to underscore the observation that HD nursing currently has little if any research or academic basis for evidence-based practice. It could therefore be considered as having less professional standing generally than other specialist areas of nursing practice.

Seidman-Carlson and Wells (1998), on the other hand, describe an evidence-based method of assessing affective communication deficit, one of the manifestations of cognitive impairment, using pictures of faces with happy, sad, and angry expressions on them. This article is written clearly and contains interesting and useful information for practice. The insights regarding the complexity of the cognitive deficits and the ease with which these can be overlooked by the less enlightened, encourage assumptions that HD inexperienced aged care nurses will find such manifestations of the disease challenging and frustrating. This is also the case in a work by Hoffman (1999), who focuses on the neuropsychiatric signs and symptoms of HD. She recommends that for nurses to improve their care of those with HD they should have a knowledge base of the neurologic and psychologic processes underlying what is described as a “complicated and challenging endeavour” (p. 313).

Insights which served to suggest possible explanations for the observed difficulties in aged care facilities included numerous references (Chiu, 1989; Gardham, 1982; Hardy, 1989; Imbriglio, 1992; Nance & Sanders, 1996; Seidman-Carlson & Wells, 1998 & Smith, 1998), to the challenging nature of care provision, particularly with regard to managing difficult behaviours. There was also mention of the lack of effective symptom management interventions for the movement disorder, the uniqueness of the condition, and the lack of experience of the staff. The allied inference of the need for special skills
and knowledge of HD in the nurse carer was noted repeatedly, as well as the lack of multidisciplinary support (Bentley, 1999; France, 1993; Gelbart, 1998; Sheaff, 1990; Smith, 1998).

Other authors mentioned the role of multidisciplinary team members in providing for acceptable standards of care. Nurses from other specialty areas were also included (Gelbart, 1998; Klimek, Rohs, Young, Suchowersky, & Trew, 1997; Smith, 1998).

There were numerous articles on symptom management by non-nursing professionals. Notable amongst them are work by Gillick (2000) on the issue of artificial feeding in advanced dementia; Imbriglio (1992) on the role of the physical therapist in designing a therapy program which allows maximum freedom and minimal risk, and Lavers (1982), who speaks from the occupational therapy point of view about managing dysphagia. In view of the manifold recommendations made by others, a question exists as to the nursing perspective on these strategies. Is the knowledge disseminated and is it proven to be useful? Indeed, embedded in the HD-related clinical topics, the need for increasing involvement by nurses in research and scholarly comment in this field was also expressed several times, and over a long period (Drapo, 1981; Kovach & Stearns, 1993; Seidman-Carlson & Wells, 1998). Kovach and Stearns (p. 271), described the situation thus:

What is missing is an empirically validated body of interventions to guide nursing practice. Nursing research is needed to validate existing care practices, generate new interventions, and to begin to build theoretical explanations that assist nurses in providing care to people with Huntington’s Disease.
The place for some scholarly work in the field seems wide open, but what should be the topic chosen from all of those described as needing urgent attention?

For example, the issue of genetics, genetic counselling and testing has received an enormous amount of academic attention. An understanding of issues related to the complex personal implications of the hereditary nature of the condition, for parents and children alike, was implicit in readings from geneticists and genetic counsellors, including nurses who have this as their primary role. This includes work by Drapo (1981), Rohs and Klimek (1996), and Williams, Schutte, Evers & Forucci. (1999). They outline the role of the nurse in genetic counselling, and the need for appreciation of the ethical issues involved in the predictive test process and decisions regarding informing children of their risk status of carrying the HD gene. The personal implications of the hereditary nature of the disease are described eloquently by Warriner (1990). These highlighted the family aspect of the condition, which would also impinge upon the work of the aged care nurse and the HD affected resident. It also indicated another complex aspect to HD care provision needing to be understood to promote best practice.

The principle of best practice being underpinned by an adequate knowledge base was stated many times (e.g. Bentley, 1999; France, 1993; Gelbart, 1998; Sheaff, 1990; Smith, 1998). Information on the specifics of the disease was found in the steady flow of work from medical practitioners and scientists investigating the demographic, biochemical, physiological, and pathological aspects of HD. This was presented in journal articles (Brothers, 1964; McCusker, et., al., 2000; Pridmore, 1990) as well as in medical textbooks (Chiu, 1990; Foltstein, 1991; Harper, 1996; Paulson, 1999; and Rosenblatt et, al., 1999). Although mention is made of the need for residential care during
much of the illness, there was little reference to studies of any of these services. The exceptions are discussed in the next section under models of care.

2.3 Models of care

It was hoped through investigating literature on models of care, to find information on ways of providing care which had been shown to enhance the quality of life for the patients and thereby, their families for those in the moderate to advanced stages. Disappointingly, as judged on the level and frequency of publication of research into the subject, academic interest in service provision for HD, institutional or community-based, appeared limited. Reports of a subjective nature, but with an emphasis on the provision of community-based care for those with HD, were less common than those reporting on HD specialist accommodation were.

Firstly then, with regard to community services, Green (1989), notes the need for a co-ordinated approach between the Huntington Clinic and community workers. Kapp (1987) discusses the contribution of an HD day care program additional to the existing residential holiday program in improving quality of life for sufferers and their carers. As the executive officer of the AHDA (NSW) Inc., the author (Kapp) writes this report based on her participation in, and subjective observation of, the effects of the program. Klimek et al. (1997) report on the establishment and achievements of a community-based multidisciplinary team program of HD care in Calgary, Southern Alberta, Canada. A limitation of their work includes the somewhat disappointing statement by the authors that “Scientific proof of the success of the program cannot be described because, similarly to many nursing care programs, this is not scientifically based.” (p. 38)
However, one community-based research study of note (Skirton & Glendinning, 1997) was conducted in the County of Somerset, UK. The participants (25 known HD sufferers) were in all stages of the disease and accommodated in various settings. The purpose of this project was to identify unmet needs as a means of planning for improved care. This extremely thorough study was based on data gathered from face to face interviews by the two researchers with the whole population of HD patients and on information supplied by the professional and informal carers of the patients. The results were used to draw up a document “Huntington’s Disease Guidelines for Assessment and Information in Somerset” to promote effective, co-ordinated care. Common ground with the work in hand is identified with regard to professional background as well as aspiration to provide reliable and valid data as a basis for improved practice. As noted in the full report (Glendinning & Skirton, 1994) information from professional carers, included details of their relationship with the patient, their experience of caring for patients with HD, and a self-assessment question regarding their need for more HD knowledge. Clinical assessment information was also included and this consisted of both functional status, and signs and symptoms. In terms of information regarding institutional care, this study includes reference to the identification of seven HD sufferers in institutions in Somerset (23% of the HD population), namely nursing homes and psychiatric hospitals. The resident profile showed 100% prevalence of expressed aggression, behaviour problems and communication problems, as well as 57% being underweight and 71% having swallowing problems, which required dietary modifications. The age and gender breakdown was not possible from the overall statistics provided. Other findings of concern included an average of 2.14 unmet needs per institutionalised HD sufferer, evidence of a lack of some allied health resources, patient resistance to using allied health
therapy and unmet staff education needs. Questions about safety elicited a 71% rate of the existence of hazards in the environment. Of the three patients in psychiatric hospital, two were judged by their carers to be inappropriately placed, on account of their age. No further details were given. The researchers commented that, “They are two examples which emphasise the need for a unit in Somerset which specialises in the care of HD patients” (p. 32). These findings generally supported the clinical observations of the researcher, although the reported inappropriateness of accommodation in a psychiatric hospital added another dimension to the issues already identified.

It is timely therefore now to discuss literature on the issue of specialist accommodation in HD and what has been said about the ideal characteristics of such accommodation. This might provide a basis for useful comparison with other facilities.

The initial literature search indicated that this topic has received generous comment from both Australian and overseas writers over time (Ball, 1982; Barczak, et al., 1987; Bentley, 1999; Chiu & Teltscher, 1985; Gelbart, 1998; Hardy, 1989; Kapp, 1987; McGillicuddy, 1997; Smith, 1998). In addition, an Australian nurse, Tinney (1983) provides detailed descriptive information on a range of facilities observed in the USA during a study tour. Her comments however, tend to be emotional and informal, and appear to provide a rather negative, subjective and limited analysis of the facilities she visited.

Hardy (1989), on the other hand, describes the Canadian approach at Runnymede Chronic Care Hospital, Toronto, from a nursing perspective, speaking against a background of professional self-awareness that is more informative and useful. She refers to the observations and insights being made there, for example, of the extreme need of those with HD to have their requests for assistance met promptly, and the hypothesis as to
whether this is an indication of a dysfunctional sense of time. She reports on the usefulness of the interdisciplinary team and of the goal of achieving with families and patients, “therapeutic changes which will result in better quality of living” (p. 5). She reflects on therapies used, environmental (especially equipment) modifications, activation such as music, pet therapy, socialisation, and permissiveness regarding decisions and control.

Ball (1982), in the next article to be discussed, emphasises in a direct and positive style the way prevailing defeatist attitudes were confronted at the first specialist HD centre in the world, the Arthur Preston Centre in Melbourne, Victoria, with additional information provided subsequently by Green (1987, 1989). Ball (1982, p.17) describes the Centre thus:

At our centre, our people are not treated as sick, dying people. During the day they are up and about unless they have a specific other illness at the time. They are up because they have work to do. Their work is to take part in the program of activities which is aimed at keeping their minds and bodies active, and which is in our view, the only and the best way that we can help them.

Myths about what the HD person could be expected to do and attitudes of encouraging a sick role in someone with years left to live, were confronted by placing expectations on the HD residents, and providing for all their routine medical and dental needs.

Kapp (1985, 1987) presents the local view for Sydney, NSW, with regard to achievements that came about due to collaboration between the voluntary organisation and health care providers. This includes reference to the establishment of a holiday
program for people with HD, a day care program, in 1983, and the opening of the 15 bed HD inpatient unit at Lidcombe Hospital in 1988.

History shows that these developments reflect more general changes in health care provision in NSW at that time with the development of specialisation of health services in general, and nursing services in particular. This was a time of social stability and affluence in Australia. Thus, there was the advent of the first community-based specialist clinical nurse consultants, stoma therapists, oncology nurse consultants and, later, palliative care nurse consultants.

With the advent of more federally funded initiatives following the election of the Labour government in 1972, this period also saw the establishment of comprehensive community nursing services, including that of the generalist community nurse role in the Western Sydney Area Health Service. Given time, it is possible that attention may have been drawn to the plight of the majority of the NSW HD affected population who were in the later stages of the disease, and unable to be accommodated in the 15 bed unit at Lidcombe Hospital. Instead, they were cared for in an aged care facility or psychiatric institution. However, it is disappointing that no effort is made in the article by Kapp (1985) to note the limitations of the specialist accommodation in terms of the overall numbers able to be accommodated, nor to highlight key features of best practice, nor to provide advice on ways of improving care in generic facilities.

The move to Western Sydney Area Health Service (Lownie, 1997; McCusker, Lownie, Curran, Bacik, Devine, Barnes, Dive, & Tran, 1997; McCusker, et, al., 2000; Turner & McCusker, 1997; Williams, 2001) is evidence of the further development of HD services. It also indicates the presence of an integrated NSW statewide service including outreach, tertiary teaching hospital, in addition to the pre existing specialist residential
facility components. With the primary service goal (NSW HD Service, 2001) stated as a “Health goal...to minimise the handicap or impact of Huntington Disease on the lives of patients or families”, advertised services offered were multidisciplinary and included education for professional carers. In the first prevalence study for NSW, (McCusker et al. 1997) there is evidence supporting a need to provide services in NSW for up to 500 HD affected people. The probability is therefore extrapolated that the 16 specialist beds falls far short of the number needed adequately to provide institutional care for those affected. Without a major change of direction and the injection of considerable funding support, most HD sufferers in NSW could be expected to spend the last years of their lives in residential aged care facilities all over the state.

There is a lack of Australian research into the efficacy of the specialist residential care model. So details are now presented of a major American medical study by Nance and Sanders (1996) into the care provided in the 35-38 bed HD specialist unit in the Metro Care Center, Minneapolis, USA, where specialist neurological consulting services were provided from the HD clinic, Hennepin County Medical Centre.

This study included data from a sample of 83 patients from the specialist facility (since closed due to funding difficulties) and 14 patients from nonspecialised nursing homes that were also run by Beverley Enterprises Corporation. The data were obtained from a retrospective audit of patient records covering 17 years. The goal was to gather baseline demographic and clinical data on the residential care of the person with HD, details of which are now given. The patients included slightly more males than females whose ages ranged between 20 and 80 years old (M = 44.6 years), with the men being, on average, six years younger than the women are. Other data gathered related to disease stage (mostly advanced), education (mostly not professionals or with no more than 16
years of education), previous accommodation (mainly from other long-term care
facilities), use of proxy (29% had a guardian), diet (67% had serious swallowing
difficulties which required a care plan such as pureed diet, thickened fluids and 3000 –
4000 calorie diet), death (38% of the 29 deaths were due to pneumonia), artificial feeding
(12% had gastrostomy tubes), behavioural problems (78% had exhibited some violent or
disruptive behaviours with 34% scored as severe on a three point scale) ambulation (26%
became immobile), hospitalisation record (none for 57%), medication usage (84% used
neuroleptics at some time), and the use of allied health therapists (10% refused any
services, 36% used physical therapy, occupational therapy, speech therapy and
psychology services, and about 66% used one or other of these). Unexpected statistics
included information of a 10% rate of chronic pain. On issues around admission, an
inability to manage behaviour was the most common reason for admission from other
facilities, whereas among patients admitted from home, reasons included the absence of a
caregiver and inability to continue home care.

In the discussion, the authors also attempted to compare HD residents with non-
HD nursing home residents across several parameters. In terms of demographics, the HD
group was very different. The average nursing home resident was usually female
(68.1%), and 65 years or older (91.7%). On the other hand, with respect to the issues of
Weight maintenance, Safety and Equipment, Aggression and other behaviour problems, or
Polypharmacy, the patients with HD were not markedly different from the rest of the
nursing home populations. With respect to reducing avoidable health problems, the
authors propose that the observed high rates of urinary infection, skin tears, ulcers and
pneumonia, should be considered as conditions for prospective intervention. They further
argued that although the HD residents were thought to be more at risk of restraint-related
injuries, these also occur in unrestrained individuals with HD. Statements of social and nursing issues included rates of unsafe smoking, bladder incontinence, bowel incontinence, unwillingness to bathe, decubitus ulcers, pneumonia, alcohol usage (before admission), and recurrent fever. Although three patients were transferred out for intractable behaviour problems, the authors suggested four principles to managing problem behaviours: tolerance of certain behaviours, attention to triggering factors, adherence to a routine and the judicious use of antidepressant and other medication.

Short-term hospitalisations were also noted for 48% of patients, 17% for psychiatric / behavioural problems and the rest for medical problems.

In conclusion, the authors nominated behaviour management, dietary management and adjustment to deterioration in condition as the most important care provision challenges. They noted that due to the inherent difficulties of such a task no effort was made to assess the quality of life for residents in this setting or to compare this with the alternatives of a non-specialised unit or care in their own home.

Whilst noting the limitations imposed by the retrospective audit method and lack of comparison of the two sub groups of the sample, this study makes a major contribution to the knowledge base on this group of HD affected people. Conclusions were drawn with some clear implications for practice. Whilst not directly addressing the clinical problem of concern for this study, it is a notable effort to produce evidence-based insights into problems and practices in the specialist HD residential care environment. It has attempted to include data on a large number of facets and certainly achieves the stated goal to “... provide a baseline against which other HD populations or interventions can be compared.” (Nance & Sanders, 1987, p. 547) However, for the purposes of the question at hand, and in view of the comments of the authors regarding similarities with other
nursing home populations, it would have been useful to have more information on the differences attributable to the specialist nature of the facility. It is unfortunately not clear whether the authors are advocating specialist facilities as the model of choice or not.

The final work to be reviewed (Barczak et al., 1987), on the other hand, does focus on care provided in nonspecialised or generic facilities, namely psychiatric hospitals and residential homes in Birmingham, United Kingdom. A copy of the publication was obtained direct from the Royal College of Psychiatrists after a fruitless search for alternative sources, and, therefore rather late into the literature search. However, it has proved to be most enlightening and in many ways is the closest both in motivation and in content to the present study. The work reports on data derived from a study of institutionalised HD patients. “This study looks at the disability of Huntington’s Chorea sufferers in hospital and other institutions in order to determine the suitability of their placement and to see whether their physical and psychological needs are being met.” (p. 187). An exhaustive attempt was made to locate all HD patients living in institutions in the West Midlands. The 20 individuals identified included eight in permanent residential care and 12 permanently in psychiatric hospitals. Reporting on the care of the person with HD in that region, the authors reflect critically on the inappropriateness of the psychiatric setting, in particular, for their care. These conclusions were based on individual assessments by the researchers as well as interviews with staff and relatives. There was high agreement between staff and relatives on whether the individual placements were appropriate. The psychiatric setting was considered inappropriate by the staff for over half of the patients. The residential setting was favoured for the increased privacy of the accommodation but staff in both settings were perceived to be lacking in HD specific knowledge. Whilst chorea, speech difficulties and mobility problems were considered the
most severe disabilities and were more advanced in the hospital patients, aggression was also a problem for 30% of this group. The problems noted for staff include lack of time or motivation in psychiatric settings for the physical attention required; lack of knowledge about special aids to assist with managing physical problems; and generally inadequate knowledge about the nature of the disease. Environmental assessment, including lack of participation in lifestyle programs, the under use of available allied health staff, and the lack of knowledge of HD voluntary organisations, was also noted. Criticisms of the physical environment included the lack of privacy in large dormitory style wards, and criticisms of the social environment were based on distress experienced by relatives and HD sufferers caused by being placed with the mentally ill. It was in such a setting that Frank Gardham (1982) chose to describe the HD affected patient as “the cuckoo in the nest.” Whilst the brevity of the article limits assessment of the methodology or results, there are many interesting comparisons to be made. Ironically, the comparative trend in NSW of accommodation within the aged care sector would probably be seen by these authors as a preferable option to years spent in a psychiatric hospital, but the question remains as to what exactly made the care of these people unacceptable in these settings? What would enhance their quality of life? Some possibilities are mooted but much remains unanswered. Aspects of aged care parameters that may enlighten the search are now discussed.

2.4 The influence of institutional care parameters

The studies discussed in this section provide information about various aspects of institutional care provision. This includes the impact of differing parameters on the experiences of patients and residents. These aspects include institution size, staff attitudes
and care planning frameworks, as well as the education levels, knowledge bases and stress levels of the staff, and the particular pathology of individual residents. This information was sought in the hope that it might provide clues from non-HD sources regarding aspects of the structure or function of aged care facilities to explain aspects of the HD phenomenon under scrutiny. Alternatively, possible theories could be excluded from the list based on the literature search. In other words, was it possible, for example that the problems with HD affected residents were exacerbated if the staff received no in-service education, or if the DON had rigid attitudes towards a neat and tidy physical environment? Studies reported under this topic include some that were explicitly evaluative as well as some in which care implications emerge from another focus of study. They were scrutinised for similarity and relevance to the clinical issue of concern.

The first to be described, a large Australian study (Courtney & Spencer, 2000) conducted in aged care facilities, focussed on the identification of measures to permit the objective evaluation of care provision in these institutions. These would provide objective means of comparing outcomes of differing facilities and differing models. Known as “clinical indicators” to be used in assessing Standard 2.4 of the Commonwealth Accreditation Standards dealing with clinical care, the study revealed agreement by different levels of registered nurses, that the presence of decubitus ulcers and incontinence rates were acceptable clinical indicators of quality aged care. Using a triangulation approach and a random sampling of the whole population of Australian nursing homes, it was also found that when the comparative ratings of all the indicators were examined, there was the highest agreement between the bedside RNs and the Directors of Nursing that polypharmacy was the best clinical indicator of lower quality care. In another part of the study, based on interviews, the discussion of the results indicates that aspects of
patient care over which nurses have direct control, such as the promotion of skin integrity
to avoid decubitus ulcers are likely to be considered by them as the most valuable
indicators of quality care. This is supported by an indication from the researchers that
"the ability to make a difference for the better" was valued highly by the nurses (Courtney
& Spencer, 2000 p. 18).

Moving onto studies which directly assess features of aged care institutions, work
by Pearson, Hocking, Mott, and Riggs (1992a, 1992b, 1993a, 1993b) was also notable for
its similarity of purpose and data source to the problem under scrutiny. This was a large
tertiary institution-based project and was funded by an Australian government
organisation, the Commonwealth Department of Community Services and Health. This
ensured that the research resources available were much greater than were those at the
disposal of the HD study being reported. The broad goal was improved care for aged care
residents. The data were of three sources: information gathered by informed observers,
information obtained during interviews of residents, and qualitative data gathered from the
ten most highly performing homes on the other measures.

The major findings of relevance to the research topic (Pearson et al., 1992a p. 775)
are now listed. Firstly, there were no significant relationships between the percentage of
registered nurses and the outcome measures of quality of care/life, as defined in this study,
nor all the other outcome measures, except for privacy and dignity. Secondly, there were
statistically significant positive relationships between the level of in-service training
activity and all the outcome measures except for privacy and dignity. Other significant
findings related to the relationships of the Outcome measures and the "Organisational"
variable. It was also reported that charitable organisations scored higher on the measures
of "Social independence" and a "Home-like environment" and medium and large nursing
homes scored higher on the “Variety of experience” outcome measure. On the other hand, medium size was related positively to measures of “Social independence, Freedom of choice, Safety” and the “Overall quality of life.” Further investigation of the finding related to the “Role of therapists” and the “Variety of experience” outcome measure consistently reported on the critical role of diversional therapists in the high performing nursing homes studied. In other words, “they make a marked contribution to the varied social experiences accessible to residents.” (Pearson et al. 1992a, p.776)

An interpretation of this finding with relevance for the HD study under discussion includes this insight. It is suggested that aged care facilities are not hospitals for sick people where complex technical nursing skills are paramount, but permanent homes for the frail elderly members of society, where an environment (both physical and social) which contributes to a meaningful life experience for that stage of their life is valued highly. This means that the skills associated with more complex symptom management would be less likely to be available in an aged care setting than in an institutional setting designed specifically for the care of a person whose main problems are disease-based, such as is the case with Huntington Disease.

Other work based in the aged care sector includes studies on a variety of topics more or less closely related to care provision for HD in aged care.

The issue of the impact of the type of care provided in care facilities was examined in another triangulated study of elderly demented people with Alzheimer’s disease, Huntington Disease, and Downs syndrome (Kanu-Oti, 1993). The broad topic of interest of this work resonated with the study being reported. Using a case study method, data were obtained from interviews, questionnaires and participant observation, including information from residents and various categories of professional care providers. With its
prime area of concern being in the use of Individualised Care Planning to guide care provision, the study specifically set out to "...establish the existence or non-existence of variations in the caring, management and understanding of dementia residents in the nursing home" (p. 14). It was hoped that the study might help with the development of a variable method of care for people with dementia in nursing homes. Special needs units based on a disease classification of the residents were seen to have the potential to meet these needs if "significant individualization of care plans" (p. 259) was part of the practice. This was not always found to be the case. The results of the study indicated that an individualised care approach in specialised units was expected by care providers to be the most successful option of care provision in meeting individual needs, but was also the most expensive option. In the words of the author:

The literature review and professional opinions showed strong support for specialised care for dementia patients, but some warned of the high costs...It also revealed that while individualised care for dementia patients is available in the private sector, public health care facilities are woefully lacking. (Kanu-Oti, 1993 Abstract)

It should be noted that the HD residents in this study were aged over 60 years, which is not the norm for the HD patient group under scrutiny. This would be a major limitation to any generalised comparisons.

In several other studies, staff attributes were investigated as of prime relevance to outcomes of care. For example aged care staff attitudes towards their clients were investigated in several studies including one by Harborne and Solly (1996) and another by Smith, Jepson and Perloff (1982), a quantitative study in Pittsburg, USA. This last used
Kogan’s Old People Scale as the self-report tool. Nursing care providers, classified as registered nurses, licensed practical nurses and nurse aides, were seen to vary in their attitudes (both positive and negative) to elderly patients according to their level of educational preparation for the job. According to the authors, “This study showed that the registered nurses were always more positive and less negative towards elderly patients than either licensed practical nurses or nurse aides” (Smith, Jepson, & Perloff, 1982 p. 97). The most experienced and best-educated staff had the most positive and least negative attitudes to care of the elderly. This demonstrated relationship between education and attitudes would be important to consider in making recommendations for practice for HD care in the aged care sector.

The broad topic of staff attitudes was also the focus of an Australian study by Retsas and Wilson, (1997). They used repertory grid completion to elicit personal constructs of gerontological nurses in general, effective gerontological nurses in particular, and the participants’ self-assessment as effective nurses. The gerontological nurses being studied generally held a low opinion of gerontological nurses in general, or did not see them as functioning effectively. Neither did they have a clear view of the work as having standing as a specialty. This evidence for a general lack of confidence of aged care staff in their abilities as a group might have a bearing on the expressed concerns of aged care nurses in NSW in caring for their HD affected residents.

These findings are echoed in another report by Hall (1999), who supports the view of gerontological nurses as having lower status than other nurses have.

Moving onto evidence from the acute hospital system, in another Australian study (Healey & McKay, 1999) nurses reported that increased staff stress levels were due to
workload and deficiencies in knowledge of various sorts. Uncertainty was reported to be particularly stressful for nurses.

The work by Benner (2001) supports these findings with regard to the importance of knowledge acquisition and experience in facilitating the skills of expert practice.

This leads into a presentation of studies that examined the impact of resident and patient characteristics on outcomes such as financial reimbursement for documented care provision, and detrimental effects on other residents.

A large, reportedly rigorous study (Rohrer, Buckwalter, & Russell, 1989) investigated the impact of aged care resident characteristics, such as cognitive deficits, aggression and emotional difficulties, on the amount and type of nursing care required. The study was conducted from the University of Iowa, and stemmed from concern regarding the reimbursement system based on the Resource Utilisation Groups (RUGS) classification system. The authors found that of various measures, the degree of physical disability of the resident correlated most highly with the amount of nursing time spent with them. Of the mental health problems identified, only those relating to “Affect” were demonstrated to increase nursing time given.

Work on the issue of resource availability and utilisation, and its impact on care, was reported by Hinton-Walker (1993), Koch and Kelly (1999), Miller (1992), and Zuch and De Bellis (1996). These studies relate to chronic illness including multiple sclerosis and motor neurone disease. In line with the work on mental health problems (Rohrer et al. 1989), described above, Zuch and De Bellis (1996), were motivated by concern for perceived inconsistencies in the aged care funding system in Australia. It had been demonstrated to be unable to provide for the increased demands placed on nursing staff in meeting the needs of residents with complex incurable neurological conditions such as
motor neurone disease. This case study, with an emphasis on the palliative care needs of the patient, provided interesting background material for the HD study under discussion.

McGillicuddy (1997) reflects on the New Zealand experience of the inherent difficulties in providing for the special needs of a relatively small but distinct group of people (with HD) when there is pressure on resources.

The next study into the effects of resident characteristics (Smith-Jones and Francis, 1992), examined the effects of problem behaviours (including physical and verbal outbursts) by certain identified aged care residents, on the non-disruptive patients, and on the job satisfaction of staff. The negative impact in both cases was reportedly minimised in a "cost-effective intervention" (p. 17). This four hour per day, five day per week hospital-based program of small group activities was set up as a pilot respite program for patients in the psychogeriatric ward in Burkeville Virginia, USA. The participants had demonstrated patterns of verbal and physical outbursts, shoving and pushing, non-compliance with activities of daily living and aimless pacing. These "disruptive" residents were given regular time away from the unit for special activities. Pre and post-test measures of quality of time for non-disruptive patients, psychomotor agitation levels for the study participants, and staff job satisfaction showed high levels of improvement following the eleven week Holiday House Program. In view of the lack of controls and the exploratory nature of the project, the authors caution against drawing too wide conclusions. Nevertheless as an objectively described example of a non-invasive, non pharmaceutical social intervention for disruptive behaviour, this report is considered noteworthy.

Other work in aged care facilities with a focus on anti-social behaviours and their management, included a careful and comprehensive study by Ryden, Bossenmaier and
McLachlan (1991), which aimed to demonstrate that aggression in cognitively impaired residents in aged care facilities, was generally triggered by nursing interventions from less educated staff. These usually related to personal care and hygiene provision, which necessitates entering the personal space of the resident. Improved quality of life for the resident, and reduced caregiver burden were reportedly achieved as described in a follow-up study by Feldt and Ryden, (1992). This detailed an education program for nursing assistants, which was aimed at reducing levels of aggression in residents. The program was reported to improve levels of staff job satisfaction and reduce frustration levels with the residents.

Finally, in the same theme, there are descriptions from various sources (Kelly & May, 1982; Johnson & Webb, 1995; Podrasky & Sexton, 1988) of the stated characteristics of patients that nurses have identified as having the least appeal to them, or of engendering anger or severe frustration. Having direct relevance to understanding the phenomenon to be investigated, these characteristics, in the words of the respondents include: "mutilation, incontinence, long term illness, confusion, mental disturbance, psychiatric conditions, deviant behaviour, non compliance, stubbornness, aggression, violence, anger, impatience, being bizarre, outrageous, independent, overly dependent, unappreciative, unhappy, irritable, depressed, anxious, fearful, apathetic, withdrawn, indifferent." Discussion relating to individual patient characteristics as predictors of staff attitudes towards them, leads onto an examination in the next section of work in the sociological field of deviance and associated nursing literature. This includes the concepts of the popular / unpopular patient, labelling, and evidence from the British acute care system for the dynamic nature of social judgement.
2.5 Deviance and allied concepts

By reflecting on the dynamic interactions involved in the clinical situations underlying the research problem, an insight was gained of the importance of the social context and of the obvious and latent meanings therein. This prompted reference to work in the field of deviance which is now reported.

Resident or patient characteristics that are distinct, or different from those of their fellow patients, have been the focus of a significant amount of nursing comment and some research. These studies are viewed against the theoretical sociological perspective of deviance which focuses on non-conformist individuals and groups within societies and the various reactions which ensue. In this prolifically debated field, the work of Conrad and Schneider (1980), Edwards and Wilson (1975), Kelly and Clarke (2003), Kittrie (1971) Merton (1968), Parsons (1951), and Roach Anleu (1999), all contribute to the examination of the constituent concepts. These include consensus, labelling, criminalisation, and power. The role of stigmatisation and the imposition of legal sanctions as the strongest form of social control is noted and is compared with the increasing medicalisation of many deviant behaviours with the medical profession thereby undertaking a social control function.

Medical control of deviant behaviour is usually a variant of medical intervention that seeks to eliminate, modify, isolate or regulate behaviour socially defined as deviant, with medical means and in the name of health.(Conrad & Schneider, 1980,p.242)

The elements of this medicalisation are described by Talcott Parsons in Conrad and Schneider (1980) p.169 thus: "When deviance is seen as wilful, it tends to be defined as a crime; when it is seen as not wilful it tends to be defined as sickness."
Parsons (1951) defined the *sick role* for both acute and chronic illness and included obligations of cooperation with the physician in order to get well or to minimise incapacity. However, this notion was challenged by Narcez (1990) using Cystic Fibrosis, a chronic condition, as the model. He developed the notion of personal responsibility with respect to the illness state further and described a framework incorporating the idea that the more extreme the debilitating effect of the illness, the more likely it is that the individual will not be held responsible for his condition.

Further work on the concept of the sick role, and possible implications for patients who appear not to conform to the accepted norm of what this entails, was done by Kelly and May (1982) with regard to the concept of “good and bad patients.” They criticise the analyses of many writers, for example Armitage (1980), Habenstein and Christ (1963), and Spitzer and Sobel (1962), whereby those patients who do not conform to the generally accepted definition of the patient role are reportedly considered deviant by nurses and doctors and labelled negatively as a result. Broadly speaking, Kelly and May (1982) see this as too simplistic an explanation from a theoretical perspective. The labelling process is criticised for being presented as uni-dimensional thereby ignoring important interpersonal and environmental factors.

One work, which appears to include a more dynamic, interactional element, is that by Tresler (1996). She outlines a theoretical framework that relates additional understandings of the phenomenon of deviance to health settings. Incorporating concepts from the work of Lorber (1975), she elaborates further by defining the career deviant as exemplified in the hypochondriacal patient, tending to have an ordinary illness, to be judged to be deliberately deviant, and therefore to be treated with condemnation. The accidental deviant, by contrast, suffers from an extraordinary illness or poor prognosis and
exhibits demanding behaviour, but is treated with forgiveness. Although somewhat simplistic, and based on work in the American acute hospital setting, this last definition did appear to fit the case of the HD affected resident in the NSW aged care settings under scrutiny. It enabled the phenomenon under investigation to be placed in a theoretical or conceptual framework following analysis of its constituents. This leads into a discussion of work dealing with one such concept, namely that of ambiguity and its application to nursing.

Virginia Henderson in a seminal lecture (1978), discusses the universal components of her concept of nursing against the backdrop of a statement that ours is the age of uncertainty in which, “The social scientists tell us we must learn to tolerate ambiguity” (p. 114). The importance of nursing and the management of ambiguity in varying contexts has received significant attention. Littlewood (1991), for example, outlined the concept of the nursing role as essentially involving the management of ambiguity arising from the necessity of dealing with intimate aspects of bodily functions which are otherwise taboo to entrust to another. In this instance, the resolution of the inherent conflict and ambivalence may occur by resorting to the negative use of power in the nurse-patient relationship. Another scenario, but one that involves structural ambiguity, may be described as a situation where the nurse is expected to give competent care to a number of patients whose needs vary and conflict due to personal factors such as their age, diagnosis and willingness to comply with routines and treatments. This last, described by Frank Gardham (1982) from a psychiatric nursing perspective as “the cuckoo in the nest”, has striking similarities to the research problem at hand. This includes probable ambivalence on the part of the nurse for the resident who “does not fit in.” It may be that this internal conflict is the psychological stimulus that propels nurses towards
labelling certain patients with unpopular behaviours, attitudes or demographic characteristics, as “deviant.”

In terms of this internal processing, Cioffi (1997), illuminates the method with reference to clinical decision making and the use of heuristics to resolve perceived ambiguities in the clinical scene. This highlights the importance of the effect of previous experience of similar signs and symptoms with regard to taking effective action to resolve the problem.

Allied to the example of the Cuckoo in the nest, a similar situation, described by Breeze and Repper (1998), relates to the individual in the mental health system with a diagnosis of personality disorder. The resolution of the internal conflict for the nurse includes some negative effects for the patient who reportedly may be stigmatised by being subjected to negative labelling, increased use of physical restraints, and distancing behaviour by staff. Falling into the general category of the unpopular patient, they are often described as asocial and deviant with respect to the norms of the ward.

Allied to the issue of staff attributes, is other work that illuminates the nature of the nurse-patient relationship. This includes attributes such as previous experience with certain clinical situations and conditions and their impact on care. In contradistinction to studies with regard to the concept of “good and bad patients” which apparently assume a uni-dimensional nature of nurse-patient relations (see criticism by Kelly and May, 1982), more recent studies (Breeze & Repper, 1998; Carveth, 1991; Johnson & Webb, 1995; Podrasky & Sexton, 1988; Trexler, 1996), appear to adopt a wider perspective. This includes interest not only in the nurse-patient interaction as the unit of study, but also in the environment in which the interaction occurs. The work by Johnson and Webb (1995), includes a re-evaluation of the work by Stockwell (1972) on the Unpopular patient. They
describe a study using participant observation in a medical ward as the ethnographic method to gather the data. Their findings stress the dynamic and fluid nature of the labelling process observed and include reference to work by Goffman (1968) on the changing nature of the moral career of the psychiatric patient. They introduce the concept of social judgement as one whereby patients are liked or not by the nurses for complex and changing reasons, which are not easily classified. However, the reality of the social context in which the sick patient finds him / herself cannot be denied.

2.6 Concepts and questions that emerged

The systematic search and study of all possible literature that might clarify the clinical problem previously described, confirmed early impressions of almost no nursing research in HD, and certainly none into any aspect of HD in aged residential care. Mention of long term residential care of those with HD was made a few times (Barczak, et, al., 1987; Glendinning & Skirton, 1994; Jolley, 1990; Gelbart, 1998; Nance & Sanders, 1996; Seidman-Carlson & Wells, 1998), but apart from the work of Kanu-Oti (1993), evaluation of care in the aged care setting was not reported. The literature review was discussed under the headings of:

- The issue of achieving best practice in HD
- Models of care in HD.
- The influence of institutional care provision parameters, and
- Deviance and allied concepts

This proved a useful, although not definitive, framework. Various recurring themes were noted which related to the research problem of HD in aged care. Details of these and some associated concepts are now given.
Recurring themes throughout the literature included statements regarding firstly, the complexity of the condition with concomitant care implications. This raises the question as to whether the profound cognitive, motor and emotional changes, which occur most commonly over the 21.4 years’ duration of HD (Foroud et al., 1999), give it a unique identity and management challenge. The key concept identified here, therefore, is that of care needs for a chronic, complex, incurable disease. Indications were found that the management of behavioural components of the disease presents the greatest nursing challenge.

Another recurring theme noted throughout much of the literature, noted the importance of education on all aspects, as well as an acknowledgement of the value of experience to overcome barriers.

These themes highlight the concept of staff attributes, particularly skill levels. This concept includes characteristics such as age, professional attitude, HD nursing experience and HD education, and raises the question of these as possible elements to the research problem. As HD is a relatively rare condition, the assumption may be that aged care staff are relative novices with respect to HD. In contrast to the familiar situations with their aged clients, clinical decisions regarding the HD residents could involve time consuming research and thought, the need for which would be likely to add to their frustrations.

Other recurring subjects included:

- the possibility of new nursing approaches to manage signs and symptoms of the disease
- suggestions for clinical indicators by which to monitor standards of care
• the availability of positive models of care provision, including an HD specialist residential unit in Sydney, NSW
• the importance of individualised care planning to meet the special needs of residents, and
• the value of a multidisciplinary approach, especially regarding lifestyle issues in aged care facilities.

With regard to this issue, it raises the question as to whether the reported problems might be seen as evidence that the existing HD specialist support services were failing to provide the necessary input to enable non-HD skilled staff to cope with HD care demands. This would relate to the concept of effective service provision and quality control.

The final recurring theme noted, and now discussed with respect to its related concepts, was the possibility of differential treatment (of a negative nature) of HD affected residents. This related to the social context, the lack of resources, or the dominant culture of that care environment.

Firstly then, with respect to the social context it was noted that apart from the nature of the disease process itself, the question is raised as to whether the anomalous social effect of the disease, described by Nance and Sanders (1996), may be a key concept in understanding the difficulties. They pointed out that the HD affected residents are younger, with equal gender representation and have a serious medical diagnosis on admission. Unlike psychiatric or head injured patients, they have a progressive dementing illness, and unlike other dementia patients, they are young and have a severe movement disorder (p. 547). Not only are the care needs quite unique in that environment, but these disabilities usually occur before the age of 50 years so the interests and social needs of this relatively young group are quite different from those of the other, generally older,
residents. The result is that the residents with HD are often apparently misplaced and isolated due to their social environment. They are often nonconformist and deviant with respect to the social norms of the dominant group and for many of the less educated carers with respect to the characteristics of the disease, they are wilfully demanding and difficult. This scenario may be postulated to create an ambiguous or unclear situation for the carers, leading at times to insecurity and even confusion. Even with insight into this situation, the nurse-carers may be expected to find this situation frustrating and difficult because of conflicting care needs between this group and those of their other elderly charges. The natural inclination may be for the concept of social judgement to run its course and for negative staff attitudes towards the HD affected resident to be expressed in inferior care. The key concept under discussion here is that of the impact of a pluralistic social milieu on the care giving staff and of their responses to it.

The second dimension to the possibility of differential treatment of a negative nature, was the question of the contribution of the existing resources, including the physical dimensions of the care environment.

Lastly, the question of the possibility of the interaction of a number of underlying elements was raised, in which case it would be helpful to confirm their relative importance. This refers to the concept of the relationship of the component variables to the research phenomenon.

Finally, the review of literature on the subject leads to the conclusion that there is indeed a clear statement of a knowledge gap which could be filled by some new nursing research in HD.
2.7 Summary

Prior to moving onto a discussion of the conduct of the research in chapter three, a summary of the research process thus far is now given. The issue of concern was identified as relating to reported care difficulties of the resident with HD in aged care facilities. Wide reading around this subject demonstrated a significant knowledge gap with respect to the availability and appropriateness of various types of accommodation for people at a moderate to advanced stage of HD (2.3). This gap has definite quality of life implications for HD sufferers whose future accommodation is under scrutiny. Observations of dissatisfaction with psychiatric hospital care were noted by Barczak et al (1987), Gardham (1982), and Skirton and Glendinning (1997). The residential aged care environment for those with HD had also received some, but not much, attention (Nance and Sanders, 1996; Smith, 1998).

A strong case is therefore made of the need to provide reliable evidence on which to base decisions.

There is no doubt that the families are vocal in support of the specialist model (Kapp, 1987, 2002), but nowhere does it yet appear to represent a viable practical alternative to placement in generic facilities. The question may be as to how the scarce dollar should be spent to give maximum benefit to the sufferers. Such crucial decisions should surely be made on the basis of knowledge rather than on myth or hearsay. In other words, did the problem really exist as a widespread phenomenon to be addressed? Could it be that the presented difficulties had been exaggerated, or were individually staff specific, or even facility specific and due to personality clashes or other personal reasons?
Chapter 2: The Literature review

The evidence should clarify not only the extent, but also the depth of any demonstrated problem and should provide guidance for action to reduce or eliminate the problem.

Reflection on the outcomes of the literature search illuminated the research problem by providing some insights into the constituent concepts of the problem under scrutiny. It was seen that answers with definite clinical value could be provided to the questions posed above, by a well designed and rigorously executed piece of research into HD care in the aged care setting. The utilization of the existing specialist HD resources in NSW would provide an ideal base. The underlying belief was that the knowledge gained would assist in improving the quality of life for this group of individuals.

However, wider application of the findings was also anticipated. It may be that staff ambivalence would be demonstrated and some underlying reasons for this suggested. It may also be that this work in an aged care setting would support the notion of the nature of deviance as structurally determined or influenced. If so, however, questions would remain as to how closely the findings from general or psychiatric hospitals elsewhere would be replicated in the NSW aged care environment. These issues will be dealt with in later chapters of this thesis particularly in the discussion chapter with reference to the work of Judith Trexler (1996), and recommendations for further work.

The next chapter includes a statement of the aims and objectives of the research, and the research design and methodology employed to generate data that, by the employment of appropriate analysis methods, should meet these objectives and suggest answers to the questions, which have been posed.
CHAPTER 3 – METHODOLOGY

3.1 Introduction

The broad purpose of this study, as stated in the letter of invitation to participate, is to provide reliable data on the residential care of people with HD in NSW. This would be made available to the NSW authorities to assist in planning for the long-term accommodation needs of the approximately four hundred people with symptoms of HD in that state (Appendix B). The data would provide insights into the problems of providing care to those with HD who live in aged care facilities as well as suggestions as to how these difficulties might be overcome. This chapter describes how this was done. Firstly, the contextual constraints are noted. Then attention is given to the issue of ethics in the conduct of research. Next, details are given of the conceptual framework that underpins the study. The conceptual approach adopted “acknowledges the action orientation of nursing, and the richness of theorising alongside experience” (Robinson & Vaughan, 1992, p. 225). Finally, the research design and details of its undertaking are provided.

3.1.1 Contextual constraints

In response to the expression of interest by the Director of Nursing of Lottie Stewart Hospital in support of the undertaking of a nursing research project, a collaborative funding arrangement, the Nepean Summer Awards Scheme, was entered into. This joint support from the hospital and the University of Western Sydney, Nepean, enabled this current nursing research to be undertaken. The decision to participate was made at short notice with implementation to occur within weeks. As the HD Outreach nursing clinical role is a very demanding one, with little time for other than clinical
activities, it was imperative for the research to be a viable project that it would progress into the data collection phase during the three months’ appointment of the research assistant. However, this should not jeopardise adherence to the principles of rigor in its conduct.

It was noted in the literature review that little had been written about the problem under scrutiny. Although it could have been argued therefore that a qualitative research approach would have been the most appropriate methodology to adopt (Roberts & Taylor, 1998, p. 100), this was not the approach taken. Instead it is argued that the researcher’s experience was sufficient to enable the major methodological approach to be of a quantitative, deductive nature (Burns & Grove, 1997). This experience included two years of face-to-face, in-depth, problem-solving case study sessions with aged care nurses, many informal telephone consultations, as well as Outreach team conferences which generated appropriate care plans. However, in order to overcome the limitations imposed by the relatively superficial data obtained by written questionnaire responses, a qualitative approach was included, giving the overall framework that of a triangulated or “mixed methods” approach (Hammersley, 1992). The following section provides detailed information on the research design, which uses as its framework, the six generic elements proposed by Schantz and Lindeman (1982) in Skodol-Wilson (1989).

3.2 Maintenance of ethical standards

Having considered the problem from many angles, a practical approach to seeking answers systematically gave rise to a research proposal (Appendix C), which was given ethics approval in early 1998 by the Quality Committee of Lottie Stewart Hospital, a Schedule 3 hospital in the Western Sydney Area Health Service. Regular reports on
progress were also submitted to this committee. The proposal was underpinned by the following ethical principles, which underpin all reputable research and are considered in full in the following section: Beneficence, Non-Maleficence, human Dignity, Autonomy, Justice and Privacy. They are derived from the Nuremberg Code (Tranter, 1997). It was the researcher’s responsibility to ensure adherence to these principles at all stages of the process.

The principles of Beneficence, i.e. doing good, and Non-Maleficence or not doing harm are met if the expected benefits outweigh the risks. They include a commitment to dealing positively with unanticipated adverse reactions precipitated by the research process.

The principle of respect for human Dignity deals with the right to self-determination, or Autonomy. The notion of informed consent implies the agreement of the participant to take part in the study after all necessary information about it is given and understood (Burns & Grove, 1997). With respect to this last issue regarding disclosure of all necessary information, even at the risk of prejudicing the results by altering the phenomenon under scrutiny, all authorities consulted consider this the right approach (Roberts & Taylor, 1998; Skodol-Wilson, 1989; Burns & Grove, 1997).

Under the principles, Justice and privacy, the researcher should respect the rights of study participants with respect to anonymity, and confidentiality, as well as meeting their expectation to be treated fairly and with respect. These include issues of trust, honesty and the balancing of costs and benefits of the research, as well as an acknowledgement of the power balance that exists between researcher and subject, and which should not be abused.
The basic underlying belief in the research process as a scientific endeavour is stated strongly at this point. This includes an acceptance of the notion of the value of absolute honesty to uncover truth without any compromise to the wellbeing of all participants involved. It includes acknowledgement that all research is influenced by the beliefs and values of the researcher, which constitute a pre-existing framework to the endeavour. However, in order for the researcher bias to be minimised, this framework should be made public and the research process described fully so that the results can be judged accordingly. These principles were put into practice in the conduct of this research in the following ways:

The major research objective was to identify means to improve the care and thereby, the quality of life for those affected by HD.

Every effort was made to ensure no harm would ensue to the resident or the nurse-respondents due to any part of the research process.

All confidential material was stored securely under lock and key to ensure no access by anyone other than the researcher.

Anyone who assisted with gathering data or with clerical tasks understood these principles and agreed (in writing) to abide by them (Appendix D).

Informed consent was implied by the nurses returning the questionnaire. It had an information section carefully drafted to ensure the rights of participants were ensured. This included clear explanations of the research, assurances of confidentiality, and contact details for questions that might arise.

The questionnaire was distributed by the Director of Nursing of the facility, as requested in the explanatory letter from the researchers. This implied their support for staff wishing to participate.
Full disclosure of the purpose of the research was made in all covering letters, even though there was the potential for this to influence participants. This is acknowledged when discussing the results.

In order to ensure anonymity, identification numbers were used on the questionnaires. All information on the mail out lists identifying the facility was available only to the researcher. Any information derived from the Outreach medical records in order to cross check demographic information, was kept to the absolute minimum and stored securely with the other data.

During conference presentations or other forms of dissemination of the results, it was understood that no identifying information would be disclosed.

All data were stored in a password secure personal computer and backed up on the personal computer of the researcher, as well as on discs kept locked in a disc box in a locked filing cabinet under the control of the researcher.

This concludes a description of all the precautions taken to ensure the maintenance of ethical standards of research practice during all stages of the conduct of this study.

3.3 Theoretical framework of the study

In this section, as outlined by Greenwood (1996) Chapter 2, the concepts identified during the literature search as relevant to the phenomenon under scrutiny, are first noted. Then, in preparation for the next phase of the research, these concepts, having been further refined, will be restated as four major objectives, which will underpin the conduct of the research.
3.3.1 Key Concepts

The most visible concepts operating in the phenomenon under scrutiny are derived from clinically based observations of the behaviour of trained, nurse carers. These observations were made following a referral to the HD outreach service for help. During the ensuing contact, the nurses described their problems and frustrations while caring for younger than normal residents with changing medical needs. There are few known effective treatments for these problems and they provide care in a less than suitable environment for this purpose, compounded by the fact that their colleagues have little relevant education or experience to draw on either.

These concepts include those of: heavy workloads, knowledge deficiencies and stress (Healey & McKay, 1999), difficult patients (Kestler, 1991; Podrasky & Sexton, 1988; Wolf, Brennan, Ferchau, Magee, Miller-Samual, Nicolay, Paschal, Ring, Sweeney, 1997), labelling (Johnson & Webb, 1995; Stockwell, 1972), novice and expert nurses (Benner, 2001), occupational health and safety risk management (Western Sydney Area Health Service, OH &S unit 2001), and behaviour management in HD (Paulson, 1999).

The research problem can also be enlightened by reference to the sociological concept of role conflict (Parsons, 1951), between the nurses’ responsibilities to provide for the needs of their elderly charges and for the young disabled population of which the HD sufferer is one. Psychological concepts of helplessness and anxiety due to the insecurity of having to deal with undefined or relatively novel situations (Littlewood, 1991), and the concept of the management of ambiguity as inherent in the nursing role (Henderson 1978; Littlewood, 1991; Cioffi, 1997), have also been considered. Understandings were borrowed from sociological theories of deviance (Conrad and Schneider, 1980; Edwards and Wilson, 1975; Erikson, 1966; Kelly and Clarke, 2003;
Kittrie, 1971; Merton, 1968; Parsons, 1951; Roach Anleu, 1995). In addition, the concept of accidental deviance, (Lorber 1975, Trexler, 1996, ), as applied to healthcare settings, helped structure the approach both to the planning and undertaking of the research as well as to understanding the findings. These ideas are therefore, reflected in the title of the thesis.

3.3.2 The Objectives of the study

The broad aim of this study would be to understand the phenomenon of caring for people with HD in the standard aged care facility as reported by nurses within these facilities. As per the research proposal, (Appendix C), the insights sought would be as comprehensive, reliable and valid as possible; in order to assist in planning for the long-term accommodation needs of the (approximately) four hundred (known) people with symptoms of HD in NSW. Objectives derived from this goal are now listed.

Objective 1: To describe the profile of HD affected people living in aged care facilities in NSW.

Objective 2: To identify aspects of providing care for HD affected residents in aged care facilities that the nurse carers perceive to be unsatisfactory.

Objective 3: To test the appropriateness and adequacy of the facility’s staffing and other resources, and whether some of these represent barriers to optimal care for the HD affected resident.

Objective 4: To determine views on aspects of the HD nursing role: namely, its skill requirements, feedback on current methods of obtaining these skills and views of the
effectiveness and accessibility of the existing multidisciplinary services in supporting this role.

3.4 Research design

A mailed survey of staff in aged care facilities in NSW constituted the basic research method. The six elements of the framework as suggested by Schantz and Lindeman (1982) will now be discussed. These are the setting, the respondents, the sample, the treatment, the data collection method, and obtaining the results through data management and analysis.

3.4.1 Setting

The setting was a naturalistic one consisting of all NSW aged care facilities, both nursing homes and hostels which had, within the time frame covered by the study, accommodated a resident with a major diagnosis of HD. A total of 109 institutions were identified in 1998/99 as meeting these criteria, giving rise to a database, which formed the basis of the survey mail outs. These institutions were dispersed throughout metropolitan Sydney, the regional centres of Newcastle and Wollongong, and all areas of rural NSW. A sub-group of 12 facilities accommodated multiple HD affected residents (HD Clusters). Aged care facilities have a common administrative structure with nursing management by a Director of Nursing (DON) and patient care provided by trained registered nurses (RNs) who supervise enrolled nurses (ENs) and untrained nurses (AINs) who in turn give most of the direct patient care,

3.4.2 Participants

This study design identified two groups of participants to be studied. One group was defined as all residents with HD currently living, or within clear recall previously
living, in NSW aged care facilities. The other group of participants consisted of all nurses working in the study setting (3.4.1).

3.4.3 Sample

The sample consisted of all respondents who were included in the survey (3.4.4). They comprised two interrelated groups.

- The HD affected residents

Known as the Affected Resident Population, and accessed through the facilities in which they lived, the sample of 111 residents included all the HD affected residents, as defined above, as it was considered practicable to access the whole population. This was achieved by compiling the Facilities database from the current Outreach records, the pre-existing HD service records, and the Hunter Genetics service.

Therefore, whilst other measures could have been taken to attempt to locate other HD affected residents for inclusion in the study, it was considered that the potentially minimal increased numbers generated would not make this a cost effective exercise.

On this basis therefore it was proposed that the identified group of HD residents be considered as constituting the population of interest, and those residents about whom questionnaires were completed and returned, therefore, constituted the HD resident sample.

- The aged care nurses

The second group of respondents, consisting of one or more per facility, and by implication also one or more per resident, was selected by the Director of Nursing of the facility according to standardised instructions. (Appendix B)

The enrolment of as many respondents as possible was a strategy to reduce external threats to validity by increasing the size of the pool of responses. This would
also ensure the results of the survey would be as representative as possible of the views of all the nurses.

Enrolling, the multiple nurse-respondents per resident would enable an assessment of reliability to be undertaken.

3.4.4 Treatment

A cross sectional, mailed, correlational, descriptive, census survey was chosen as the most practical and cost effective method of obtaining answers to the research question.

This method was also justified as appropriate in response to the contextual constraints described in the introduction to this section, as well as to the geographic dispersal of the participants. Whilst it is acknowledged that first-hand observation by trained observers might produce information of greater depth and richness, this compromise was nevertheless expected to generate useful and accurate information for the purpose outlined. This was based on the assumption that registered nurses in NSW who, by definition, have some tertiary educational preparation, could be expected to have sufficient critical reflective ability and documentation skills to provide the information sought.

It was also noted that the nurses appeared to be highly motivated with regard to the challenge of HD care in their setting, which would offset the lower response rates often associated with mailed surveys. (Skodol-Wilson, 1989 p. 149).

Records were kept (the Mail out Master List) to enable cross-referencing of data on returned questionnaires.

The survey was conducted by six separate mail outs over the period 5/5/1998–10/6/1999 including a re-survey of non-respondents from the first mail out. The mail out
involved the distribution of a survey package to aged care facilities in the mail out master list.

The survey package included a stamped, self-addressed envelope, a covering letter to the Director of Nursing (Appendix B), two copies of the questionnaire per known HD resident, and a copy of The NSW Huntington Disease Service brochure (2001).

3.4.5 Data collection method.

A significant feature of the design of this survey was the development of a custom-designed questionnaire. As an integral part of the research process, this important preliminary to the data collection proper, will now be discussed (Appendix E).

3.4.5.1 Preliminaries: Custom-designing the questionnaire

The decision to custom-design the questionnaire was taken because the search for existing tools to gather the required information and to measure the opinions of interest was not fruitful. Another early decision was to adopt a triangulated approach which would include both fixed choice and open-ended questions. According to Bull and Hart (1995), this triangulated approach produces richer research data and outcomes. The inclusion of open-ended questions enabled responders some freedom of expression of opinions and ideas.

In order to ensure the questionnaire met accepted research standards, a considerable amount of time and energy was invested in its construction.

Designed by the closely supervised research assistant this process involved balancing simplicity of expression, the need to include as much as possible, and at the same time ensuring that for respondents, its completion would take no more than 40 minutes.
The questionnaire design process utilised a qualitative approach that adhered to the ethical principles discussed in 3.2. The goal was to design a questionnaire that would be effective in meeting the study objectives (3.3.2).

To this end, a randomly selected sample of four expert HD registered nurses (from both aged care facilities and the HD specialist residential unit) participated in four audiotaped semi-structured interviews (Appendix E). The purpose was to identify topics considered by these experts to reflect the four study objectives and issues of concern to nurses caring for residents with HD. As they represented the potential users of the questionnaire, this process would promote content validity of the document.

Content analysis of the taped interviews (Skodol-Wilson, 1989, p. 470) identified the following eight themes that are arranged in descending order of frequency.

- Accommodation of patient or resident
- The specialist facility unit
- Funding
- Details of the needs of the HD affected person
- Specialist care
- Safety measures
- Staff education and training
- The value of experience

This information was a key component in decisions regarding the content of the finalised questionnaire.

3.4.5.2 *Utilisation of the finalised questionnaire*

The finalisation of the questionnaire followed administration of an advanced draft as a pilot to five senior registered nurses with some experience or knowledge of HD
nursing but not eligible for inclusion in the survey. Their task was to complete the questionnaire for an imaginary patient and to identify ambiguities, inconsistencies, grammatical errors and potential problems with data entry or analysis due to layout or lack of clarity of instructions. The quite extensive written feedback from these reviewers was discussed and many changes made. This draft was then reviewed by volunteer outreach team members to assess face and construct validity. In all, ten drafts were written prior to the first mailout. Returned copies from the first mailout were also scrutinised for obvious problems by the users, and approximately three minor corrections were made to this version.

Following analysis of these results, the work in progress was presented at a local advanced practice research seminar for peer review. The results received positive feedback and there was encouragement from nurse academics to proceed further and complete the work.

The final questionnaire consisted of 76 questions arranged in six parts. They included a range of question options including fixed choice, questions requiring rating on a 4-point Likert scale, multiple choice responses, and open-ended questions which were associated with specific fixed choice questions. Nominal, ordinal and interval level data, as well as qualitative data would thus be generated. The questionnaire included questions pertinent to all four study objectives. It was a comprehensive document providing demographic facts, self reported views on nursing care, opinions on the performance of the facility and on the perceived effectiveness of the HD outreach services.

The final questionnaire was called: "The institutional care of people with moderate to advanced Huntington Disease—the essentials in the components of care" (Appendix F).
The administration of the questionnaire was delegated to the DON of the Aged Care with clearly written instructions (Appendix B).

3.4.6 Data management and analysis

This process involved coding the written responses on the questionnaires, entering this information into an established statistical database (Statsoft Statistica), and using this computer software to analyse the data using appropriate tests to produce meaningful results. These statistics were then interpreted to generate the meaning of the phenomenon under scrutiny.

The database was set up with the assistance of the University statistician who also advised on statistical matters not able to be resolved using texts or by the academic supervisor. Data entry followed the routine conventions of the program.

As the analysis progressed, several data subsets were created to enable additional analysis of derived measures to be undertaken. These included the Resident demographics subset, Nurse-respondent subset, Specialist nurse contact subset, Barriers to care subset, Outreach not essential subset and Disapproval of care subset.

Both descriptive and inferential statistics to provide information on the spread or dispersion of the data, and summaries of the data, both numeric and graphic, using frequency distributions were undertaken. If appropriate, relationships between measures were sought using the Pearson product-moment coefficient (Pearson $r$), and Phi (Nominal data).

This completes discussion of the research design. The following diagram (Figure 3.1) below was devised to clarify the detail of the components of the research design.
The setting for the research
A total of 109 in NSW, with current or recent HD affected residents, were sent the survey. 5 had more than 1 resident with HD.

The measurement tool
This was a questionnaire and included fixed choice (quantitative data), and open ended (qualitative data), questions. It was derived from a qualitative study using face to face interviews to identify issues of concern.

The respondents
90 aged care nurses completed the questionnaire.
They represented 59 institutions.
There were one or more nurses per institution.
They were selected as those “most able to give an informed opinion of HD care.”

The HD affected population
A total of 110 residents with HD constituted the affected resident population.
63 constituted the resident subject sample.
There were 15 who lived in a facility (HD Cluster) with one or more other residents with HD.
11 had lived in more than one facility included in the survey.
9 lived in a hostel, 54 in a nursing home.
17 (27%) were 50 yrs or younger
34 (54%) were 60 yrs or younger
40% male 69% female
21 had multiple nurse reporters

FIGURE 3-1 COMPONENTS OF THE RESEARCH DESIGN
3.5 Measures of reliability and validity

The issues of reliability and validity were central considerations in the conduct of the research. Procedures to ensure the highest standards included the following.

Firstly, there was the adoption of a triangulation methodology in order to minimize investigator bias (Roberts & Taylor, 1998 p. 165).

Secondly, to ensure standardised recruitment of respondents, the provision of full and unambiguous instructions in the letter to the Directors of Nursing on the recruitment of survey respondents, was included. This letter stated that those completing the survey should be "the Director of Nursing, or other relevant staff....Choose the person/s with the most knowledge of the resident." Including unambiguous instructions and the involvement of a key person in each institution were strategies to reduce the possibility of variation in the criteria applied to the choice of a nurse-respondent. This was done to create the conditions where each nurse-respondent would have an equal chance of completing a questionnaire. External influences, which might affect the likelihood of the DONs participating in the research, were controlled by the standardised invitation to do so.

3.5.1 The interrater consistency study

Reliability, or the extent to which consistent results can be achieved on repeated undertaking of the research project (Roberts & Taylor, 1998), was assessed by comparison of responses from multiple respondents from the same facility and represented an alternative to a test/retest method.

As discussed in the research design (3.4.3), it was hoped that more than one nurse would report on each HD affected resident, by completing a questionnaire. This occurred
in 21 cases and these responses formed the basis of this interrater consistency study designed to provide information on the reliability of the data gathered.

A subset of those nurse-respondents, who reported on more than a single resident, was created. The questionnaire relating to each of these respondents was placed in a named (alphabetical) group along with the other questionnaire/s relating to the same resident. Following removal of those questions referring to factual, including demographic, information, the responses within the group were compared for agreement or congruency and the results recorded on a reporting schedule (Appendix G). To simplify the process of assessing congruency, the four groups of three and four respondents respectively were removed leaving only pairs of respondents (17) who had reported on the same resident. The total number of paired responses was 618 and the total number of congruent pairs was 477.

To calculate the value of the interrater reliability index, the number of congruent responses was related to the total number of responses made. Thus, $477/618 = 77\%$

This is an indication of a high level of consistency among respondents, which suggests that the instrument performed with consistency across users.

3.5.2 Criterion-related Validity

The issue of whether the instrument and research study measures what is claimed has many components. Reporter bias is an important one. Instrument validity is another one. In other words, does the questionnaire elicit responses that mean what they appear to mean and from which we can therefore make deductions or generalisations about the larger group represented by the sample? The following study was undertaken to provide a measure of criterion-related validity of the constructed tool by comparing a measure of one part with objective data from another source (Appendix H). According to Skodol-
Wilson, 1989 (p.357), this should be considered as a type of Criterion-related validity as it compares responses to the questionnaire to those from another, more credible, source.

The measure selected for this scrutiny was the frequency of affirmative statements by the nurses of having had contact with an HD specialist nurse. A new measure, called “Recorded specialist nurse contact”, was based on the Outreach service records of the specialist nurse having had contact with HD residents and their carers. The nurse-respondents who reported having had contact with a nursing specialist were compared with the record of contact by the nurse specialist with the related HD resident/s, the facility, and / or the actual nurse carer in question. Based on the comparison, both Discrepancies and Agreements were noted and tallied.

According to the responses of 67 nurses, there was an over-reporting of contact by 6% of respondents. This conclusion was based on their identification from the master facilities database as working in facilities that, at that time, had never been visited by the HD nurse specialist. There was, however, a consensus rate of 70%. On the other hand, 58% of the respondents reported contact with an HD specialist nurse, whereas the Outreach records indicated that 73% of the residents reported on by the nurses in the sample, and by implication, staff in the same aged care facility, had had contact with the specialist nurse. In other words, 15% of the nurses did not personally report contact although there had been contact with the facility. This indicates an underreporting rate of 15%. On the other hand, it could be argued that with respect to the pronoun “you,” the question “have you had contact with an HD nursing specialist?” was ambiguous and could be interpreted as referring either to the respondent personally or the facility.

Taking into account the discrepancy described above, it nevertheless seems acceptable to report a criterion-related validity rate of 70–94% for this study, which to the
researcher appeared to be an acceptable indicator of the tool measuring what it purports to measure. On the other hand, it highlights an ambiguity with regard to the wording of that particular question.

### 3.5.3 Ensuring rigor for the qualitative analysis

The process of analysing the qualitative data generated by the questionnaire was by a method of content analysis. Effort was directed at ensuring a rigorous approach that would reduce researcher bias to a minimum and promote repeatability. Hammersley, (1992) cited in Nolan (1995), proposes that rigor in qualitative analysis should be judged against criteria related to the following questions:

- Firstly, are the claims consistent with empirical evidence and are examples of the evidence supplied?
- Secondly, how credible are the results to those studied?
- Thirdly, are the results transferable to other settings?
- Finally, is the impact/influence of the researcher and the research process on the results accounted for?

Answers to these questions should establish a view of the trustworthiness of the results. A clearly described “decision trail….indicating research decisions and influences should be present throughout the study and the entire study should function as an inquiry audit” (Koch, 1994 p.978). These principles underpinned the methods used to analyse the words of the nurse-respondents to the open-ended questions. In particular, efforts were made to ensure an unambiguous decision trail for the reader of this research through the inclusion of examples of all methods and stages of the analysis.
3.6 Data Analysis

This account of the statistical analysis of the data generated by the survey, includes details of the process for both the quantitative and qualitative data, using a personal computer and appropriate software.

3.6.1 Quantitative data analysis

This includes both computerised statistical analysis and manual analysis of the responses in the database.

3.6.1.1 Data entry

The 70 questions in the questionnaire (Appendix F), yielded measurements regarding various aspects of providing care for the HD resident in the facility. Sixteen questions relating to a single or group of fixed choice questions were open-ended, producing text for content analysis. Of the remainder, 54 questions yielded nominal, 8 yielded ordinal, and 8 yielded interval measurements. All items related to one of the 4 research objectives stated in 3.3.2.

For those questions that sought opinions, or individual views, data was entered for all 90 nurse-respondents (cases). On the other hand, information on the resident profile was entered into the demographics data set for the 63 individual residents in the sample.

The coding of responses was done at the time of data entry from a pre-coded questionnaire template to ensure uniformity. Ambiguous responses were discussed with the research supervisor before data entry. To ensure an acceptable degree of accuracy, the coded responses were checked several times during the whole research process.

Once the database was complete, data “cleaning” was undertaken. This included the entry process, which was checked for accuracy by comparison of a random selection of questionnaires against a printout of the data set, and errors corrected. The printout was
also inspected visually to identify the omission of data and for any obvious departures from what would be expected. Following relevant alterations, the analysis proper then proceeded. The results are reported in Chapter 4.

3.6.1.2 Data analysis using statistical tests

The complete data set was summarised by computing frequency values for each measure. Graphic representation by histogram or pie chart was used to highlight the relative values.

Descriptive statistical measures (mean, median and mode), were used to provide measures of central tendency and to enable estimation of closeness to a fit to a normal distribution. The results for those questions which quite closely approximated the normal distribution curve, were noted as fulfilling the criteria for inferential statistics, and therefore statistical relationships between these measures were sought. The Pearson product-moment correlation Index (r), Chi-squared and Cramer’s Phi were the measures used.

3.6.1.3 Analysis of selected subsets by visual scrutiny

Questions with highly skewed distributions (Healy & McKay, 1999), led to additional analysis of these subsets as potentially they could present discriminatory variables representing extreme views. The analysis included a review of the raw data, both quantitative and qualitative, of some selected subsets. These results are presented in 3.5.2, 4.2.3.13 and 4.2.5.11, and others are discussed in 6.5.3.1 and 6.5.4.5
3.6.2 Qualitative data analysis

3.6.2.1 Content analysis method

The qualitative data, in the form of written responses by the nurse-respondents to 16 open-ended questions related to key fixed choice questions was content analysed using Microsoft Word software. The questions had space for two or three lines of writing and the purpose was to give respondents the opportunity to explain their point of view in their own words.

Essentially the analysis involved reducing the transcribed data into constituent segments (usually a phrase, which, for convenience will be known as a language unit), coding these into mutually exclusive categories based on the context of the question, and collating the categories to suggest meaningful topics or themes for the question generating the data.

The process of uncovering the meaning is derived from that described by Skodol-Wilson (1989, p. 473) as “The Unfolding Tributary Method of Evolving Categories,” whereby the categories are extracted from the data rather than being pre-determined. Both the “semantic” or obvious meaning, and the feeling tone or inferred content were considered in the process.

Firstly pre-coding, or data preparation, was a method of identifying the language units to be coded and sorted, secondly coding involved giving the unit some identification, thirdly collating the units into categories involved combining them with other units of similar meaning (Figures 3.2 and Appendix I), and finally summarising the content of groups of like categories by counting, totalling, and paraphrasing the meanings of the concepts under a heading that described the overriding theme. For a summary of all themes see Appendix J and for a full description of the method see Appendix I.
An example of this process is shown in Figure 3.2 on the next page. The figure illustrates the sorting of the words units into categories and then themes. This example shows data generated by the question regarding ratings of staff care for the HD resident. Having first been categorised as "elements of more adequate staff care," the words were collated and placed in mutually exclusive categories in text boxes, each representing a constituent theme. The following themes were described by the nurses:

- Goals of care delivery
- Strategies to meet organisational objectives
- Organisational attributes
- Equipment
<table>
<thead>
<tr>
<th>Goals / Objectives of care delivery</th>
<th>Strategies to meet care objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>All residents receive same high standard of care</td>
<td>Basic needs: Physical needs are met + All needs met +</td>
</tr>
<tr>
<td>Prevent preventable clinical deterioration</td>
<td>++ Meeting individual needs Monitoring of needs</td>
</tr>
<tr>
<td>Maintenance of functional abilities</td>
<td>High standard of personal hygiene + +</td>
</tr>
<tr>
<td>(ADL) Strategies to counter deficits +, maintain independence + + +</td>
<td>Environment adapted (for needs) + +</td>
</tr>
<tr>
<td>High standards of care +</td>
<td>Meeting nutritional needs of resident ++</td>
</tr>
<tr>
<td>Satisfactory care outcome for resident &amp; family more likely with ongoing education</td>
<td>Close supervision +</td>
</tr>
<tr>
<td>Adequate staff care giving includes resolving problems</td>
<td>Skin integrity through P.A.C. +</td>
</tr>
<tr>
<td>Organisational attributes</td>
<td>LMO kept informed of problems +</td>
</tr>
<tr>
<td>(Not under control of care giving staff)</td>
<td>Timely medical response</td>
</tr>
<tr>
<td>Adequate staffing for safe interventions +</td>
<td>High standard of grooming</td>
</tr>
<tr>
<td>Sufficient time allocated</td>
<td>All care given</td>
</tr>
<tr>
<td>Equipment</td>
<td>Single room</td>
</tr>
<tr>
<td>e.g. Facility has sufficient equipment</td>
<td>Monitoring of care given</td>
</tr>
<tr>
<td></td>
<td>social interaction</td>
</tr>
<tr>
<td></td>
<td>1:1 activities</td>
</tr>
<tr>
<td></td>
<td>counselling (emotional support)</td>
</tr>
<tr>
<td></td>
<td>Family made welcome</td>
</tr>
<tr>
<td></td>
<td>Note feedback (verbal and non verbal) from resident</td>
</tr>
</tbody>
</table>

Note * = additional instances of the same phrase

**FIGURE 3-2 ILLUSTRATION OF CONTENT ANALYSIS : THE USE OF TEXT BOXES**
3.6.2.2 Deriving meta themes for core opinions

Having analysed all sixteen open-ended questions, the results from all were combined in an effort to extract maximum meaning from the data. This last level of abstraction endeavoured to uncover what were termed meta-themes, from the data. A meta-theme comprised themes with similar meaning from several different questions. These over arching generalisations identified the topics of primary interest to the nurses as a whole. Firstly, the 16 questions were classified as either “Probes,” (7) or “Openers” (9). Probes had been designed to obtain more information on specific topics, whereas Openers were included to give the respondent the maximum freedom to express their views. The results from this last group were considered likely to provide evidence of the issues of primary concern to the nurses. Therefore, the themes generated from all the Openers were examined, collated and placed in mutually exclusive categories according to the information they represented. The frequency of each of these was considered an indicator of the overall level of interest of the nurses in this subject. The results of this analysis are incorporated, as relevant, into discussion of the findings related to each of the four research objectives.

Further discussion of the principles guiding the analysis process is now presented.

Coding involved making decisions about the meaning of the language units. The overriding consideration was what the respondent was attempting to convey in the context of the question. An attitude of openness was cultivated to reduce researcher bias. Precise meanings of words used by respondents were obtained from an Australian dictionary (Knight, 1997) and texts on Huntington Disease. Awareness was maintained of the semantic meaning of the words as written, as well as of the underlying or intended meaning in the context of the question and the common usage of some words by this
particular group of respondents. In some cases, this meant interpreting meaning contrary to the actual words to make sense of the response, as it was assumed in the light of the rest of the response that the respondent had omitted the clarifying word for the sake of brevity.

In order to uncover meta-themes from the qualitative data a further analysis was undertaken to derive over arching generalisations regarding the topics of primary interest to the nurses. Firstly, the 16 questions were classified as either “Probes” (7) which had been designed to obtain more information on specific topics, or “Openers” (9) which were included to give the respondent the maximum freedom to express their views. The results from this group were considered likely to provide evidence of the issues of primary concern to the nurses. Therefore, the topics generated from all the Openers were examined, collated and placed in mutually exclusive categories according to the information they represented. The frequency of each of these was an indicator of the overall level of interest of the nurses in this subject. The results are incorporated into discussion of the findings related to each of the four research propositions.

As the final contribution to this section, a brief description is now given of the physical technique used to code and sort the words of the nurses.

In order to visualise as much text as possible simultaneously, thereby aiding in conceptualising the data, and after unsuccessful trials of alternatives, a novel method was developed to achieve this goal. The font of the text was reduced to size 8, and the line spacing was reduced to single, and by using the text box function in Microsoft Word the words were able to be sorted to fit onto a single page. They were then sorted according to their meaning into text boxes with those of similar meaning and the categories thus created were named. These could then be condensed into themes.
This completes the description of the methodology employed to meet the study objectives. Chapter 4 provides information on the results of the data analysis, which is presented according to which of the four research objectives the data illuminates.
CHAPTER 4 THE RESULTS

The details of the responses to the mailed survey of the NSW aged care institutions with a resident with HD are presented first. The next section of the chapter reports the results of the analysis of the data generated by the questionnaire, *The institutional care of people with moderate to advanced Huntington Disease—the essentials in the components of care* (Appendix E).

The discussion throughout the rest of the thesis will demonstrate how the data generated by the research answers the research questions by meeting the four research objectives as presented in 3.3.2.

4.1 Survey responses

The research design (Section 3.5, Figure 3.1) identified three components to the survey, namely the aged care facilities, the HD affected residents, and the nurse-respondents. The results related to these are now presented together with details of the relationships between these components.

4.1.1 Aged care facilities

In response to the survey, nurses working in 59 facilities returned 91 completed questionnaires. This represents a 54% return rate for the 109 facilities invited to participate, and an average of 1.5 per facility. Of the non-participants, three DONs stated in writing that because they had never accommodated an HD affected resident they had been surveyed in error.
4.1.2 HD affected residents

Of the 111 (3.4.3) known HD affected individuals in aged care facilities in NSW at the time, questionnaires were completed on 63 (57%).

Ten residents had relocated between institutions within NSW during the survey. Eight HD residents had lived in two of the facilities surveyed and two HD residents had lived in three facilities.

4.1.3 Nurse-respondents

A total of 91 nurses returned a completed questionnaire. One respondent’s questionnaire was eliminated following initial scrutiny because insufficient questions had been completed, making the final sample size 90 nurses.

Additional knowledge of the nurses as respondents was ascertained in the nurse-respondent accuracy study reported in Chapter 3.

4.1.4 HD clusters

It was assumed that accommodating more than one HD affected resident would have implications for both staff and residents; therefore, the details of numbers both in the population and in the sample are reported.

From the outreach records it was known that 12 out of 109, or 11%, of the total number of facilities surveyed accommodated multiple residents. These were known as “HD clusters.” On the other hand, eight out of 59, or 14% of the facilities in the sample, were HD clusters. From the outreach records, the number of HD affected residents in each cluster was known to vary from two to four per facility.
4.1.5 Multiple reporting figures

In line with the design (3.4.2), more than one nurse-respondent completed a questionnaire on the same HD affected resident.

The HD affected resident to nurse-respondent ratios of the sample were as follows. In 42 cases, there was 1 nurse-respondent per resident, described as single reporters (47%). In 17 cases 2 nurses responded on one resident (34 nurses); in two cases 3 nurses responded on one resident (6 nurses) and in two cases 4 nurses responded on each resident (8 nurses). Adding these last four instances together, 48 nurses (53%) are described as multiple reporters.

Ninety nurses reporting on 63 residents represent an average of 1.44 nurse-respondents per resident.

4.2 Responses to the questionnaire

4.2.1 Introduction

Prior to presenting the results of the analysis of the data that were generated by the questionnaire some general points are made. Referring to topics with recurring relevance, this is done to reduce the need for repetitive explanatory text.

- The number of missing responses varied from one analysis to another, and the results show only the numbers of nurses who provided valid answers. Therefore the sample sizes vary from one analysis to the other.

- Another reason for variation in the reported sample sizes in this section lies in the following feature of the research design. The research design (3.4) dictated that the results were based on two basic data sets. The main data set included
information from all nurse-respondents where multiple opinions were required on the characteristic being scrutinised. The demographic subset on the other hand, related to independently verifiable information such as the resident’s age or address location, and was based on the sample of HD affected aged care residents who were cared for by the nurse-respondents.

- Standard abbreviations for statistical terms have been used throughout.
- The significance level of $p<0.05$ has been used as the criterion for statistical significance throughout.
- Percentages have been rounded to the nearest whole value so may not total 100%
- In order to maintain anonymity, any names included are pseudonyms.
- In order to facilitate retention and comprehension for the reader, the results of all analyses of the same question, including open-ended questions are presented in conjunction with the results of the corresponding fixed choice question, followed by details of any statistically related measures.
- When presenting the measures that are statistically related, the research objective to which each individual measure refers, will be indicated.
- The terms “nurse-respondents” and “nurses” are used interchangeably throughout this chapter.
4.2.1.1 Responses to the open-ended questions

In general, the response to the open-ended questions was considered good. In terms of the number of respondents who provided information, this varied from 62 to 14 respondents per open-ended question. In terms of the amount of information written by the nurses for each of these open-ended questions, the most productive was that requesting details of the signs and symptoms of HD of their resident. The least productive question related to views as to whether the facility catered for all the essential needs of the HD affected resident.

The results of the final stage of the qualitative data analysis involved deriving Meta themes from those open-ended questions designated as Openers (3.6.2.2). Seven meta themes were derived from these pooled results. Presented from the greatest to the least percentage of the data they represent, they were:

- Affirmation of needs being met, staff managing
- The specifics of the disease and its management is the problem
- Staffing resources are unsatisfactory
- The environment is unsatisfactory
- Statements of the need for specialist skills or other resources
- Factual details and additional information
- The social mismatch of the Cuckoo in the Nest

4.2.2 Objective 1: The affected resident profile

The goal of the first objective was to describe the profile of HD affected people living in aged care facilities in NSW. The following results give a picture of the 63 people with HD in the resident sample. The description has three main components: the resident’s demographic profile, the psychosocial profile, and the physical profile.
4.2.2.1 *The demographic profile*

This section provides an overview of the identifying characteristics of the sample of HD residents.

- **Age**

The age of HD residents ranged between 30 and 85 years, the $M$ of the sample was 58.39, the Mdn 58, and the SD, 13.55 ($N = 63$). The size of the SD indicates a more dispersed distribution around the mean. On the other hand, the mean and median are very close in value, a characteristic of a normal distribution. The frequencies are shown in Figure 4.1 below with a normal distribution curve superimposed. The sample distribution is seen to follow the curve quite closely. It should be noted that this age distribution is abnormal for the average aged care facility.

![Histogram of ages of HD residents in sample $n = 63$](image)

**FIGURE 4-1 AGES OF HD AFFECTED RESIDENTS IN YEARS**
Age was seen as a key demographic variable for the study. Using figures from an Australian Institute of Health and Welfare: Department of Health and Family Services (1996) publication for the aged care population, the ages of these residents were compared with the ages of the HD affected residents in the sample. (see Appendix K for more detail). The result is summarised in Table 4.1. This indicates that, with respect to this important characteristic, the HD resident is very different from most other residents with whom they live.

**TABLE 4.1 AGE RELATED INFORMATION ON NSW AGED CARE RESIDENTS**

<table>
<thead>
<tr>
<th>Aged care residents</th>
<th>% residents ≥ 65</th>
<th>% residents &lt; 65</th>
<th>Total number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>All residents</td>
<td>94</td>
<td>6</td>
<td>28708</td>
<td>100</td>
</tr>
<tr>
<td>HD affected residents</td>
<td>36</td>
<td>64</td>
<td>111</td>
<td>100</td>
</tr>
</tbody>
</table>

From these figures, it can be calculated that HD residents make up 0.4% of the population of nursing home residents in NSW. We can also see that the percentage of NSW nursing home residents under 65 years is only 6%, whereas the percentage of HD residents under 65 years is 64%. Therefore, in NSW nursing homes, there are approx 11 times more HD affected residents under 65 than those not having HD. Figure 4.2 on the next page illustrate these findings as pie charts.
FIGURE 4-2 HD AFFECTED AGED CARE RESIDENTS ARE YOUNGER THAN OTHER AGED CARE RESIDENTS
Relationships between the measure the *Ages of the HD affected residents* and other measures (3.6.1.2) will now be discussed. There was a moderate correlation between the increasing age of the HD affected resident and the nurses’ views of the *appropriateness* of the facilities ($r = .51, p = .0001, N = 46$). These results show that the younger the age of the resident, the lower was the rated appropriateness of the facilities. This supports the notion that the relative youth of the resident is associated with increasing dissatisfaction with the overall suitability of the facility as reported by the nurse-respondents.

Using Chi Sq and Cramer’s Phi test, Table 4.2 demonstrates the relationship between the *youth of the resident* and the nurses’ *preference for an HD diversional therapist*.

| TABLE - 4.2 RELATIONSHIPS BETWEEN PREFERENCE FOR HD DIVERSIONAL THERAPIST AND YOUTH OF RESIDENT |
|---------------------------------|-------------------------------------------------|--------|---|---|
| Relative youth of the resident  | Preference for HD diversional therapist         | $\chi^2$ | $\phi$ | $p$ |
| (< 60 years)                    | Yes                                             | No     |     |    |
|                                 | N %                                             | N %    |     |    |
| Resident < 60 years             | 40 68                                           | 10 60  | 5.63 | .26 | .017 |

Of the nurses who stated a preference for the specialist in leisure activities, the large majority (68%) were reporting on a resident younger than 60 years. This relationship was of a weaker nature but the Chi-square value was within the 97.5% probability of not being due to chance.

- Gender

The sample consisted of 60% female, and 40% male residents. This is in spite of the fact that the disease has been shown to affect males and females equally as the chromosome responsible is an autosome (not gender linked).
• Gender combined with Age

In order to seek understanding of the unexpected result presented under Gender above, the figures for Gender combined with Age were examined. The results showed that for the sample of HD affected residents, 24% were female and \( \geq 65 \) years; 37% were female and \(< 65 \) years; whereas 14% were male and \( \geq 65 \) years, and 25% were male and \(< 65 \) years. Expressed as ratios, the younger age group of both sexes, \((1.4 : 1)\), was closer to the expected 1:1 than for the older age group of both sexes \((1.7 : 1)\). This means that while HD affected women of all ages appear to be overly represented in residential care as compared to HD affected men, this applies more to the older group than to the younger group.

As a comparison, the distribution according to Gender and Age was also examined for the whole group of all aged care residents. This showed that when all residents were included, the younger men \(< 65 \) years), represented 25% and the younger women represented a similar percentage of 24% of the whole. This means that compared to young aged care residents with other conditions, young women with HD are overly represented.

• Address

This identifies whether the person lives in a rural or metropolitan facility. There are two possible definitions of “rural.” The first, based on commonly experienced usage, defines addresses outside of the Sydney metropolitan area as being in regional or rural NSW, in which case 61% of the sample \((N = 63)\), lived in the metropolitan area. The second, based on NSW Health Department guidelines, defines Metropolitan as including
the regional centres of Newcastle and Wollongong, the outer Area Health Services of Wentworth, Central Coast and South Western Sydney as well as the commonly accepted Sydney areas. In this case, 81% of residents (N = 63) would be classified as residing in metropolitan areas, with 19% considered as having a rural address. In either case, the majority resided in metropolitan locations, and at least 19% (or 39% using the broader definition of rural), were living in clearly defined rural locations.

- Type of accommodation

According to the Commonwealth Department of Ageing and Aged Care booklet (2001), "Aged Care Assessment Teams giving you the choices," entry to residential aged care, for either Low level (hostel), or High level (Nursing Home), is dependent on an assessment by an Aged Care Assessment Team (ACAT). It is their responsibility to approve the application and decide which level of care is appropriate. In the current study, 86% of the HD affected residents were accommodated in nursing homes whereas the remaining 14% were living in hostels. Nursing homes are defined as facilities providing 24 hour, high level nursing care. Some staffing implications of this finding will be discussed in 4.2.4.3 related to Objective 3; To test the appropriateness and adequacy of the facility's staffing and other resources, and whether some of these represent barriers to optimal care for the HD affected resident.

- Relocation history

Included as an indicator of failed admissions due to insurmountable difficulties in providing care for HD affected residents, information was available on 58 HD residents. Of these, 11 HD residents (19%), had lived in multiple facilities since being placed in institutional care. They had lived in from two to three facilities each. Ten of the 11
individuals, who had relocated, had done so (as recorded in the outreach medical record) because of specifically identified problems. Similarly, only one was known to have moved from a hostel into nursing home due to increased care needs.

4.2.2.2 Physical profile

The following information refers to disease related physical features and their functional effects.

- Functional ability

Firstly, in response to a general question about functional ability, there was a predictably affirmative response by 99% of respondents \( (N=85) \) that the HD affected residents had many difficulties with activities of daily living. As a global measure of comparison with respect to providing nursing care, the dependency ratings of the residents are now given.

- Dependency rating

On a five-point scale, the nurse-respondents \( (N = 86) \) gave an indication of the greatest number of staff required for any nursing activity. This indicated the workload associated with these residents. Two nursing staff reportedly could manage most (45%) residents, and 32% needed three staff. As an indicator of how intensive the care needs were, 6% needed 4 or more nurses for some care. A single nurse was considered sufficient for only 18% of HD residents. The mean number of nurses required was about 2 \( (M=2.28, \ SD = 0.88) \). Further analysis of the Hostel subgroup \( (N=12) \) indicated that for these residents (by definition assessed by the Aged Care Assessment Teams as requiring lower level care), six reported that 2 nursing staff were needed at times and one, reported the need at times of 3 nurses. Whilst this is consistent with the description of the residents as requiring less assistance from staff than in the Nursing Home setting, the finding that
over half were judged to need more than one staff member at times should be considered significant. In practice, the ready availability of a second nurse to assist could vary depending on such factors as the time of day and size of the facility.

With respect to relationships with other measures, a moderate to high positive correlation was noted between the dependency rating of the resident and the rated immobility of the resident. \( r = .63, p = .000 \ N = 46 \). This means that the more dependent the resident, the more immobile they are likely to be; conversely, the less dependent, the less immobile.

- Immobility

As an indication of the disability of the residents, a 4-point scale measured nurse-respondents' ratings of the Immobility of the HD affected resident. Twelve percent of the nurses rated their resident's mobility as *Very mobile*, 27% rated it as *Mobile*, 18% rated it as *Slightly mobile*, and 43% rated the mobility of the resident in their care as *Immobile* \( N = 74 \). These results indicate that most nurses rated the residents as being towards the Immobile end of the scale. On the other hand, nearly one third chose the most mobile category. To illuminate this finding it was noted that inspection of the data regarding Type of accommodation (Hostel or Nursing Home) indicated that the Hostel subset varied from the rest of the cohort on this measure. Thirty percent of the hostel-based respondents \( N = 12 \) rated the mobility of their residents as Very mobile, 50% chose the Mobile category and the remaining 20% chose Slightly Mobile. These findings are consistent with the Federal government system of categorisation for subsidised entry to Hostel level care.

The relationship of this mobility measure with that indicating the rated dependency of the residents was noted in the preceding section.
• Weight of HD residents

Of the 83 nurses responding to this question, most (68%) rated their resident as “underweight.” However, 12% gave an “overweight” rating, with 20% scoring “normal.” No significant relationships were found between this measure and other comparable ones.

• Observed communication problems

As a major indicator of whether the time needed to provide for the needs of residents might be above the average, almost all, (92% of 88) nurse-respondents reported that communication problems were experienced with the HD affected resident in their care. This is consistent with the natural history related to this stage of the disease and has complex causes including both muscular deterioration and cognitive changes.

• Observed swallowing problems

The great majority (89% of 87 nurse-respondents), reported that the resident in their care had swallowing problems.

• Dietary modifications

Answered by a smaller number of respondents (N=63) than most of the other questions, only 68% (by comparison with the above the rate) reported that the resident ate a texture modified diet (which is the standard intervention for patients with dysphagia).

4.2.2.3 Psychosocial profile

The following information relates to HD specific features of first the social, and then the emotional and cognitive functioning of the residents being described.

• Social functioning of the HD resident
Of 71 nurse-respondents, just over half (56%) acknowledged social problems for the resident or their family. On the other hand, 85% (N=82), indicated that the patient had contact with their family. This information was amplified by responses as follows to the related open-ended question.

There was about 1.5 times the amount of material written for the theme of “Positive observations of family contact”, compared to the theme of “Negative observations of contact.” The following is a typical example of a positive statement made by a registered nurse in a rural nursing home regarding a 36-year-old man with two HD affected brothers of paternal inheritance:

*Very supportive mother and occasional visits from other family members*

- Emotional and cognitive functioning of HD residents

The great majority of nurse-respondents (85%, N=80) reported the presence of emotional problems for the resident or their family. In addition, as an indicator of an executive functioning deficit, the appointment of a surrogate decision-maker was noted for 65% of residents (N=60). This was either a guardian or a financial manager whose appointment was verified against the medical record. As evidence of reduced impulse control, a history of expressed aggression was reported by 69% of nurse-respondents (N = 86). On the other hand, as an indicator of the complexity of the dysfunction associated with the disease, a sizeable majority (78%, N = 81) reported that the resident displayed behavioural problems in addition to aggression. This information was augmented from the open-ended question as follows.
• Psychiatric and problem behaviours

Content analysis of the data revealed the following underlying themes:

“psychiatric symptoms, self-centred behaviour, psychological / controlling behaviours, antisocial and disinhibited behaviours and descriptions of underlying causes of behaviours.” Two examples of psychiatric problems were reported. The first relates to a 66 year old metropolitan nursing home resident: “this gentleman has experienced deep, continuing depression proceeding to suicidal tendencies.” and the other was given by an experienced registered nursing home nurse, of a recently admitted 67 year old male HD resident: “rigid routine, obsessive compulsive behaviour, will not wait for attention.”

Another nurse-respondent described the self-focused behaviour of a 67-year-old male resident: “One occasion, pushed another resident off the toilet because he wanted to use it; will not wait for attention.”

The nurses also noted psychological/controlling behaviours such as this description by a hostel registered nurse with 10 years of nursing HD affected residents: “passive aggressive behaviour with staff at times.”

An example of anti-social behaviour by the 58 year old female HD resident in her care was described by a registered nurse with 25 years HD experience thus: Spits, throws things at people.” Another was given by an enrolled nurse with 3 years of HD experience, when reporting on a 58 year old female, rural, nursing home resident: “often has loud vocal outbursts which tend to upset other residents as well.”

Finally, others, like this enrolled nurse in a remote nursing home facility, described the underlying cause of the reported aggression: “becomes aggressive usually due to frustration or upset.”
4.2.2.4 Other resident characteristics

- Lifestyle information

As an indicator of a holistic view of the resident in their care, over half (61%, N = 80) of the nurse-respondents reported knowledge of the patient having hobbies and interests.

- Reported signs and symptoms of HD

This open-ended question was included to both augment knowledge on the clinical status of the HD residents and as a gauge of the nurse-respondents’ level of clinical knowledge of the disease. With the range between 1 and 11, an average of 4.4 signs and symptoms per HD affected resident were reported by 83 nurse-respondents (92%). The standard deviation was 1.84. Analysis of the text identified two main themes: “the Movement disorder and the Emotional and Cognitive disorder theme.”

Most of the information related to the movement disorder theme, which was comprised of seven categories, listed in descending order of frequency: involuntary movements of various parts of the body, altered speech and communication, altered swallowing, alterations in voluntary movements, altered muscle tone, altered nutrition, and finally, altered elimination.

The cognitive and emotional disorder theme consisted of three categories. Listed in descending order of frequency they were: Statements of altered performance in the cognitive areas of impulse control, temper control, social awareness, judgment, initiation and organic unawareness: Statements of altered emotional functioning, and Statements of altered perception or cognition.
Finally, a small number could not be subsumed into one of the above themes but were classified as “information on perceived handicap, alterations to sense of personal safety and other signs and symptoms.”

Some examples of the sort of information provided by the respondents regarding the Signs and Symptoms of HD are now given.

An experienced assistant in nursing with two years’ experience of caring for someone with HD reported that her 58-year-old resident had these signs of the movement disorder of HD: “Unsteady gait, involuntary movements, swallowing difficulties and loss of weight.”

Statements considered to represent the cognitive and emotional dysfunction of HD include these reported by a registered nurse who had 10 years of HD experience in a Sydney Hostel: “Emotional lability: limited awareness and insight re physical needs; some irrational paranoid ideation re food and dietary intake of late. Some anti social behaviours.”

Of a 53-year-old male resident, a registered nurse of over 15 years experience reported: “Physically aggressive. He invades other people’s space and possessions. He continually strips his clothing off.”

Representing perceived handicap and increased risk include these by a registered nurse with over 15 years nursing experience, which included 3 years for someone with HD: “ataxia, falls, multiple hits to head.”

A registered nurse in a rural location reported that the 61-year-old female resident with advanced HD: “needs restraint for safety.”

Evidence that the disease and its management is the problem.
Of all the themes (44 in total) derived from the pooled responses to the non specific open-ended questions (4.2.1.1), the second most prolific group (23%) were subsumed under a meta theme: *The disease and its management is the problem.* The least common group of themes (10%) volunteered by the nurses included reference to the social mismatch of the HD resident in the aged care facility due to age and medical condition.

4.2.2.5 *Objective 1: The affected resident profile – a summary*

The HD affected resident profile described by the nurses was consistent with clinical expectations of being about 58 years of age. This is much younger than the majority of residents in the aged care facilities where most of them live. The average age of HD residents living in aged care facilities was 58 years, whereas only 6% of people in nursing homes were under 65 years of age. Most (60%) were women. This is disproportionate to the expected gender balance and applies more to older women. Most of them lived in accommodation with care provision consistent with their disability and stage of disease. They were placed in either a hostel, low care (14%) or nursing home, high care (86%). The majority of these facilities are in the Sydney metropolitan area and 10 of the residents have moved more than once because of failed admissions.

All of these residents are reported to have a high level of difficulty with their ADL (85%) with the concomitant higher dependency needs. In nursing homes the average staff: resident ratio needs to be two staff per resident and in the hostel sub-group over half the residents needed the attention of more than one staff member at times. In the nursing homes over half are at the immobile end of the scale whereas in the hostel over half are described as mobile. Sixty eight percent of residents are reported to be underweight; a large majority has observed communication problems and swallowing problems, but only 68% of residents are reported to eat a texture-modified diet.
Families and residents experience some social problems but the majority has contact with their families. However, the majority of residents or their families have emotional problems as well and the smaller majority has surrogate decision-makers. Problem behaviours are frequently mentioned and most residents seem to exhibit some form of psychiatric or anti-social behaviour, which involves *inter alia* expressed aggression, disinhibited behaviour and extreme impatience.

In addition, the nurses were able to report that they knew about their residents’ hobbies and interests. They were also able to report on an average of 4.4 (in a scale of 11) signs and symptoms of HD in their resident. This section of the study indicates that the disease and its management is the problem.

4.2.3 Objective 2: Unsatisfactory aspects of care provision

4.2.3.1 Introduction

The goal of this objective was the identification and description of aspects of providing care for HD affected residents that the nurse carers perceived to be unsatisfactory. This care provision includes both the direct, “hands-on” care provided by staff to overcome the effects of the illness, and the care context as provided by the facility to all residents. The results for each of these general categories will be presented in turn.

4.2.3.2 The Adequacy of direct staff care: nurses’ self-assessment:

The concept under scrutiny, “care”, in this question related to the views of the overall care given by the nurse-respondents themselves and by their peers. This process
could be defined as self-assessment with an emphasis on personal responsibility to

distinguish it from the responsibility of the organization for which they worked.

A 4-point scale measured nurse-respondents’ perceptions (N = 87) of the adequacy
of the care for residents by staff. This was an indication of a general level of satisfaction
with the staff performance.

On a scale of 1-4, where 1 represented Very adequate, staff care was rated
positively and was considered Adequate (M = 1.8 and SD = .73).

Examination of the frequency distribution of the scores indicated that 38% of the
nurses rated their care as very adequate; 52% as adequate; 7% as somewhat adequate, and
3% as inadequate. These results support the picture of a high level of satisfaction being
stated for the staff care of the HD affected resident.

This measure of the adequacy of care was correlated (with statistical significance)
in a positive direction with three other measures. Firstly, the adequacy of care rating was
strongly correlated to the concept of the facility meeting higher-level needs (r = .83, p =
.0001, N = 46). It was less strongly correlated to the nurses’ opinions of the
accommodation being appropriate (r = .38, p = .008, N = 46) and less strongly correlated
to the accommodation being sufficiently spacious (r = .34, p = .02, N = 46).

The next section presents the responses to the related open-ended question
regarding ratings of staff care. Following several readings of the data generated, the first
stage of the analysis involved separating the responses into two groups reflecting either
positive or negative views of care. The results of the analysis of each group are now
discussed, beginning with the positive views of the adequacy of care provided by staff that
are summarised in the following list. The themes are listed in order (most to least) of the
amount of material written for each theme.
Adequacy of staff care: Group 1: Positive themes from the nurses’ words

Theme 1: The role of the nurse in meeting residents’ needs

Theme 2: The role of staff attributes including attitudes and training

Theme 3: The role of perceived barriers

Theme 4: The role of environmental factors

Theme 5: The role of the medical officer

Theme 6: The role of a nursing philosophy

Theme 7: The role of family

These are now presented in detail.

Adequacy of Care (Positive)

Theme 1: The role of the nurse in meeting the residents’ needs

The role of the nurse in meeting the residents’ needs included terms such as: needs, care, monitoring, supervision, hygiene, grooming and one-to-one activities. This is based on observed individual deficits and universal holistic needs, which lead to nursing interventions. As reported by the respondents, these included the following categories: the monitoring of both resident needs and interventions undertaken to promote stated high standards of care, the resolution of care delivery problems, the prevention of clinical deterioration where possible, and the acknowledgement of the interactive nature of the staff-resident relationship.

This theme is exemplified in the words of an experienced RN with little HD experience: She is given the attention she seeks without the ‘condition’ of socially acceptable behaviour.

Adequacy of Care (Positive)

Theme 2: The role of staff attributes including attitudes and training
This theme elaborating on a positive rating of staff care was that of staff attributes, including personal attributes and attitudes, and descriptions of nurses as: accepting, caring, empathic, trying hard, and [having a] respectful attitude.

Also included in this theme of staff attributes is a category with respect to special education and training attributes. A less experienced RN caring for a 47-year-old male nursing home HD resident, reported: “Staff received education which helped them nurse HD.”

Adequacy of Care (Positive)

Theme 3: The role of perceived barriers

The third theme included reference to satisfactory physical aspects, adequate staffing levels, absence of financial constraints, sufficient time allocation, and satisfactory equipment.

An RN with little HD experience explains with regard to the nursing home resident from Hong Kong in her care: “Staff and environment have been adapted for his care needs.”

Adequacy of Care (Positive)

Theme 4: The role of environmental factors

This theme regarding positive aspects of staff care, relates to what the respondents reported as barriers to more than just adequate care, suggesting a minimum standard for the HD affected resident. This theme consisted of the following four constituent categories that are now discussed with illustrative examples:

- Environmental factors: time, staffing, and the physical environment
- Problems in the nurse’s role in meeting the residents needs.
- Barriers due to characteristics of the disease, and
- Staff attributes (lack of experience)

With respect to this last theme, one of the RN respondents, with little previous HD experience, was currently caring for three in the dementia specific unit of which she was the nurse unit manager. She had rated the staff care as very adequate in the previous multiple-choice question, and was clearly seeking to describe optimal care in her response: "...but it would be interesting to have ideas on encouraging resident to interact socially."

Other examples of details of barriers to higher standards of care are now given:

A registered nurse caring for her first resident with HD, a 31-year-old woman in a rural nursing home, said: "Majority of staff have not looked after a HD patient before."

A registered nurse with less HD experience than most of the nurses in the sample, who was caring for a mobile, very tall man in his forties with a tendency to become violent towards staff, said: "More care is available if resistiveness is not an issue."

An experienced assistant in nursing caring for a 58-year-old nursing home resident in far Western NSW said: "If we had more time [(it) would be nice to spend with her. Her care is adequate for the amount of staff available."

Adequacy of care (Positive)

Themes 5-7: The role of the medical officer, The role of a nursing philosophy, and The role of family

The final three positive themes regarding the role of the medical officer, the role of a nursing philosophy, and the role of family members, are exemplified in the following quotes: "M.D [local medical doctor is] aware of problems." (A very experienced RN).
An inexperienced RN caring for a 51-year-old female nursing home resident described their nursing philosophy thus: "The resident is treated with respect and dignity and her independence encouraged."

An experienced HD RN in a church run hostel stated their philosophy: "We deliver[a] high standard of care [to] any person [afflicted with] any other disease. [It] doesn't make any difference to the care being delivered."

A metropolitan nursing home RN reported that: "Family [are] made welcome."

Adequacy of staff care: Group 2: Negative themes from the nurses’ words

The next group of findings from the analysis of the open-ended question regarding views of staff care are now reported. These are the responses from nurses reflecting negative views about staff care.

The following quotations by nurse-respondents exemplify the four themes they represent concerning the inadequacy of care.

- Firstly, with respect to the negative impact of the environment, an enrolled nurse with little HD experience from a rural hostel, who had rated the care of her 39 year old male resident as “inadequate,” said: "Public care isn’t the right environment for stage 3 or 4."

- Secondly, regarding the negative effect of the disease on standards of care, an assistant in nursing with less than one year of HD experience said: "Behavioural issues cause many problems for staff and other residents.”
Thirdly, regarding the problem of staff attributes, a registered nurse in a metropolitan nursing home explained her care rating of *somewhat adequate* for her 78 year old female resident thus: "...*need for more education / in-service about HD*"

Finally, in this section of *Negative themes from the nurses' words* an example is given to illustrate negative aspects of the nursing role.

An RN with many years of HD and generic experience, reporting on the care of a 44 year old woman with both HD and another chronic neurological disease, says:

"[She] *has been improving e.g. staff are interacting better.*"

This completes the discussion of the open-ended responses regarding general views of staff care.

The presentation of the results of the data analysis now moves to the description of the views of the nurses with respect to aspects of care provision for specific HD related problems. They are presented as follows: Activities of daily living, Communication problems, Weight loss, Social and emotional problems, Lifestyle maintenance, Medication management, Frequency of medical assessments, Adequacy of facility care provision, Provision for essential needs, and finally, Catering for nonessential needs.

4.2.3.3 *Managing difficulties with activities of daily living (ADL)*

This was intended as a measure of overcoming the gross disabilities associated with HD. In response to this question, 88% of nurse-respondents (N=81) reported that a strategy was in place to overcome difficulties with activities of daily living.
4.2.3.4 Management of communication problems

As an inevitable symptom of HD causing serious disability, this measure of communication problems was included to highlight deficiencies and frustrations in providing support to overcome this deficit.

Agreement with the statement that management strategies were in place for any communication problems of the residents, was stated by 77% of the sample (N = 81). This result indicates widespread satisfaction with this element of care provision, although not as high as with the ADL management.

4.2.3.5 Managing weight loss

Two aspects of this problem were measured, namely, planning to overcome weight loss, and monitoring weight changes.

- Planning to overcome weight loss

Knowledge of a plan to improve the reported underweight status was reported by 93% of the sample (N = 57), indicating that this was very commonly part of the care plan for the residents with HD. On the other hand, the number of respondents was noticeably small, possibly indicating less confidence by the nurse-respondents with this aspect of care.

- Monitoring weight changes

This measure was included as an indicator of the practices of the nurses with respect to weight loss. This is a common and debilitating sign of HD which can sometimes be reversed, if not halted, with an increased intake of a high calorie diet (1.3).

A large proportion (79%) of the nurses (N = 87) reported the practice of regular weight monitoring, as an essential element of overcoming the problem of weight loss.
4.2.3.6 *Dealing with the emotional and social problems*

This question was included as an index of awareness of, and the ability to provide assistance with, the social and emotional problems associated with HD.

Based on an affirmative response by 81% of nurse-respondents ($N = 75$) to a statement of attempts by the respondent to deal with emotional and social problems of the resident and their family, it can be inferred that by far the majority do so. This is also an indication of satisfaction with this aspect of care provision.

4.2.3.7 *Participation in lifestyle activities*

Associated with the meeting of higher order needs (4.2.3.12), this measure was included to indicate the extent of care defined as *superior to just basic care*. With regard to the question of staff involvement in lifestyle activities (including activities, hobbies or similar diversional therapy), 86% of the nurses ($N = 84$) reported in the affirmative, suggesting a high level of staff involvement with activities which recognise motivation for self-actualisation and self-esteem.

4.2.3.8 *Satisfaction with medication management*

In response to a question seeking their opinion as to whether the medications of the resident were appropriately managed, 88% of the nurse-respondents ($N = 80$) chose the "yes" option. This indicates a generally positive view by these nurses of this aspect of care provision.

4.2.3.9 *Satisfaction with medical assessments*

There was expression of dissatisfaction with the rate of medical assessments by just over half (58%) of all the nurses ($N = 85$), by 54% of nursing home nurses, and by 90% of all the hostel nurses. This indicates a divided opinion amongst the nursing home
nurses and dissatisfaction of almost all the hostel staff with the current regularity of medical assessments. Enlargement on these results was obtained from responses to an associated open-ended question which is now presented.

Responses to this question were made by 17 nurses. Content analysis extracted three underlying themes with the first two being the most prolific and representing equal interest in terms of the amount of information written. The themes are Satisfactory medical and medication management, Dissatisfaction with medication management, and Support for more specialist medical input. Examples are now given to illustrate the meaning of each theme.

- First regarding the theme of Satisfactory Medical and Medication management, are these words by an RN with three years HD nursing experience: “Our facility is committed to regular reviews and updates of all medications and seeking alternative therapies to medication if and when appropriate.”

- The second theme was Dissatisfaction with medication management. Analysis revealed the following five categories within this second theme of Dissatisfaction with medication management. These were: Dissatisfaction with the prescribing, Lack of confidence in the prescribing medical officer, Disagreement with the judgment of the medical officer, Information regarding unsatisfactory resident response to medication, and Concern regarding lack of resources. An example illustrating this theme is from the words of an RN caring for a 46-year-old lady in a nursing home. “Medication [is] changed without consult with the specialist at times.”

- With respect to the third theme: Support for more specialist medical input, the following is an example. The DON of a rural nursing home with many years of
nursing (including HD nursing) experience wrote: “When GPs (rural) have approximately 3000 patients on their books and only two having HD how much time can they give on education/assessment of the one patient.”

Whilst these results indicate that concern for things medical exist for a small, clearly defined group who are critical of this aspect of care provision, this is not the view of very many nurse-respondents.

In the next three sections, the views of the nurses on the contextual aspects of direct care provision, namely the Facility care provision, are given. These move from the more general to the more specific measures of satisfaction with care provision for the HD affected resident.

4.2.3.10 The adequacy of care provided by the facility

- Views of the majority

The aim of this measure was to provide a general view of the nurse-respondents’ opinions of how effectively the organisation met its care obligations to the HD affected residents. The nurses (N=88) responded substantially in the affirmative (88%), indicating a satisfactory view of the care context in which they worked.

- Views of a dissenting minority

However, as a means to completing the picture, a data subset “The adequacy of care dissenters”, was examined and the following findings noted.

- Characteristics of nurse-respondents and their HD residents reporting inadequacy of care

Firstly, the HD residents represented within the subset “The adequacy of care dissenters” group had several characteristics in common, which are now listed. The group included the hostel HD residents and were overwhelmingly below the average HD
resident sample age of 58 years. They were predominantly males (70%), were relatively more mobile than the rest of the sample, and, without exception, were classified as exhibiting behaviour problems.

Secondly, the group of nurse-respondents had some distinguishing characteristics. They were predominantly, from the least educated group of nursing staff (AIN's), and represented the majority (63%) of this group of staff. The other staff in the subset included one EN and (five) RN’s (only 11% of all RN’s in the sample).

Thirdly, those who denied that the facility was adequate also held some attitudes in common. They had responded overwhelmingly in the affirmative to three out of the four items in the section in the questionnaire that related to barriers to optimal care. They stated that fears for safety, less than adequate staffing, and insufficient staff support were barriers. They also predominantly regarded the effect of insufficient funding as a barrier, and with regard to their views on the HD specialist services (4.2.5), they were generally in favour of the input of the specialists whose contact they reported helped improve the care of the HD resident. Regarding the environmental aspects of care provision, it was noted that in addition to unanimously expressing dissatisfaction with the care provided by the facility, there was a general trend for this group towards dissatisfaction with adequacy of space, appropriateness of the accommodation and with staff care.

In summary then, the dissenters appear to be a homogenous group of nurses representing the less educated nurses, based in hostels, and caring for a particular group of patients, mainly younger, still mobile, generally male HD residents displaying behaviour problems and aggressive tendencies. The next section deals with other specific aspects of the care context, namely the issues of the meeting of "essential" and "higher order" non-essential needs.
4.2.3.11 Providing for essential needs

The question regarding essential needs was based on an assumption that all essential needs of residents would probably be reported as being catered for. This assumption is in line with the establishment of the Nursing Home Standards Agency by the Aged and Disability Department of the Australian Federal Government to ensure the maintenance of minimum standards of care in Australian aged care facilities. The inclusion of the phrase “i.e. meet minimum standards” in the questionnaire, (Appendix E) was designed to strengthen this understanding.

In response to this question, 93% of the nurse-respondents (N = 88) reported that the facility catered for all essential needs. This finding indicates a predicted high level of confidence in the facility but with an apparent 7% rate of perceived failure to meet minimum standards.

The associated open-ended question provides amplification of the nurses’ views of the provision for essential needs.

Two themes emerged from the statements generated by the 14 nurse-respondents:

- the theme of meeting minimum standards, and

- the theme of failing to cater for essential needs.

The affirmative statements in the first theme included information about disease-related needs being met. For example, accommodating for the HD characteristic of being unable to wait; the provision of a safe environment which is modified for disability; the provision of a spacious environment with outdoor access, and care which meets Federal Government outcome standards.
Examples of the second theme of *failing to cater for essential needs* included the following words of a registered nurse with 15+ years nursing experience, including three years caring for those with HD: "*Needs more emotional support/volunteer visitors in his own age group.*"

Another nurse, a hostel RN with 10 years HD experience said: "*Our resident is the only one with HD—our low resident/staff ratio does not permit enough time to meet her needs fully—either emotional or physical.*"

The next section reports responses to a question requesting explanations of essential needs not catered for. It generated responses from 44 nurse-respondents. Apart from the affirmative theme: *How essential needs are met,* four additional themes were also generated from the responses.

- Firstly, there was the denial of the identity or personhood of the resident. This theme was manifested by failures with providing care and resources such as age appropriate interactions, for the needs of the young disabled resident. It is illustrated thus: "*Needs younger company—needs an appropriately designed activities program.*"

(Respondent was a very experienced RN with 4 years HD experience reporting on the needs of a 58-year-old male resident in a rural nursing home facility).

- The second theme: *The inadequate provision for basic physical needs* was manifested by a failure to meet essential or minimal standards such as for personal private space and equipment. Regarding this issue, an RN said of a 74 year old lady in a rural nursing home: "*Furniture, separate room. Family have made padded lining for inside of bedrails, needs a soft water bed, resident very emaciated now.*"
The third theme: *Illness related needs are sometimes unmet*, is illustrated by these words of a very experienced RN caring for her fifth HD affected resident: “*Needs alway met, but challenging meeting them because of aggressive behaviour despite correct approach.*”

Finally, the last theme: *The lack of diverse expert care* was manifest particularly with regard to adequate quality and quantity of expert care. It is exemplified by the words of an RN with 2 years of HD experience who said: “*no physio... not enough time for 1:1 socialising. With DT—needs to be encouraged to join in activities—a more specialised program.*” Another example regarding the care of a 64 year old female metropolitan hostel resident was described by her very experienced (HD and general nursing) RN carer: “*... needs intensive one on one interaction and this is [a] difficulty if not impossible to provide on constant basis.*” Yet another example of this theme is provided by the experienced RN carer of a 75-year-old lady with very advanced HD in a nursing home: “*It would be wonderful to have a therapist to visit who was skilled in HD problems and It is difficult at times to feed resident.*”

The next section will focus on the issue of higher order, or nonessential needs.

4.2.3.12 Catering for nonessential needs

The concept of nonessential needs is loosely derived from Maslow’s hierarchy of needs (Clark, 1992) which stems from humanistic ideology and underpins the concept of holistic care provision. The term refers to the provision of opportunities for the meeting of needs other than those probably perceived by most nurses as limited to Safety and Survival. These could also be termed *Lifestyle* issues. Whilst this definition has obvious flaws, the three questions about to be discussed were included on the premise that nurses
do identify differences in the way facilities attempt to provide for higher order needs. The first question as to whether the facility catered for nonessential needs was responded to in the affirmative (N = 73) by 88% of the nurse-respondents. This suggests that the great majority of the facilities are judged to provide for more than just basic, or survival needs.

These results were amplified in the second question, an associated open-ended question, as follows.

Twenty five nurses provided information from which two themes emerged: Nonessential needs are catered for, and Difficulties meeting nonessential needs.

Examples of the first theme of Catering for nonessential needs are now given. Of an unpredictably aggressive man in his 50's, an RN with 10 to 15 years of nursing experience but only one year of HD nursing experience, said: "Yes—every effort made to provide outing opportunities."

A very experienced RN with 8 years of HD nursing experience gave several examples with regard to the care of a 73 year old lady in a rural nursing home: "Yes—her need to ring family members several times a day—about bringing in any items she needs—the importance of not making her wait. The structure and routine to her day—that it is the same."

An example of the second theme Difficulties meeting nonessential needs, is given by an experienced nursing home (and HD) RN: "Yes—I would like more information on how to relate to resident or knowledge of what abilities resident has of awareness."

The resident referred to was an elderly lady with very advanced disease who communicated by loud guttural grunts and calls.

The results seem to indicate awareness of the concept as outlined above and a concern that the higher order needs are hard to provide for in the setting.
The final question regarding higher order nonessential needs gave the opportunity to rate facilities on a 4-point scale where 1 stands for Very adequate and 4 for Inadequate ($M = 1.98$ and SD $0.73$ N=83).

The third question requested respondents to rate the performance of the facility in the provision for nonessential or higher order needs. Twenty four percent of nurse-respondents rated the facility's catering for nonessential needs as Very Adequate, 58% rated it as Adequate, 14% rated this as Somewhat Adequate and 4% rated the provision for nonessential needs as Inadequate.

These results indicate that the respondents held strong views that needs to do with leisure, spiritual beliefs and aesthetic aspects of life, were catered for.

With respect to the measure of Meeting nonessential needs, there was a strong positive correlation between it and the Adequacy of staff care ($r = .83$, $p = .0001$, N=46). There was a moderate positive correlation with Spaciousness of the accommodation ($r = .48$, $p = .0013$, N = 73), and a weak to moderate positive correlation with the measure of global satisfaction, the Appropriateness of the accommodation ($r = .34$, $p = .02$, N = 46).

4.2.3.13 More evidence of divided opinions of care standards

Of all the six themes (called meta themes) derived from the list of pooled responses to the non specific open-ended questions, the most frequently occurring (27%), was that called “Affirmative perceptions of needs met, staff coping.” This is considered a strong statement that problems described by the nurses are not universally experienced by all staff for all residents at all stages of the disease.

4.2.3.14 Objective 2: Unsatisfactory aspects of care provision – a summary

In fulfilment of the objective of identifying perceptions of unsatisfactory aspects of care provision, the major finding was that of substantive satisfaction with care by staff
of the needs of residents being met, and of satisfactory management of all major signs and
symptoms and functional disabilities associated with HD.

The majority of nurses’ self-assessments indicated that they considered individual
care as adequate or very adequate. They expressed positive views concerning the roles of
the nurse, the nursing philosophy of their facility, their medical officer and the residents’
families. They were also positive about staff attributes, perceived barriers, and
environmental factors. They were satisfied with the care for specific HD problems like
managing ADL, communication difficulties, weight loss, and emotional and social
problems. Overall, they were also satisfied with provision for lifestyle activities,
medication management, and the frequency of medical assessments.

There were however, dissenting voices that expressed dissatisfaction with
medication management by medical staff that involved prescribing. They also described a
lack of confidence in the MO’s prescribing and judgment, and were concerned about the
resident’s unsatisfactory response to medication, and a lack of resources.

Most (88%) nurses indicated that facility care provision was satisfactory however,
some responded otherwise. These reported dissatisfaction with care provision for HD
hostel residents in particular. Fears for other residents’ safety was expressed. Perceptions
of inadequate staffing, insufficient staff support and inadequate funding were also stated.
Dissatisfaction was also expressed with the facility’s care, and space was considered
inappropriate and inadequate. They agreed that the input of specialists would be helpful.
The carers in the hostel were generally AINs and ENs and their residents were younger,
usually male, with behaviour problems and higher mobility ratings than the elderly
nursing home residents were.
The facility was perceived generally to cater for essential needs (93%), however, the responses to open-ended questions indicated some perceptions of failing to cater for essential needs. References were made to inadequate emotional support, inadequate time to meet emotional or physical needs, denial of identity or personhood of the HD resident, inadequate provision for basic physical needs, for personal private space and equipment, a lack of diverse expert care, and unmet illness related needs such as the need for younger company and an appropriately designed activities program.

Catering for non-essential needs was positively reported by the majority (88%), however, there were difficulties identified by some respondents. For example, more information was needed on how to understand and relate to the resident. The facility’s performance in catering for non-essential needs was generally rated adequate or very adequate. The degree to which the facility met non-essential needs was significantly positively correlated with the adequacy of staff care and with the spaciousness and appropriateness of the accommodation.

4.2.4 Objective 3: The impact of internal resources

4.2.4.1 Introduction

The goal of the third objective was the testing of the appropriateness and adequacy of the facility’s staffing, physical attributes and other resources. This included testing to see whether certain of these represent barriers to optimal care for the HD affected resident.

The results of measures to answer questions that relate to this objective are now described. Moving from a description of relevant aspects of the individual nursing staff profile and their number, the environment is appraised for suitability and safety and
finally, assumed barriers to best practice are tested. Relationships between various measures are also described.

4.2.4.2 Nursing profile

- Identity disclosure

Forty-three respondents, nearly half the sample, accepted the optional invitation to provide their name. This indicates openness and a high level of trust and of confidence in the research, amongst this group.

- Educational qualifications

  - Of the 88 nurses (98% of the sample) who responded, 85% were Registered nurses (RN), 6% were Enrolled nurses (EN), and 9% Assistants in nursing (AIN). This indicates that the vast majority (85%) of respondents had achieved at least three years educational preparation and had met the professional requirements of the NSW Nurses Registration Board to practise as a registered nurse. This measure can be considered as placing respondents into categories on a continuum from more, to less educated. This measure of education level was moderately positively correlated with the amount of nursing experience \((r = .50, p = .0001, N = 46)\). This indicates that less education was associated with less nursing experience. Less education was also weakly correlated in a positive direction with the reported inappropriateness of the accommodation. \((r = .31, p = .034, N = 46)\). That is, the lower the level of the nurse’s education, the more likely they were to report that the accommodation was inappropriate (Appendix L).

Nursing Experience
In order to gain as full a picture as possible, measures were made of four different parameters of nursing experience:

- the number of HD affected residents previously nursed
- current numbers of HD affected residents being nursed
- tally of years nursing people with HD, and
- overall duration of all types of nursing experience

Firstly then, with respect to the number of HD affected residents previously nursed, the 83 nurse-respondents to this question indicated that they had previously nursed from zero to 35 residents with HD \(M = 3.8, SD = 5.3\). Of these, 74\% of nurse-respondents had previously each cared for 0 - 5 residents; 11\% had each cared for 6 - 10 residents; 11\% had each cared for 11 - 15 residents and 5\% had each cared for 16 - 35 residents.

This indicates that whilst there was quite wide variation in the number of residents the respondents had cared for, the greatest majority had cared for fewer than five and for just under half they were caring for their first or second HD affected resident. According to this criterion, this was therefore a group relatively inexperienced in HD nursing. Next, with respect to the current numbers being nursed, 82 nurses reported currently caring for between zero and four HD affected residents each \(M = 1.1, SD = .83\). Eighteen percent reported not currently caring for any HD affected resident. They reported on a resident who was no longer at the facility. These nurses had been invited to participate in the study to discuss their views about recently deceased or relocated HD affected individuals.
Of the remaining 68 nurses, 51 reported currently caring for only one resident, 10 reported caring for two, six reported caring for three and only one was caring for four residents. These results indicate that only 17 (21% of all the nurses) were known to work in an HD aged care cluster, which by definition includes more than one HD affected resident. These figures were supported by the clinical data held by the HD service of NSW. For the nurses working in facilities with only one HD resident, the effect of this more isolated experience is to reduce the opportunity for direct comparisons which facilitate understanding the commonalities of caring for HD residents and which also increase the confidence of staff in caring for these residents.

The nurses reported that the number of years they had nursed people with HD ranged from zero years to 35 years ($N = 78$, $M = 6.3$, $SD = 7.9$).

Examination of the related frequencies indicated that 62% of the nurses had cared for those with HD for 5 years or less. Fifteen percent had 6 - 10 years of caring to their credit, and 6% had 11 - 15 years. Of the remainder, 5% of nurses had been caring for 16 - 20 years, 5% for 21 - 25 years, 5% for 26 - 30 years and the last one percent had cared for HD affected residents for between 30 and 35 years.

As a global indicator of HD experience, relationships with other measures were sought and found with two other measures. Firstly there was a weak positive correlation between years of HD nursing experience and the amount of all nursing experience of the nurses ($r = .31$, $p = .032$, $N = 46$), and secondly HD nursing experience was weakly positively correlated with the rated spaciousness of the accommodation ($r = -.35$, $p = .043$, $N = 46$).

That is, nurses with more HD nursing experience also rated the spaciousness as being adequate for the residents.
The final measure of experience, concerning the overall duration of nursing experience, is now discussed. Six percent of the nurses (N = 83) had been nursing for less than five years; 10% for 6 – 10 years, 7% for 11 – 15 years, and 77% for more than 15 years. ($M = 15+, SD = 4.5$). These results indicate that on average, and using time as the yardstick, the nurses in the sample had a substantial amount of nursing experience to draw on when confronting nursing problems in their work. However, when this is compared to the total number of years of HD experience they had, there is a marked contrast. This highly experienced group of predominantly professionally qualified nurses was represented ten times more frequently in the least experience category for their HD nursing experience compared to their total nursing experience. This finding illustrates the relative rarity that this type of nursing constitutes for the aged care nurses.

Relationships have already been reported in the preceding sections between this measure, the amount of HD nursing experience, and with the amount of education achieved by the nurses.

4.2.4.3 Impact of variation in Staff: Resident ratio

The following information relates to the staffing ratios of the setting in which the nurses worked, namely hostel or nursing home. By definition, fewer nursing staff are required for the hostel resident population who are assessed by the Aged Care Assessment Teams as being more independent than nursing home residents are. Of the 13 less educated staff in the sample (EN and AIN), seven worked in a hostel. However, those seven represented 78% of the nurse-respondents who reported on a hostel resident. In comparison with the better educated nursing home nurses, differences were noted with respect to two other survey questions in particular.
Firstly, with respect to their opinion that insufficient staff support was a barrier to optimal care, 70% of hostel responders, as against 27% of nursing home nurses responded in the affirmative.

Secondly, with respect to a perceived need for more regular medical contact, 91% of the hostel nurses as compared to 58% of the nursing home nurses answered in the affirmative.

4.2.4.4 Rating of Appropriateness of facilities

A 4-point scale measured nurse-respondents' (N = 88) opinions about how appropriate they considered the facilities were for the HD affected resident living there. The term appropriateness is one observed during clinical visits to aged care facilities to be used frequently during discussions with the nurses regarding problems with the HD affected residents. It was considered a subjective indicator of general satisfaction or dissatisfaction with the situation. According to the Microsoft Word Thesaurus it means suitable, or fitting. On a scale where 1 stood for very appropriate and 4 as inappropriate, $M = 2.58$ $SD = 0.98$. Fifteen percent of nurse-respondents rated the facilities as very appropriate, 33% rated them as appropriate, 32% as somewhat appropriate, and 20% as inappropriate. The results suggest that with respect to this concept, they were almost equally divided as a group. Whilst there was satisfaction with the facilities, opinions were widely spread and supported the appropriate, rather than very appropriate, rating.

Correlations have already noted between this measure of appropriateness and the ages of the residents (4.2.2.1), ratings of nursing staff care (4.2.3.2), the meeting of nonessential needs (4.2.3.12), and the education levels of the nurses (4.2.4.2). In addition there was a moderate to strong positive correlation between the measure of appropriateness and the measure of satisfaction with the spaciousness of the
accommodation \( (r = .60, p = .0001, N = 46) \). Thus, the concepts of general acceptability of the facility and the physical features of the facility were moderately strongly correlated in this case.

4.2.4.5 Roominess of the accommodation

This measure was designed to investigate the nurses’ views on the spaciousness of the facility. This is relevant with respect to HD as the high prevalence of involuntary choreiform movements of all parts of the body necessitates increased personal space to avoid injury to the affected resident, other residents and staff.

A 4-point scale where 1 stood for Very adequate and 4 as Inadequate, measured nurse-respondents’ opinions about whether the accommodation was sufficiently spacious for the HD affected resident. Thirteen percent of nurse-respondents rated the spaciousness as very adequate, 44% rated it as adequate, 27% rated it as somewhat adequate and 16% rated it as inadequate \( (M = 2.43 \, SD = 0.91 \, N = 88) \).

These results indicate that the accommodation was rated as sufficiently spacious for the resident, but at the adequate rather than the very adequate level. Just over half of the nurses considered the accommodation sufficiently spacious for the resident, which implies that the group was almost equally divided on this issue.

As has already been noted there were demonstrated significant correlations between the spaciousness of the accommodation, and the ratings of the care given by staff (4.2.3.2), the ratings of provision for higher order nonessential needs (4.2.3.12), the overall nursing experience of the nurses (4.2.4.2) as well as their ratings of overall appropriateness of the facility (4.2.4.4).
4.2.4.6  *The environment is hazardous, increasing risks.*

This measure was included as an index of the risks the nurses associated with the facility. Of the 84 nurses who responded, 74% reported hazards existed putting residents or carers at risk. This result implies that there is a very high degree of perceived riskiness associated with the work environment.

4.2.4.7  *Amplification regarding the hazards*

Responses were provided by 53 nurse-respondents that yielded two themes: *Internal risk factors* and *External risk factors*. The theme of internal factors contained the following two categories: *Disease characteristics* and *Personal*, or individual features. *The External factors* subsumed three categories: The physical environment, The social environment, and The staffing environment. The most commonly reported hazards relate to *characteristics of the disease*, a category subsumed under the theme: *internal risk factors*, rather than *aspects of the care environment*.

The following examples illustrate why the nurses perceive disease characteristics as risk factors.

The NUM of a dementia unit in a nursing home caring for three residents with HD notes the following with regard to the impact of physical signs of the disease:

*"Involuntary movement is a potential hazard to other residents; and often interpreted by them for aggression."*

The cognitive difficulties, particularly with respect to making self-interested decisions is exemplified in these words of an RN with 6 years of HD experience regarding her 76 year old resident, a lady with a strong Christian commitment to service to others: "*fetching for another resident always puts [her] at risk of falls. Insufficient space for movement i.e. room is crowded and she is in a 4 bed room."*
The next lady, 44 years, living in a nursing home, and with a clinical history of being very withdrawn, depressed and particularly rigid in her attitudes, was described like this by the RN respondent: “self isolates; potential for choking on food; staff at risk of injury due to resident’s resistiveness and stiffening of body.”

Another quote further illustrates the impact of the personal features on the increasing of risks. This registered nurse, who had previously cared for two HD affected residents, and the current one for two years in the nursing home setting, gives her view of the problem, “Tom”, in his 60’s, a mild mannered man, has become disinhibited and without insight into the effects on others. “Extremely untidy—leaves clothing all over floor, eats in the toilet—poor hygiene... also tends to be on floor anywhere to attend to his exercises [to] pray ’Drops to the floor without notice to prayer.‘”

A very experienced (also in HD nursing) RN in a metropolitan hostel, had cared for a 64 year old lady who was regularly disinhibited in public. She illustrates the daily problems of life in this setting using the example of extreme irritability to show how untreated signs of the disease increase risks for staff and residents: “Our dining room is v. congested and when our resident throws a tantrum she put not only herself at risk but other frail aged residents.”

The words of a less experienced EN reporting on the 39 year old man in her rural hostel illustrates both the impact of the social and staffing environments, as well as disease features, in these words: “Interference from other attendants had to be kept under control. He needed more special HD activities programmes. His ravenous appetite would upset other residents. Then if you isolated him - that upset him and he became, aggressive. He needed lots of TLC.”
These examples, which are amplified in the next section regarding other perceived problems, clarify the nature of the risks the nurses associated with their workplace.

4.2.4.8 Other perceived problems with the accommodation.

The four substantive themes that emerged from the analysis of the responses to this question were:

- Spaciousness is a problem
- Lack of HD specialist accommodation is a problem.
- HD and its management are the problems and finally,
- Lack of specialist equipment is a problem

In addition, a small group of nurses reported that there were no additional problems to describe. One respondent included details of a lack of staff education as an additional problem.

Regarding the most prolific theme, lack of space, the following seven categories emerged. They were: lack of personal space being a problem; space in general being a problem; lack of special purpose rooms; the need for more freedom of movement/privacy; the need for fewer obstacles; the need to reduce intrusion by the HD resident into other residents’ space; and the possibility of an improved lifestyle if there was more outdoor space. The following example of the lack of space theme was made of an older man in a secure (locked) nursing home with little garden space. An RN with less than one year of HD experience said: “We need more space. He shares a room and sometimes roommates don’t understand. Other residents think he is being “silly.” These comments must hurt.”

Another RN with less than one year of HD experience, reinforces the importance of this problem for the Chinese man in her care: “Little space available for his needs. Encroaches on the other residents’ space and privac.”
This resident had always exercised daily by doing Tai Chi. He had been self-preoccupied for many years and prior to admission to the nursing home, was used to prompt attention from his devoted wife.

Regarding the second theme of the lack of HD specialist accommodation, one nurse said: "Aged care facilities are not the ideal environment. Often need to be with younger people." This RN with 4 years of HD experience was caring for a 58-year-old man in a rural nursing home.

An EN in a rural charity run hostel said of a 39 year old man, rejected by his wife, and unable to see his children due to the two hour drive. "They need to be in their own age group. Living in aged Hostel wasn't the right place. It worried him very much, that he was mixing with older people." In addition to the hostility from his wife, reference to the outreach medical record indicates that he was eventually rejected by the hostel because the hostel management blamed him for damage to fittings and fixtures due to his extreme choreiform movements.

The theme of the problems related to the disease and its management, had no subsumed categories and included comments relating to: the gait disorder, the problem of the resident who "yells" to communicate, an inability of the resident to organise their possessions, and delusions and paranoia. For example: "Some of the less experienced nurses find the delusions and paranoia difficult to understand and resolve."

The next example relates to a 70-year-old nursing home resident who was in the end stage of her disease, and was nursed in bed in the foetal position she had adopted.

An experienced RN with an additional dementia care qualification said of her: "Resident cannot vocalise now other than yelling, her excessive jerky movements generally upset most of the residents in this wing."

141
Chapter 4 – The results

The final theme emerging from this question is the need for specialist equipment. With regard to this theme, which had no constituent categories, a nursing home RN working in an HD cluster said: “...nursed in cumbersome water chair. Another experienced RN with three years of HD experience in a metropolitan, church-run, dementia facility wrote that: “Non weight bearing residents require mechanical devices for lifting and transfers—ample room is required to safely manoeuvre”

Additional insights were sought from the pooled non-specific responses to all open-ended questions. Relevant to the issue of resources, is the finding that 12% of all the data, which was comprised of six meta themes (4.2.1.1), was subsumed under the theme of “Perceptions of an unsatisfactory care environment.” This means that although the fixed choice responses did not indicate significant dissatisfaction with the care environment, those nurse-respondents volunteering additional information produced significant amounts of data on the topic.

4.2.4.9 Barriers to optimal care

As a means to gaining further understanding of what might make care of the resident with HD difficult, four possible barriers to optimal care were suggested in the questionnaire. With nurse-respondent numbers ranging from 83 to 89, well over half the respondents denied that Insufficient staff support (73%), Fear for safety of staff or residents (64%), or Less than adequate staffing (62%) represented such barriers. On the issue of Insufficient funding the numbers were equivocal (55%). Further amplification on potential barriers to optimal care was obtained from the analysis of 30 nurses’ written responses to an open-ended question asking for Comments. This revealed that 38% of the text produced, referred to the theme of “Funding is a barrier.” The themes of “Fears for
safety is a barrier” and “Staff characteristics are a barrier”, received almost equal attention (23% and 20%). Although 13% of data denied the presence of any barriers, 7% conveyed a belief that the facility was absolutely inappropriate.

Additionally, of all the six themes (called Meta themes, 4.2.1.1) derived from the list of pooled responses to the non-specific open-ended questions, 16% related to the theme Staffing resources are unsatisfactory. This indicates that for those who chose to give freehand information, staffing issues were the third most frequently mentioned.

Thus it can be stated that although most nurses did not perceive either less than adequate staffing or insufficient staff support, as barriers to optimal care, those that did, tended to avail themselves of the opportunity to explain their position.

The written responses were then compared with the fixed choice responses for consistency and it was found that in 90% of the cases (N= 27), the written responses served to clarify the fixed choice responses. Those that did not raised other issues rather than contradicting their previously stated views.

Examples using the words of the nurses will now be presented.

Regarding the barrier of inadequate funding for patient care needs, an enrolled nurse in a rural hostel said: “... equipment... staff numbers to cope with special needs of HD patients. ... a government responsibility...”

A rural nursing home RN with 8 years of HD nursing experience said: “There is no recognition by authorities of the special needs for HD.

An assistant in nursing with 5 years HD nursing experience said: “... insufficient funds to change his bedding and his water chair.

The theme of Fear as a barrier was linked in all cases to problems caused by the disease.
A rural nursing home EN with 3 years of HD nursing experience described how the disinhibited behaviour of her 58 year old resident caused concern for safety: “The resident requires lots of TLC and tries to hug people as they walk past, often pulling them off their feet.”

The NUM in a metropolitan facility said of her non compliant 50 year old (since deceased) male HD resident: “…we have had difficulty in providing care for this resident previously because he has refused all interventions…”

On the other hand, an AIN with less than one year of HD experience provided insight into the reduction of these fears for the 68-year-old hostel resident in her care, by successful interventions: “In the past [the] resident has had many verbal outbursts and now on medication we have not had many at all.”

Regarding the theme of adequate staffing as a barrier, an experienced RN with less than one year of HD nursing experience said: “[There is a] need for increased 1:1 care; less experienced, less educated staff have more difficulty.”

An EN in a rural nursing home said of her church run facility: “…staffing levels are less than adequate at times.”

With regard to theme four: the denial of any barriers to optimal care, an RN with little HD experience in the rural nursing home where she works said: “at this moment this resident’s needs are met & has not deteriorated to the extent that the above would present a problem.”

This was also expressed by an RN respondent in a metropolitan nursing home, regarding their care of a 47 year old man: “We received help, education, support from Lottie Stewart.”
Finally, an RN in a church run hostel said of her 66-year-old female resident: “The resident is no threat to staff. Aggressive outbursts are few.”

The words reflecting the final theme of the inappropriateness of the facility as a barrier include those of an RN in a rural nursing home who said of her 58-year-old male resident: “Needs specialised care and a specialised facility.”

Another, who was inexperienced in HD nursing said: “Adequate care is given but I still feel this placement is inappropriate.”

The final words are from another RN at the same institution:

“Whilst we give very adequate care, this facility would not be the ideal placement for our resident.”

4.2.4.10 Objective 3: the impact of the internal resources – a summary

An appraisal of the impact of the resources included evidence that this group of nurse-respondents are mostly RNs who have a substantial amount of nursing experience but have cared for an average of fewer than five HD patients each. They mostly worked in nursing homes with low staff: resident ratios and very few of them reported on staff: resident ratios impacting on quality of care. In contrast, the hostel nursing staff who are a minority in the sample and the majority of whom are either Ens or AINs, usually reported that their less favourable staff: resident ratio was a barrier to optimal care. This group mostly, wanted more medical input. They are usually the lesser educated, less HD expert staff who cared for more mobile, younger residents in low care facilities.

Seventy four percent of the whole sample reported that the characteristics of the disease caused a more risky environment for both staff and residents. All the nurses generally approved of the appropriateness of their facilities but in terms of their roominess, they were equally divided in their responses.
They reported on other problems as well: a lack of specialist HD accommodation, lack of specialist HD equipment, a lack of privacy and outdoor space, were all issues relating to the accommodation and were connected with issues of the global difficulties in managing HD, although were not reported as barriers to best practice. However, although staffing and safety issues are not considered barriers to best practice, funding is by some.

4.2.5 Objective 4: The HD nursing role and its support

4.2.5.1 Introduction

The goal of the fourth and final objective was the determination of views on several aspects of the aged care HD nursing role. This included its skill requirements, and feedback on current methods of obtaining these skills. Information was also provided on the contribution of external providers of medical, nursing and allied health services, both generic and HD specialist. Questions about these categories of staff produced rates of access, contact, and preference for the specialist services in supporting the nursing role. The results of questions elucidating these issues will now be presented.

4.2.5.2 Perceived HD nursing skill requirements and their attainment

These issues were canvassed by means of several questions.

Firstly as a measure of a general view of the nurse-respondents towards the skill requirements of nursing people with HD, the 95% affirmative response (N = 88) indicates a very strong statement of support for this concept. The question was worded to explore the concept of the required skills being of a different or expert nature.

The next result indicated a contact rate of 58% (N = 90) with a specialist HD nurse. By implication however, more than a third did not report contact. This result
should be taken at face value only in light of results from the *Nurse Contact Study* reported on in Chapter 3.

On the other hand, as an indicator of both acceptability of specialist nursing input, and the effectiveness of this in improving nursing care, the result of all but one nurse (N = 50) reporting in the affirmative that: *this contact was helpful in delivering better care to the patients*, indicates a very positive response to this question.

With respect to the attainment of the expert skills needed, the next two questions were designed to record the prevalence and timing of any formal training or education about HD. With respect to having formal HD education prior to caring for an HD affected resident, 27% (N = 88) reported in the affirmative. This result indicates that only a minority of nurses were prepared in advance for the task of caring for the HD affected resident, which from the resident’s point of view, would probably be seen as an indicator of best practice.

By comparison with the above, well above half (62%, N = 87) reported having HD education subsequent to the admission of an HD affected resident. This indicates that it is far more common to receive the education after the resident has been admitted than before.

Table 4-3 summarises the demonstrated association between the participation by the nurses in HD education, and the reported contact with an HD nurse specialist. Of those who reported having formal HD education, the large majority (73%) also reported contact with the HD nurse specialist. This relationship was statistically significant although of a relatively small size. This is an indication that contact with the HD specialist nurse was associated with the provision of education to this group.
TABLE 4-3 THE ASSOCIATION BETWEEN HD SPECIALIST CONTACT AND HAVING HD EDUCATION

<table>
<thead>
<tr>
<th>Provision of HD education subsequent to admission of the resident</th>
<th>Contact with HD nurse specialist</th>
<th>( \chi^2 )</th>
<th>( \phi )</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>Affirmative</strong></td>
<td><strong>Negative</strong></td>
<td>df = 1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Nurse has had HD education</td>
<td>38</td>
<td>73</td>
<td>16</td>
<td>54</td>
</tr>
<tr>
<td></td>
<td>6.55</td>
<td>.28</td>
<td>.010</td>
<td></td>
</tr>
</tbody>
</table>

These results were clarified by written responses to a request for *Comments*, as follows.

The nurses’ (N = 41) responses were found to represent four themes elaborating on their educational preparation for the HD role. Three of the themes quoted either HD specialist input as the source, formal self-education as the method, or that the education was obtained by experience.

The final theme gave details of unmet educational needs, which included an expressed need for information covering ongoing deterioration, family support, impact of HD on the individual, and behaviours. Some extracts from the questionnaires will now be given.

An example of the first theme is from an RN nursing her first patient with HD (an older man in a nursing home), which she had done for less than a year: “*Before admission...contact (with) neurologist and Huntington’s CNC to enquire about person’s needs.*”

Another nurse, an EN caring for a 39 year old man in a rural hostel said: ‘*Only what I gathered, by reading the Huntington Disease Booklet and information I got from visiting other Day/Care centres.*’

An example of an RN taking responsibility to obtain the necessary skills to provide confident care, (formal self education) is now described. This less experienced (0
- 5 years experience), RN with only one year of HD nursing experience who was caring for a female nursing home resident said: "I have no special nursing skills (re the above) but through discussion with my senior staff I have managed to nurse this resident."

Education by experience is exemplified by these words of an assistant in nursing with less than one year of HD experience. Reporting on the care of a 68 year old hostel resident they said: "[The] resident had been coming from her unit to the hostel for all meals before resident moved into the hostel, so all staff were learning the problems as we were going along and before resident moved into hostel."

Finally, the theme of unmet educational needs is exemplified by the words of an RN of more than 15 years nursing experience. Having cared for a 66 year old man, her first HD affected nursing home resident, for less than one year, they said: "As an educator, I feel HD is a specialised area and needs to be covered ongoing by people with experience."

An RN reporting on her experience caring for a 44-year-old nursing home resident with both HD and MS said: "Due to frequent turnover of caring staff ongoing education would be optimal in understanding [the] condition and special care needs."

The discussion now moves from the nursing role to the responses dealing with the input of other health care professionals, firstly, information regarding medical specialists.

4.2.5.3 Frequency of medical specialist contact

The referral of the HD affected resident to see a medical specialist was reported by just over half (53%) of the 80 nurse-respondents. The doctors would commonly include neurologists and psychiatrists.
The following table, 4.4 summarises a statistically significant relationship between this measure of accessing expert advice and the resident problem behaviour measure. The data indicate that a very large majority (88%) of those residents who do see a specialist also display expressed aggression and behaviour problems. This relationship was shown to be quite weak but met the 95% probability test of not being due to chance.

**TABLE 4.4 RELATIONSHIPS BETWEEN CONSULTING A MEDICAL SPECIALIST AND THE RESIDENT PROBLEM BEHAVIOUR MEASURE**

<table>
<thead>
<tr>
<th>Problem behaviour measure</th>
<th>Resident sees a medical specialist</th>
<th>$\chi^2$</th>
<th>$\phi$</th>
<th>$p$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
<td>$N$</td>
<td>%</td>
</tr>
<tr>
<td>Resident has behaviour problems as well as showing expressed aggression</td>
<td>35</td>
<td>23</td>
<td>88%</td>
<td>13</td>
</tr>
</tbody>
</table>

**4.2.5.4 HD physiotherapy in a supportive role**

Provided routinely as part of the statutory requirements for aged care facilities, the issue of whether these physiotherapy services were rated as effective in comparison with HD specialist therapists, was the motivation for this bracket of questions. Predictably, there was a high reported access rate of 92% ($N = 86$) to generic physiotherapy for the nurse-respondent and the resident.

By contrast the reported access rate to HD physiotherapy for the respondent and resident ($N = 82$), was only 11%. This indicates a low level of specialist access for the problems described in the questionnaire as being improved by physiotherapy – namely improvement in mobility, the maintenance/improvement of disabilities, maintenance of posture when seated or in wheel chairs, or learning effective coughing techniques.
Quite considerable dissatisfaction with this situation is evident in the affirmative response rate of 56% \((N = 79)\) with regard to whether these access rates to physiotherapy were considered satisfactory.

4.2.5.5 \textit{HD Speech pathology in a supportive role}

With respect to speech pathology, there was a low utilisation rate of 46% \((N = 85)\) for the HD affected resident. On the other hand, an affirmative rate of 70% for the statement that the HD speech pathology service \((N = 87)\) was, or would be, more beneficial to the staff and the resident, indicated a strong preference for the HD specialist against a low utilisation rate for this group of therapists in general.

4.2.5.6 \textit{HD Dietetics in a supportive role}

For a contact rate of 63% \((N = 82)\) with a dietician, a perception of increased benefit from a specialist was reported by 60% \((N = 80)\). This result indicates a preference for the specialist therapist by the majority of respondents although not as high as for speech pathology.

4.2.5.7 \textit{HD Diversional therapy in a supportive role}

The diversional therapist (sometimes also known as the recreation officer), has responsibility for the provision of leisure activities which are also termed lifestyle. The question was aimed at identifying whether the nurses saw value in having a therapist who was an expert in HD care.

An affirmative rate of 71% was calculated for the view that HD diversional therapy would be beneficial for the resident \((N = 85)\). This is amplified by reference to the words of the nurses in response to an open-ended question \textit{Views on lifestyle and the diversional therapy role}. 

151
The question to which 22 nurses responded generated the following three constituent themes, which will now be discussed:

Successful lifestyle interventions (38 statements),

Difficulties with lifestyle issues in this setting (21), and the

Specialist HD diversional therapy role (DT), (6)

- Theme one: Successful lifestyle interventions

Successful lifestyle interventions described included the categories of: solitary activities (such as TV, smoking, reading; therapy activities such as music, manicure, massage, aromatherapy, letter writing); and one to one activities which are described as dependent on a relationship and included visiting, and individual discussions with family and staff. Group activities were described as non-participatory but interactive and included bingo, and craft afternoons. Outings, the most common single activity mentioned, were mentioned five times. These comments are exemplified in the following extracts from the completed questionnaires.

An experienced RN with 5 years HD nursing experience said of a 77-year-old man in a dementia specific metropolitan hostel: “Resident joins all group activities and goes on regular outings and drive[s] with D.T. staff.”

This theme is exemplified in the words of an experienced EN who had cared for three HD affected residents previously, and had 3 years experience of HD nursing. She described the difficulties with the 58-year-old female resident, herself a registered nurse, with advanced HD and unable to communicate except by noisy sounds and grabbing passers by, like this: “Most times the resident likes one on one contact and just talking to her or cutting her nails is therapy enough.”
Written by a less experienced RN of her 44 year old female nursing home resident, another example is: "Resident's condition too advanced for much D.T. but was regularly massaged and gently spoken to by our D.T."

Finally, the words of a most experienced RN with 10 years HD nursing experience: "DT—attends DT in nursing home workshop, does not partake in activities but enjoys the social interaction."

- Theme two: Difficulties with lifestyle issues

This theme generated two categories: firstly, reactions to the disease, the environment, and some solutions to the problems, and secondly, the category of self-inflicted isolation, which included an implied element of control by the resident, blaming by the respondent and frustration for the respondent with the described behaviour. These are illustrated by the following extracts:

A registered nurse with 10 years HD experience, said of her 64-year-old Welsh-born hostel resident: "problem(s)—all relate to her variable mental and emotional state."

Another respondent, an EN caring for a 39 year old man with severe choreiform movements in a rural hostel, since deceased, said: "they need the special attention and working with people more their age group. Resident unable to follow instructions."

Another EN, also caring for a young man, 35 years of age, also deceased now, but in the same nursing home as two other family members, said: "[He is] withdrawn, doesn't mix socially."

An RN who had cared for three other HD affected residents said of her 58 year old male resident: "Pleasant but aloof, and very room centred/spends day on verandah."

- Theme three: The role of an HD specialist DT
Representing only 9% of all the data for this question, half the data indicated reservations about both the feasibility and the need for an HD specialist diversional therapist. For example, an experienced RN with 2 years HD nursing experience said:

"Not at present—comes to all activities daily."

On the other hand, the other half of the data expressed a positive interest in the involvement of a diversional therapist with specialist knowledge of HD. An RN who had cared for three HD affected people over 2 years, said: "consultant specialist DT would be an advantage for our RAO’s (Recreation officers)."

4.2.5.8 HD Social work in a supportive role

For an access rate of 60% (N = 82) to a social worker, a perception of increased benefit to staff / patient / family from a specialist social worker was reported by well over half of the respondents (64% N = 78).

These findings are amplified in the words of the respondents in response to the request for comments. This request follows five fixed choice questions canvassing the social and emotional needs of the resident and their family, as access to and a preference for, HD specialist social work input.

Four themes were generated from the words of 23 nurse-respondents. The themes were:

Needs are non-existent or satisfied
Unmet social needs
Unmet emotional needs
Needs for specialist contact
Examples are now given of each theme in turn.
Of a 71 year old Anglo Indian man who was still mobile, had a single room with 
ensuite in a metropolitan hostel, the RN, who had 5 years of HD nursing experience, 
said: "Has regular contact with eldest daughter and wife."

Examples of nurses stating unmet social needs are contained in the two following 
quotations. First, of a moderately visually impaired 76-year-old lady with recurring 
psychotic episodes, as well as HD, an RN with 6 years HD nursing experience said:

"There is not much family contact."

Next, a very experienced RN with 4 years HD nursing experience said of her 75 
year old Dutch - Indonesian born resident who had severe dysarthria and so 
communicated by uncoordinated grunts and shouts: "I have only spoken to the daughter 
who doesn't feel her mother acknowledges her anymore. Therefore daughter doesn't 
visit."

An experienced RN with 5 years HD experience reported of her male nursing 
home resident: "Our particular resident's family require a lot of emotional support... any 
help in this area would benefit all—the family, the residents and the staff."

Yet another nurse expressing unmet emotional and unmet social needs, said: 
"Would like tips to reassure/support family so they accept deteriorating condition & visit 
more frequently."

4.2.5.9 HD Occupational Therapy in a supportive role

For a contact rate of 26% (N = 78) with an occupational therapist, a perception of 
increased benefit to staff and patient from an HD specialist occupational therapist was 
reported by 71% (N = 80) of nurse-respondents. These results indicate that although less 
than a third of the nurses have had contact with any occupational therapists, a high 
proportion state a preference for a specialist therapist.
This completes the presentation of the results on the perceived impact of various categories of professional colleagues on the role of the nurse and the resident with HD. The last two sections deal with nurse-respondents’ views of the HD specialist residential and outreach services.

4.2.5.10  *The indispensability of an HD inpatient unit*

This question was included to investigate how important the availability of a specialist facility was perceived to be. It was assumed that if there were extreme dissatisfaction with the status quo then an alternative model of care in a specialist unit would be seen as essential by a substantial number of nurses. There was an affirmative response rate of 56% (N = 71) regarding the *indispensability of an HD inpatient unit*, which indicates divided opinions on this strongly stated issue. This finding was amplified by the information from the associated open-ended question as follows.

The words of 23 respondents were coded and sorted into two themes: *Positive views* and *Negative views*.

Positive views comprised three underlying categories: *Opportunities for enhancement of quality of life* (with reservations in two cases); *Provision for specific, periodic needs* (for example reassessment, or symptom management), and finally, *End stage care*.

Negative views, on the other hand, had two underlying categories: Firstly: The *numbers do not justify this*, and secondly, *No perceived need*. The following examples illustrate these points.

A most experienced RN (including 20 years of HD nursing) said of the 61 year old nursing home resident in her care: “*It would be desirable but [the] patient needs to be nearby to family too.*”
Another RN who had cared for three HD affected residents for a total of two years said: "Should this be regional—I think so. I am unfamiliar with how many HD sufferers there are—but this requires specialised care. Best practice Specialist unit but organise lots of education."

The RN carer (with 8 years of HD nursing experience), of a 62-year-old male nursing home resident supported a periodic need model like this: "Particularly at critical times when a specialist facility could more accurately assess."

In support of the use of a specialist facility for the more advanced stage of the disease, a hostel RN said of her 64-year-old female resident: "When resident deteriorates she needs to be in a specialist unit and ongoing support”

An RN from an HD nursing home cluster stated her reservations thus: “[It is] desirable but would depend on number of HD patients, funding.”

The final words on this topic are from a remote nursing home nurse caring for a 58-year-old lady:

"Yes][but] not for this resident she has all her needs met here & appears settled."

To investigate the notion that affirmative views of a specialist inpatient unit being essential might be linked with support for views of HD nursing requiring special skills, statistical relationships were sought for these measures of the nurses’ views. Table 4.5 summarises the findings. Of the nurses who thought that HD nursing required special skills, only a small majority supported the notion that a specialist inpatient unit is essential. The relationship was not statistically significant (p = .2001) and was of a small order (\( \phi = .15 \)).
TABLE 4.5 RELATIONSHIPS BETWEEN VIEWS OF A SPECIALIST INPATIENT UNIT BEING ESSENTIAL & OF HD NURSING REQUIRING SPECIAL SKILLS

<table>
<thead>
<tr>
<th></th>
<th>HD inpatient unit is essential</th>
<th>χ²</th>
<th>φ</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>N</td>
<td>%</td>
<td>No</td>
</tr>
<tr>
<td>HD nursing requires special skills</td>
<td>37</td>
<td>100</td>
<td>1.637</td>
<td>.153</td>
</tr>
</tbody>
</table>

This report now moves to present the findings from an in-depth analysis (3.6.1.3) of both the personal characteristics as well as the responses, of a subset, the negative respondents, to this question. These respondents were unified as a group by having the following characteristics in common. First, it is noted that the group of respondents with the lowest professional qualifications, namely assistant in nursing, is more heavily represented in this cohort. They had also generally not had any education on HD either prior to, or since, the admission of the resident, in spite of noting contact with an HD nursing specialist. Notably, this group contains the only nurse-respondent who did not feel that contact with the HD nursing specialist was helpful in giving better care to the HD resident. In short, they might be described as nurses who had least responsibility for monitoring care standards and who had little knowledge of best practice guidelines to promote a positive response to the question.

Secondly, the respondents consistently (for most categories), did not support the need for any HD specialist therapists, except with regard to social work. They also denied having access to an HD physiotherapist as well as reporting dissatisfaction with this situation. On the other hand, the subgroup consistently expressed satisfaction with the current level of medical input.

Finally, the profile of the residents nursed by this group of respondents was also consistent in having the following characteristics. Firstly, all residents in this group were in the advanced stage of the disease, were all classified as immobile and, for the majority,
were reported to need two nurses for any intervention. Secondly, clinical experience indicates that they would be likely to have a degree of dementia, be mute and often quite unresponsive, with little ongoing interest in the outside world. In short, these residents could be described as being in a stable state of advanced disease and highly dependent for every need.

4.2.5.11 The indispensability of an HD outreach service.

There was a 91% affirmative response rate (N = 74) for this question indicating very high support for the notion that an outreach service is essential.

Only five nurses rejected this proposition, prompting examination of the subset of data consisting of their responses to the rest of the questionnaire. The data was subjected to visual inspection of a printout to see whether patterns were evident with the aim of identifying possible explanations for this skewed result. With respect to most of the variables, these five respondents represented a range of views and demographic characteristics. However, it was observed that all five respondents were also unanimous in rejecting the notion of a specialist HD inpatient unit being essential. All five also reported that hazards were present in the environment that put patients or carers at risk. They were unanimous, along with most of the rest of the respondents (98%), in their belief that HD nursing required special skills. With respect to characteristics of the respondents, four of the five had had previous experience with residents with HD. The fifth had been nursing the current resident with HD for one year, so was also considered experienced. Four of the five reported no education on HD either prior to commencing care of the resident with HD, or since then. One of the respondents was the only one of the whole cohort who reported contact with the HD nursing specialist and disagreed with the statement that the contact had been helpful. Two of the respondents worked in the
same facility. With regard to the profile of the residents in their care, it was noted that all nurses reported that their resident had swallowing problems, and was underweight, but only two reported that the “resident can only have a modified diet.”

In summary: this last examination of the subgroup of dissenting respondents did not see specialist knowledge as vital for the care of their resident. Whilst they were relatively less educated on HD than their peers, they were experienced in HD nursing and two of the five worked in the same facility.

The comments by 27 respondents, provided as amplification of views on an outreach service were almost unanimously positive (96%) and generated three categories in the major theme of the ideal HD outreach service.

The other theme, Dissent, represented a lone voice. Only one of the 27 respondents, an RN with 0-5 years nursing experience and one year of HD nursing experience, did not support the concept of an outreach service saying: “Our resident's condition was too advanced to have any benefit.”

The three constituent categories of the ideal HD outreach service were: the role of an outreach service, Experiences of an outreach service, and in support of the concept (with some qualifications). Examples follow for each of these categories in turn.

The role of an outreach service included an expectation of support, advice, information, and symptom management, to enhance resident functioning. A very experienced nursing home RN, with 5 years of HD nursing experience, said of the care of the 71-year-old man: “An aged care facility can only do so much. We need more assistance & expert help to provide the best quality of life for our resident.”
Regarding *Experiences of an outreach service*, another very experienced RN who had cared for 2 other HD affected residents said of the 64 year old hostel resident in her care: "*[Our] resident likes going to outreach programmes."

As an example of the category, *In support of the concept*, but with qualifications regarding its accessibility, an RN who had cared for four HD affected residents previously said: "*It is essential that this service is 24 hr, and quickly accessible.*"

The final quote for this question is from an RN with over 25 years of HD and other nursing experience. Writing from a rural setting, this respondent had had supported the idea in the fixed choice question and elaborated on this response by saying: "*You normally only have one or at the most 2 residents with H.D. and their needs are never the same or the stage of the disease the same.*"

4.2.5.12 More evidence of lack of skills for the HD job

Additional information from a review of the Meta themes, which, is relevant to answering this final objective, is now presented.

Firstly, the analysis of the pooled themes from all the open-ended questions indicated that 10% of nurse-respondents described a need for *specialist skills* or other *specialist resources*. This is a statement of a lack of confidence by the nurses in their current skill level to give optimal care to the HD affected resident.

Secondly, half the responses by 45 nurses to the final, optional, question inviting "any other comments", indicated the presence of unmet needs for *HD specialist input, education and (particularly in rural areas), accommodation*. The significance of this result is awarded additional weight by virtue of the position of this question and its optional nature.
This concludes the presentation of results related to the nursing role of the aged care nurse and the support of this role, particularly by other professionals, expert in the field of HD.

4.2.5.13 Objective 4: the nursing role and its support – a summary

In pursuit of views to elucidate the HD nursing role and its support, the evidence indicated that this role was considered to require expert skills, which were sought by education from various sources.

By far the majority of respondents supported the concept of HD nursing requiring specialist skills. Few of them had had any HD training before they started to care for their HD resident, however the majority had some specialised education afterwards and viewed their contact with specialist HD nurses as helpful.

Other expert HD professionals were generally valued over their generic counterparts. This applied in the cases of physiotherapy, speech pathology, dietetics, diversional therapy, social work and occupational therapy. The amount of contact and utilisation of the generic therapist varied but in all cases, a wish for contact with an HD specialist in the field was expressed. In terms of medical specialists, those mostly consulted by HD residents were reported to be neurologists and psychiatrists and they predominantly saw residents who exhibited behaviour problems.

On the issue of whether a specialist HD in-patient unit was essential, there was an equivocal response. Fifty six percent of respondents supported the idea on the basis that it presented opportunities for the enhancement of the quality of life of the HD resident, and that the provision for specific periodic needs and for end stage care. Those who disagreed stated that the numbers did not justify it or there was no perceived need.
However, there was a clear confirmation of support for HD outreach services, particularly in rural areas. The five respondents who rejected the idea were among those who had also rejected the indispensability of the in-patient unit and supported the notion of the need for special skills.

Responses derived from an open-ended optional question about lack of skills indicated the presence of unmet needs for HD specialist input, education, and accommodation. These findings are seen as evidence of general support for the status quo, although with some modifications.
CHAPTER 6—LOOKING AHEAD: RESEARCH, PRACTICE
AND POLICY IMPLICATIONS

No research endeavour, however comprehensive and well executed, is complete
without consideration of what has been left undone, what new challenges have been
uncovered, and the implications for practice that are proposed in response to the findings.
These topics are now discussed with respect to this work on HD in aged care.

6.1 The need for further research

As an exploratory study, this work has achieved a specific goal of research,
namely the identification of concepts (Greenwood 1996) of major importance with respect
to providing nursing care for HD affected residents in NSW aged care facilities. Having
identified some of the most important concepts, mention is made of four particular areas
considered worthy of further research.

The concepts identified, include the central position of the disease characteristics,
which remain so difficult to modify due to the lack of effective medical treatments.
Alongside this is the need for improved nursing management of signs and symptoms or
the so called “ability enhancing and ability-compensating strategies” of Seidman-Carlson
and Wells (1998). Also highlighted were the concepts of ambivalence or complexity as
being at the core of the inconclusive results regarding global appropriateness of the
facilities, and the indispensability of the specialist inpatient unit. Also confirmed as
central to the whole thesis was the “Cuckoo in the nest” concept relating to the
differentials of age and disease status compared to other aged care residents. Also raised
as of crucial important were the concepts of differing levels of general educational
preparation and HD knowledge, and also the provision for higher order needs as a concept which is linked to higher standards of care. With regard to support for the nursing role, the concept of multidisciplinarity in general, and specialist support in particular (Smith, 1998), was found to be relevant to the issues under investigation. Finally, the issue of the expertise required by this nursing role including the critical appraisal of the role of medications was raised, allied with a question regarding the effectiveness of the self-assessment of individual care provision.

This discussion now moves onto the presentation of four specific areas of potential further investigation.

6.1.1 The importance of the skills mix of the nurses

The preponderance of more highly educated, registered nurses in the sample, and the possible bias thus introduced, would be fruitfully scrutinised. The main influence to be discounted would be that of reducing the tendency for deviance. This would be done by different sampling techniques whereby the impact of the educational and professional differentials would be assessed.

In addition, it is reported that (Ballantyne 1994) the skills mix of aged care staffing is changing towards increasing levels of less educated and less experienced staff. In terms of this research the predicted detrimental impact on HD affected residents, of increasing marginalisation, avoidance and frustration due to ignorance and lack of skills, needs to be confirmed, and urgent changes to policy and financing instituted to prevent these discriminatory outcomes.
6.1.2 Education for the job

The discussion in 5.7.3.1 highlighted the need for further research to identify the relative importance of educational preparation as against the need for specialised information for specific contexts.

6.1.3 Which model is best?

The testing of an hypothesis that the “Cuckoo in the nest” phenomenon is reduced or eliminated in the specialist facilities or HD clusters, would also be a potentially fruitful study. Another survey, using an adapted questionnaire could be undertaken whereby a comparison would be made of the views of nurses in NSW aged care facilities with a single HD resident and those working in the specialist facility in NSW, in HD clusters, and finally those in specialist facilities in other states of Australia. Statistical tests could be used to identify differences between the responses of these groups. If significant, this would add weight to the evidence presented in this thesis, of the existence of a phenomenon that is believed to depend upon the rarity of a resident’s condition in relation to the condition of other residents in the care environment.

6.2 Practical implications

6.2.1 An ideal-type HD nurse

The issue of the impact of some staff characteristics has already been discussed (5.5.3.1). The particular challenges of HD nursing in aged care have also been addressed (5.5.1, and 5.5.4). The implications of these observations are now directed towards writing some tentative guidelines for an ideal-type HD nurse. This does not relate to usual standards of professional competence, they are a given, but focuses on some particular attributes that this research has promoted as being of importance.
The first one relates to an ability to *cross the divide*. The argument goes thus. If it is true that the person with HD in the aged care setting is alien in some sense (Gardham, 1982), it may be that they would be best understood by those who are themselves different from most other professional carers. Indeed, as a tentative suggestion based on observations made in several multicultural settings, it is postulated that nurses from cultural backgrounds which are different from the dominant one in which they are working (particularly if they are the first generation in the new culture) may be more skilled at crossing into the “unknown territory” of the person with a rare condition (in this case HD), than those who are less used to adapting to *alien or foreign ways*. The need for carers to be able to *cross such a divide* is increased when one considers that the disease also affects residents’ abilities to advocate for themselves. This is due to cognitive changes and communication disabilities which predispose (due to cerebral frontal lobe involvement), towards relatively disinhibited and socially unacceptable methods such as yelling or hitting as substitutes for saying “No,” or grabbing and calling to indicate “Yes.” This applies while they can still communicate, while later the problems increase, as they are unable to express anything much at all! Writers such as Chiu (1990), Gardham, 1982, Hardy, (1989), Plane, (1996), and Smith, (1998), have described the difference made by nurses who were able to overcome these challenges. This discussion regarding the impact of overcoming disabilities on the life of the person, is extended by the story of Helen Keller whose unmanageable behaviour resulting from sudden blindness, was tamed by the arrival of a teacher who gave her back her ability to connect to the outside world by teaching her how to read using *Braille*. Other suggestions on effective means of *crossing the divide* come from the field of health promotion, an endeavour that is dedicated to understanding and facilitating change on both a small and large scale. Based on work on
Australian Aboriginal health issues, Eckerman & Dowd (1991), have the following to say: "Sound cross cultural interactions – prerequisites for effective health promotion- are based on empathy, tolerance of ambiguity (i.e. an ability to cope with differences in culture, values and behaviour) and the capacity to suspend judgement.” p.20

The field of dementia care has also contributed to this discussion in the work of Kanu-Oti (1993) which included a focus on the care of HD affected residents in nursing homes in Maryland, Washington D.C. and Virginia. Amongst others, the following relevant positive characteristics were listed for the “unit care worker” (Kanu-Oti p. 266): Flexibility and resilience, Patience, Ability to think creatively, Ability to learn, Willingness to expand belief system, People, not Task oriented, Good nonverbal communication skills, Sense of humour, Ability to note and report nuances of change in resident. Negative characteristics to avoid were Moody personality, Authoritarianism, Rigidity, Lack of initiative, Negativism, and Uncontrolled enthusiasm.

The discussion now moves on to some of the implications for nursing practice that are proposed in response to the findings from this research of HD in aged care.

6.2.2 Focus groups: shared knowledge to guide change

Wolf, et al (1997) developed guidelines for care of “difficult” patients based on the results of focus groups of staff nurses who were interviewed about strategies they used when dealing with “difficult” patients or families. It is proposed that a similar method could be used to bring together HD-experienced nurses from aged care and specialist facilities for the drawing up guidelines for care of people with HD. These would be based on the development of concept maps regarding essential concepts that need to be grasped to provide effective care for the person with HD in a residential setting.
6.2.3 Making a difference

6.2.3.1 Making a difference through increased resources

This research has highlighted through methodical data gathering and analysis, systematic deficiencies that are often well known to clinicians in this area of practice. It is time to talk money! Without changing the model dramatically, many of these deficiencies could be reduced through the injection of specifically targeted funding for specific purposes such as appropriate furniture, and equipment. Financial subsidies to HD clusters to enable: more single rooms, more age appropriate recreational activities, more frequent education sessions, and the development of more diverse educational material using varying media, (to name just some possibilities), would make a huge difference to the quality of life of HD affected residents. It is argued that because of the relatively small numbers involved, this is an achievable and not expensive goal. However, it is recognised that this would be dependent on the resolution of the current apparent Federal-State political standoff to be resolved with regard to the acceptance of responsibility for the welfare of young disabled adults requiring residential care (Kapp 2002).

6.2.3.2 Making a difference through education

In the final analysis, the most useful insight to emerge from this work is the knowledge that the redefinition of the status of the HD affected resident in the aged care facility from deviance status to that of accidental deviance, holds the key to changed outcomes. The results indicate that the current formal education programmes are highly valued by nearly all the respondents. In-service education has been identified by Pearson et al. (1993a & b) and others (Smith, et al., 1982; Feldt & Ryden, 1992) as contributing to improved care for the elderly. Therefore it is recommended that in order to reduce the impact of the “Cuckoo in the nest” phenomenon, the current education program be revised
and restructured around the concepts of “problem based learning.” An effective model based on the work of Brazilian educator, Paulo Freire has been outlined in the Teachers Guide (Auerbach & Wallerstein 1987). Concepts related to adult learning and the advantages of self-directed programmes are proposed as effective elements in proven models of industry based learning. The existing model could be systematically reviewed in terms of both content and outcomes. Recommendations from the review for planned change would be implemented and evaluated in terms of increased job satisfaction for the nurses and most importantly, improved quality of life for the resident. In this way there could be some assurance that the HD affected resident would be better understood and cared for by increasing numbers of staff. With increased expertise, it is predicted that increasing tolerance and creative problem solving will complement scientific advances to provide the quality of life that they and their family deserve.

6.3 Summing up

This study was undertaken as part of the clinical role of an HD clinical nurse consultant to examine the issues surrounding the care of the person with Huntington Disease in aged care facilities in NSW. It has shown that the 63 residents are a diverse group in terms of age and other variables, and very different from the other aged care residents with whom they reside. A sizeable group (90%), of their professionally qualified, experienced nurse carers reported many concerns about this situation. They identify hazards which create risks to themselves and the residents and which they see as largely due to characteristics of the disease, especially the physical aspects of the disease that require space and special furniture, as well as the challenges of aggressive and other difficult behaviours. However, the nurses appear to want to continue caring for them with
the support of multidisciplinary, community based specialist services. They look to education as a means of improving their effectiveness in their role, which they see as requiring special skills.

However, the study underlined the importance of more complex issues regarding an interactive process with the total care environment. This is now described with reference to \textit{deviance theory}. Lack of knowledge, skill, and experience (particularly in the hostel environment) of the carers, as well as the need for increased funding to meet the needs for specialised equipment, have been demonstrated to impact on the inferred likelihood of the designation of deviance status to the HD affected resident. The argument is made that, in spite of the impact of the factors just mentioned, this likelihood can be changed by a redefinition of the “Deviant status” to that of “Accidental Deviance.” Consequent on this, the removal of stigma, discrimination and distancing, and their replacement with \textit{evidence based} appropriate “nursing attitudes and approaches” (Chiu, 1989; Gardham, 1982; Kovach & Stearns, 1993; Smith, 1998), nursing care plans (Drapo, 1981; Fillingham, 1998; France, 1993; van der Weyden), and “ability enhancing strategies” (Hardy, 1989; Plane, 1996; Seidman-Carlson & Wells, 1998), would revolutionise both the work of HD aged care nurses, and the lives of the HD affected resident, and their family. (Kovach & Stearns, 1993; Warriner, 1990)

This study is believed to be the first nursing research survey focussed on HD affected residents in generic aged care facilities.

By comparison with the two U.K. studies cited in 2.3 (Barczak et al, 1987; and Skirton & Glendinning, 1997), the numbers of HD affected residents accessed for scrutiny in the present NSW study (63, representing 54% of the HD affected population in NSW), were substantial. Pro rata for the population of the USA, the same comparison can be
made with the study by Nance & Sanders (1996). The assertion is made that based on the sampling process and efforts to minimise bias, the resident characteristics may be close to representative of the whole group of HD affected residents in NSW aged care facilities. The contribution of situational factors (as distinct from personal factors), to patient outcomes, was investigated as a core issue as compared to the major foci of other studies. For an illness that is notoriously difficult to treat, this may represent a more pragmatic approach. On the other hand, whilst practice based, the work claims to have application to a theoretical nursing framework of deviance. It is believed that this has increased understanding of incompletely described constituent concepts in the theory and has shown applicability to settings other than the acute hospital system in which the framework was developed.

Furthermore, although the study is firmly embedded in a small specialist area of chronic neuroscience nursing, the insights gained may be applicable to other similar situations where poor nurse-patient relations, and even discrimination based on lack of knowledge, or power differentials due to the size of the group, are an issue of concern. There could be other patient groups with rare conditions or those with antisocial tendencies due to the effects of other diseases.

Alongside non-researched accounts of the value of more expert nurses helping those with less expertise (Gardham, 1982; Klimek, 1997; van der Weyden, 1994), the value of the advocacy and educational role of specialist nurses and other multidisciplinary team members, in particular, is also underscored by the results of this current work.

In the current political climate in Australia where the plight of all young disabled residents of nursing homes is receiving particular attention, increased understanding of the operational variables to improve quality of life, is also particularly timely.
Finally, the study claims to contribute to the advance of nursing practice and thereby to the development of the profession, by meeting some of the challenges stated nearly 10 years ago.

*What is missing is an empirically validated body of interventions to guide nursing practice. Nursing research is needed to validate existing care practices, generate new interventions, and to begin to build theoretical explanations that assist nurses in providing care to people with Huntington’s disease (Kovach and Stearns, 1993)*

### 6.4 New knowledge for a better world

As has just been stated, in these findings lies a wider application both in the clinical, academic, and professional domains of nursing. It is believed that this study has contributed to filling an identified knowledge gap. This new knowledge includes an increased understanding of the condition, Huntington Disease as it occurs in the aged care facilities of NSW. However, not only has the study added to the knowledge of the disease itself, but most importantly, greater understanding has been gained of the nursing challenges which exist in providing care for those with HD in aged care facilities in NSW. Finally, as generic aged care facilities are still the setting for much of the residential care for people with HD in NSW and elsewhere in the world, it is hoped that these findings will contribute to changes in both policy and practice (Kovach & Stearns, 1993). It is thereby hoped to make the contracting world of the person with advanced Huntington Disease a better place in which to spend their remaining days.
CHAPTER 5 - DISCUSSION OF THE RESULTS

This chapter describes the last stage of the research process. Firstly comparisons are made of the findings from the current research with those from relevant studies in the literature, and new knowledge which has been gained from the conduct of the research will be identified. These results will be highlighted in terms of their significance to the overarching research goal (3.1) and the meeting of the four derived objectives (3.3.2). The implications of the findings will include recommendations for changes to nursing practice and policy in order that the goal of improved care for those with HD in aged care facilities can be achieved. The findings will also be related to the nursing application of Deviance (Trexler, 1996), and related concepts of Social Judgement (Johnson and Webb, 1995). In other words, giving the results “practical and conceptual meaning” (Polit & Hungler, 1987 p. 490). This discussion will relate to relevant aspects of all stages of the research process, and will include a section on what the findings may suggest for further investigation.

However, the contextual constraints, research training and other factors have resulted in a work with inevitable limitations. These are now discussed.

5.1 Some limitations of the research

Some of the limitations include the participant recruitment process, the dual role of the researcher, the extended nature of the survey, time constraints in the planning stage and imperfections in the questionnaire.

- The participant recruitment process
Whilst the involvement of the DON of the facility being surveyed was a deliberate strategy to provide positive sanctions for staff involvement in the research, and hereby maximise return rates, it is acknowledged that using this person to recruit nurse participants might have at the same time, introduced uncontrolled bias in their recruitment. The confidentiality of the responses could also have been jeopardised if the completion of the questionnaires was presented as a work related activity and returned via the facility rather than by the nurse. In other words, the responses might be more likely to represent the general attitude of the facility rather than the individuals. The provision of specific instructions to the DON to “choose the person with the most knowledge of the resident” were included in an attempt to standardise this process. The covering letter also attempted to convey an accurate statement of the goals of the research in order to minimise any concern that criticism of the institution was implied. However, it is probable that the design of future research to validate the findings of this study, would include mechanisms to overcome this limitation.

- The dual role of the researcher

Whilst the dual role of researcher and clinician (Huntington Outreach Co-coordinator / Clinical Nurse Consultant) is believed by the researcher to have been an advantage in several ways, there may be negative aspects as well. This aspect is now discussed.

Whilst the relationship between the nurse-respondents and an unseen author of a questionnaire might be assumed to be relatively neutral, the attitude of these nurses towards a nurse specialist who may have provided education to assist in the care of a
potentially "difficult" resident, would not be value free. On the other hand, the nature of
the research role of the nurse specialist was only stated twice: firstly as the "principal
researcher" in the covering letter to the DON, and secondly, in point 6 in the "Guidelines"
on the questionnaire. This states: "If you need more information please contact Angela
Lownie."

The impact of this minimal information on the responses generated by the
questionnaire must remain speculative. Suffice it to say that it is the view of the
researcher that whilst the nature of the relationship might affect the attitude of the nurse
towards participating at all, or completing the questionnaire adequately, the impact on the
nurse with respect to individual questions is considered minimal. This is with the
exception of that one (3.3) regarding the helpfulness of contact with an HD nursing
specialist. In other words, a desire to please, or a desire to be unhelpful, could influence
responses to this question, and possibly, to the one, in Part F of the questionnaire
regarding whether an outreach service is perceived to be essential.

It should also be noted that, in an effort to provide reassurance of respect for the
views of the respondents, the importance of the statement in the introduction to the
questionnaire that "All information you give will remain strictly confidential" was
emphasized by bold printing and uppercase lettering.

With regard to the positive impact of the dual role, it is asserted that this included
the provision of a thorough knowledge of the structure and workings of the research
environment, and, very importantly, enabled access to clinical records to verify details.
On the other hand, the possibility of this influencing the view of the researcher when
looking at the data was acknowledged. Efforts were therefore made to reinforce the
research role at this time to maximise objectivity. For example, all of the data entry and analysis occurred away from the work place, which helped to separate the roles.

- Extended nature of the survey

The research design included multiple mail outs over an extended time frame of about 18 months. The procedure for each was standardised and enabled the workload to be divided into manageable lots. Although not standard practice, this period was regarded as an acceptable parameter for enrolling the study group. This decision was made based on a scrutiny of Outreach medical records. This showed that major changes to the HD population in aged care facilities in NSW were minimal over a one to two year period, and therefore unlikely to cause statistical distortion to the characteristics of the sample. There were also no known unique historical events related to this population over this period likely to reduce the representativeness of the sample. On the other hand, those residents who did relocate during this time, sometimes to more than one facility, had to be carefully identified in order to avoid duplication of data, particularly for those analyses based on demographic information.

- Time constraints in the planning stage

The initial research proposal (Appendix C) was written with speed in order to meet the deadlines for submission of an application for financial resources to employ a research assistant. This is seen as a weakness in the process but has been accepted as one of the constraints present at times in all research, and particularly in clinically-based work where research interest and resources appear to be thinly spread. The challenge was to propose a workable project with the possibility of useful results. One of the original objectives, the comparison of data from nurses in the specialist HD unit with those in generic facilities, was abandoned due to inconsistencies from a statistical point of view. Nevertheless, it is
considered, generally, that the speed of the preparation has not affected the overall outcome of the project.

- Imperfections in the questionnaire

Whilst every effort was made in the research design to ensure that possible sources of bias were minimised, it is acknowledged that the resources available, and the time constraints operating, did not allow for the input of maximum specialised advice regarding the construction of the questionnaire (3.4.5.1). In particular, the results from the question on the input of the multidisciplinary team would have been more meaningful without the variation in the phrasing of the questions. In addition, it would have strengthened the validation process to include a study using external sources to assess the questionnaire in addition to the trial that did occur as part of the questionnaire construction process. The limitations of the trial of the questionnaire by comparison with some recommended methods (Babbie, 1995; Roberts & Taylor, 1998) may indeed be reflected in the deficiencies in the tool as noted above.

Some ambiguities with respect to the lack of sufficient direction for the open-ended questions, which followed several brackets of questions, reduced the usefulness of these results. For example, the "Comments" following a bracket of questions about several resident characteristics, and another about the perceived expert nature of HD nursing and acquisition of the appropriate expertise. It would have been more useful to write these questions clearly as either openers or probes (3.6.2.2).

The lack of clarity in the phrasing of the question asking for confirmation of contact with the specialist nurse (3.6.1.3) has already been discussed.

The inclusion of discussion of the above issues should be considered in the context of the rest of the document, which aims to provide evidence of the successful conduct of
an investigation into, and the meaningful interpretation of, a phenomenon not previously studied from this particular nursing perspective.

The effectiveness of the research design in enabling the research objectives to be met will now be discussed.

5.2 An effective research design

Generally, the research design functioned as a satisfactory blueprint for the planning and conduct of how the answers to the research problem would be obtained. The methods adopted are argued to have been in line with, or more effective than those described in previous studies.

- The population studied

By comparison with three reported studies (Barczak et al 1987, Glendinning & Skirton, 1994, Nance & Sanders 1996), the residential population surveyed was much larger than those by Barczak et al (20 people), Glendinning & Skirton (7 individuals) and about the same as for Nance & Sanders (97 people). The advantage over this last study is that the findings should be also be representative of the wider HD population as the study sample derived from 109 facilities rather than just one.

- Triangulation method

In addition, in an attempt to minimise the tendency of the survey method to restrict the information gained, the inclusion of face-to-face interview data and open-ended questions, provided opportunities for unspecified information to be included. This again was an advantage over the work by Nance and Sanders, (1996) although both other studies, (Barczak, 1987 and Glendinning and Skirton, 1994) had included face-to-face
interviews, none was tape-recorded. The recording increases the accuracy of the understandings gained from the interviews.

- Evidence of a reliable tool

The high interrater reliability result (77%) provided evidence (3.5.1) of consistency of information provided between pairs of nurse-respondents. Consistency was sought and found concerning responses to questions seeking judgements rather than facts. The judgements were requested regarding phenomena experienced by both raters in the pair, and between which there would therefore predictably be a degree of agreement. On the other hand, some variation in views would be expected making the 70% rate an acceptable one. This indicated that the questionnaire construction had been successful in eliminating possible ambiguities of meaning or usage to the extent that discrepant results would reflect different opinions rather than misunderstandings of the questions. This was an important finding to support the interpretation of responses to the questionnaire.

- Evidence of reliable raters

The enrolment of nurses as proxy gatherers of data on the HD population was based on the premise that they would provide accurate and reliable information on which to make judgements about the problem at hand. Although the Specialist Nurse Contact study produced some ambiguous data (3.5.2), there is other evidence to support this claim. This includes repeated instances of information from the medical record corresponding to that provided on the questionnaire: for example, all demographic details including age, relocation history, and the appointment of a guardian.

- Additional information on the nurse-respondents

*Rates of contact with HD specialist nurse*
The introductory letter to the DON of the facility (appendix B) requested the enrolment of nurses into the study "with the most knowledge of the HD affected resident." It could be argued that this selectivity introduced bias that was not controlled for in the design. Potential to include nurse-respondents with negative attitudes to the resident such that they might exhibit avoidance or distancing behaviours (Trexler 1996, p.5) might have been diminished by this strategy.

In fact, the case is now made that not all the nurses whom the Directors of Nursing asked to complete the questionnaire were from a select group in terms of HD education or special interest, and so might be expected to represent wider views. This is based on the finding from the Specialist nurse contact study (3.5.2), that although there had been contact with the facility by the HD nurse specialist, (and usually formal education was given as an integral part of that contact), 15% of the nurses did not personally report contact. This group should therefore be considered as naive responders to the survey, providing knowledge of this aspect of the nurse-respondents and thereby enabling this to be taken into account when discussing results of questions related to educational preparation for HD nursing.

- Confusion over specialist staff roles

The issue now discussed relates to evidence of a probable error by some nurses regarding the professional identity of staff that provide educational support on HD. Results regarding the Nurse Specialist Contact study, indicate that according to the Outreach records, there was a 6% over reporting error of contact that did not happen. Scrutiny of the data indicates that all five respondents who did so came from the same region where HD education is provided by the local genetics social worker, and where very little face-to-face contact had occurred with the HD nurse specialist. The social
worker appears to have been identified by the nurses as a specialist nurse. It is not uncommon for the role of the Outreach Co-coordinator / Clinical Nurse Consultant, to be misunderstood in spite of correct verbal introductions and supporting literature. She is quite often identified as a social worker! In the light of this additional information, the 6% error rate is considered small and no indication to doubt the responses of the nurses.

This concludes the discussion of issues relating to the research design. Next is a discussion of the results of the survey and then the results of the analysis of responses to the questionnaire.

5.3 Results of the survey

5.3.1 Introduction

The response rates for nurse-respondents, facilities, and HD affected residents, and the significance of these figures, are now discussed. These are based on data from the survey (3.4.4).

The survey response rate is an important figure, both as “one guide to the representativeness of the sample respondents” (Babbie, 1995 p. 261) and as an indicator of interest by those surveyed in the topics presented for comment. It could be predicted, however, that the larger the response rate, the bigger the sample of data for analysis would be, and therefore, the greater the options for statistical analysis when sample size is a determinant (Martin & Pierce, 1994 p. 157). In the case of a census survey, such as the one being described, the issue of an acceptable response rate differs from that where the data for analysis are derived from responses to a survey of a sample of the population under scrutiny. In general, a lower response rate for the former as compared to the latter would be considered acceptable. Related to the size of the response rate, is the need for
evidence of a fit of the sample to the actual population. The evidence from the current study regarding the response rates for the three components of the study population in detail, namely: the nurse-respondents, the institutions, and the HD affected residents, is now presented.

5.3.2 Response rates

5.3.2.1 Nurse-respondent rates

Whilst a percentage response rate was not recorded for the nurse-respondents because the population figures for this group are not known, the nurse-respondent to HD affected resident rate was calculated as a useful indicator in considering their responses. This ratio, 1.4 nurse-respondents per resident is evidence of success in meeting the requirements of the study design for multiple reporting on HD affected residents (3.4.2) and also achieved a useful sample size (n = 90). Forty-eight of the 90 nurse-respondents (53%), (4.1.5) were in the group known as multiple reporters. This group was of sufficient size to enable the conduct of the interrater consistency study (3.5.1) with results indicating acceptable reliability in the performance of the questionnaire.

5.3.2.2 Facilities response rates

A response rate of 54% (4.1.1) which represents more than half of all the facilities with an HD affected resident in NSW is considered a good result. It can therefore be considered unlikely that variation in responses from the nurses could be attributable to individual differences between facilities. This source of bias has therefore been adequately controlled.

Unsolicited correspondence from several facilities was also received, which adds to the evidence of considerable interest in the study. In the case of three letters which
justified non-participation on the grounds of an error of identifying them as having
accommodated an HD affected resident, access to the Outreach files did not support these
claims.

In one case the researcher, in fact, had visited the facility to see the HD resident
with an independently confirmed diagnosis. In the second instance, it was known that an
HD resident had spent a short but very difficult time at the facility. It is probable that, as
this was a hostel with few trained staff, knowledge of the diagnosis was lost. In the third
case, a completed questionnaire was actually returned from the facility independently of
the DON's letter, possibly indicating confusion within the institution regarding the
medical diagnosis of residents.

This is further evidence supporting the accuracy of the records on which the study
was based as well as justifying the value of the dual role of the researcher as a check on
the error rate.

The population of facilities included a number of HD clusters (3.4.1). They were
over represented in the sample of respondents (4.1.4). The nurse responders therefore
have more pooled experience than did the non-responders.

The implication of this is not clear and would be worthy of further investigation
(6.1). It should, however, be considered as a possible source of bias when interpreting the
results of the analysis of the questionnaires.

5.3.2.3 Resident response rates

The response rate of 57% (4.1.2) is considered to represent a good response rate,
with the expectation of little sample bias due to variation of the characteristics of the
residents.
This evidence strengthens the credibility of the results whilst falling short of meeting the criteria for a statistically representative sample of the population from which they are drawn.

5.3.2.4 Implications

According to Babbie (1995), for surveys based on population samples, response rates may be judged as indicators of relative lack of response bias and reporting ability to generalise to the population. He suggests that a 50% response rate is adequate, 60% is good and 70% is very good. Therefore, as this study was based on a survey of the whole population, the response rates for the facilities and residents, if compared to Babbie’s criteria, should be viewed as acceptable response rates with respect to sample bias. Evidence to strengthen this argument includes the following calculations in support of the argument of a close fit between the size of the population sampled and the actual population size.

Published western institutionalisation rates for HD affected individuals (all types of institutions), were 16 – 30% (Barczak et al 1987, Glendinning & Skirton, 1994, Harper, 1996, Nance & Sanders, 1996). By extrapolating these to the NSW prevalence figures for 1996, (McCusker et al., 2000), the 111 individuals identified for the current study (non specialised facilities) fell well within the range of the estimated 65 - 121 (all residential facilities) for NSW. In fact, if the 15 residents of the specialist facility are included, the 126 exceeds the top of the range figure.

Whilst Curran, Mahant and McCusker. (1999) reported a finding of 96 people in long-term care at the time of their independent study based on the records of the NSW Huntington Disease Service; this lower figure did not include information from the Hunter region that was made available for the present study.
This leads to a conclusion that the sample was based on an accurately identified population, thereby eliminating bias from this source.

5.4 Responses to the questionnaires

In this discussion of responses to the questionnaire, the focus is first on the meaning of the responses in general, and then in terms of the new knowledge gained from the analysis of responses to the completed questionnaires. Finally these will be viewed against the background of the previously described “Cuckoo in the nest” (Gardham, 1982) phenomenon as well as looking to Deviance theory in nursing, with the concept of accidental deviance in particular, providing a meaningful framework to explain the findings.

5.4.1 General impressions

On scanning the completed questionnaires, the general impression was that overall, much thought and effort had gone into this process. In spite of reservations by one of the expert reviewers of the draft, the lengthy document was completed fully in many cases. In only one instance was the amount of information generated too small for inclusion. In line with field experiences with the nurses, the general tone of the responses was one of deep concern for the plight of the HD resident. Naturally, this was most evident through the question responses, which produced much rich data, which is addressed more fully in the next section. Inferences based on observations of some response patterns of the nurses included the following insight.

The open-ended question associated with the catering for essential needs was notable in generating the least amount of data. Reflection on this included the observation that this question was presented differently from the others in that a blank line was
inserted after the fixed choice question without any instruction like "Comment" or "Please explain." The text that was generated is seen as an indication that the respondents were keen to participate and to comply with the instructions. However, in light of the issues about dealing with ambiguity this dissertation has raised, this overall response could be interpreted as an indicator of less confidence within the group as a whole in an unclear situation, a characteristic of populations less comfortable with autonomy and more used to taking orders. The military background to the development of the nursing profession supports this hypothesis, which might be examined more fruitfully at another time.

It is not an over statement to say that the experience of the process of data entry and then analysis was like unpacking a parcel and finding interesting objects inside! Appreciation of the personal nature of the process under scrutiny engendered a sense of deep respect and a wish to do justice to the information entrusted for scrutiny.

An awareness and statement of this attitude is made in the belief that a conscious appraisal of some of the internal processes of any researcher is appropriate to avoid unacknowledged bias in dealing with the research process. However, in this instance this attitude is seen as a positive motivating influence towards a systematic and thorough approach to managing the questionnaires, data entry, and analysis. On the other hand, an unacknowledged over enthusiastic approach could tend towards a less critical attitude to the significance and applicability of the findings.

5.4.2 Reliability

In addition to the material presented in 3.4.1, other results (4.2.2.3) demonstrating moderate to high correlation between the ratings of the mobility and dependency of the residents, adds to the confidence claimed for the questionnaire and the respondents. This relationship mirrors clinical expectations that the less mobile (and disabled due to the
more advanced stage of the disease process) the resident becomes, the more staff is needed for nursing procedures, which was the definition of "dependency."

5.4.3 The value of a triangulated approach

A triangulated methodology was used as a way of finding out as much as possible from the respondents in order to meet the study objectives. This included allowing the themes, which emerged from the words of the nurses to inform the results of the statistical analysis of the related question. However, the variable amount of qualitative data produced per question also appeared worthy of scrutiny. Reflection on this issue of understanding apparently incongruent data from the survey, produced the following argument.

Based on the unreferenced, but logical premise that the amount of written information the nurses produced might be an indicator of a positive response to the issues being canvassed, the information in 4.2.1.1 was seen to indicate a high level of interest and willingness by the respondents to share their views.

To develop this concept further, comparison was made of responses to the open-ended questions, Opinions on social and emotional needs and the social work role, and Comments on hobbies, interests or the specialist diversional therapy role. Both questions could be classified as Openers (3.6.2.2.) and the responses to each were made by an almost equal number of respondents. With respect to the volume of written material they generated, a discrepancy was noted as the first question generated significantly less (50%) material than did the second.

Another discrepancy was noted when comparisons were also made between the fixed choice responses and the open-ended responses. This related to the social work questions whereby the majority of the qualitative data (62 %) described the theme of
unmet needs, and included equal amounts on the three themes of the meeting of 1. emotional, 2. social and 3. contact needs. This finding was incongruent with that from the analysis of the associated fixed choice questions which found that 85% of respondents reported that residents/family have emotional problems and only 56% reported that the patient/family has social problems. The diversional therapy open-ended responses by contrast amplified the fixed choice responses by providing significant information on lifestyle activities in which 86% had said they participated.

Whilst this seems to raise more questions than it provides answers, the far more prolific responses to lifestyle issues than to social and emotional issues is interpreted to indicate much greater ease of discussing the former than the latter. With respect to aged care nurses whose core work is caring for frail elderly people in a homelike environment, this finding supports the notion that the demands of HD could be difficult for them to meet. These demands include the characteristic social and emotional problems, which are not always obvious without skilled probing, and which, regardless often require the specialist skills of social workers or psychologists to deal with.

5.5 Results of the data analysis

It is claimed that that the credibility of the responses is strengthened by the reported rigor of the research process and the size of the response rates, which leads to the possibility of a discussion of the implications of these findings in terms of how the research objectives (3.3.2) were met. Added meaning is gained from relating the findings where appropriate to Trewler’s nursing theory of deviance (Trewler, 1996).
The initial section comprises comment on the profile of HD affected residents in aged care facilities in NSW and their comparison with related studies from other countries.

5.5.1 Objective 1: The profile of HD affected aged care residents in NSW.

Introduction

The following discussion highlights knowledge gained with respect to study objective one: To describe the profile of HD affected people living in aged care facilities in NSW.

With respect to the original problem scenario of aged care nurses unhappy with the care they were giving to HD affected residents, an accurate description of the HD affected residents in their care was seen as a prerequisite first step to understanding anything else about the problem. This pooled knowledge would also be useful to the Outreach service in general, and the nurses in particular, in improving service provision to HD affected residents and their aged care nurses. What was needed was knowledge of common features of the residents as a group so that general solutions could be sought and individual differences identified and addressed. Using information both from other studies and from the findings discussed in Chapter 4, elements of this profile are now discussed. Firstly, a group of four characteristics common to both the current NSW study and three other studies of residential care for those with HD.

5.5.1.1 Signs and Symptoms of HD

The review of the literature identified three tangential studies (Barczak et al, 1987; Glendinning and Skirton, 1994 and Nance and Sanders, 1996) related to residential care for those with HD. They all included some data pertinent to the HD affected resident profile being sought, but because of differences in methods of assessment, comparisons
are limited. All included information on *Disability or Mobility* status and on levels of *Aggression, Behaviour problems and Swallowing problems*. The following picture emerged. With regard to immobility, the same percentage, (44%) of those in residential care were rated as immobile in the NSW study under discussion and also in the study in Somerset (Glendinning and Skirton, 1994), whereas this rating applied to only 26% of those in the specialist unit in Minnesota (Nance and Sanders, 1996). With respect to the Mean score as the unit of comparison, and on scale of 1 - 4, the Mean Mobility score in the Birmingham study (Barczak et al, 1987), was 2.12 compared with $M = 3.7$ (Glendinning and Skirton, 1994) and $m = 3$ for the NSW study being discussed. No mean score was given for the work by Nance and Sanders, (1996). With the exception of the specialist facility in USA with which comprehensive comparisons on this measure could not be made, the scores quoted predictably indicate an average level of immobility above the halfway mark for all, and well above halfway for two of the three.

With respect to *Expressed aggression*, the high level (69%) noted for the HD affected residents in NSW, was a bit above that (60%) for the Minnesota study (Nance and Sanders, 1996) but less than that (100%) for the Somerset Study (Glendinning and Skirton, 1994). These figures, by contrast, are much higher than the 30% rating for the psychiatric patients in Birmingham (Barczak, 1987), which was noted to be higher even than the rates in their residential facilities. Although it is significant to note that *Aggression* is a consistent feature of the resident profile across all studies, the lack of precise definitions of *Aggression* made it difficult to interpret the discrepancies with the last-named study.

Comparisons across the same studies regarding reported *Behaviour problems* are now made. Once again the Birmingham study (Barczak et al, 1987), quotes lower levels
(M = 1.58 for the psychiatric setting and M = 0.88 for the residential setting), compared with rates of 78% for both the current NSW study and that from Minnesota (Nance and Sanders, 1996), and a 100% incidence for Somerset (Glendinning and Skirton, 1994). As with Aggression, the lack of clear definitions of Behaviour problems limits an interpretation of the lower rates for the study by Barczak et al. although Behaviour problems are clearly a general problem in institutional care for those with HD.

Finally, evidence of a consistent degree of difficulty with eating across all studies is noted. This is noted with regard to reported Swallowing problems, where similar rates are noted (68% of residents in NSW facilities; 67% reported in the Minnesota study, Nance and Sanders, 1996) and 71% in the Somerset study Glendinning and Sanders, 1994), and the “Feeding” disability score of M = 2.41 for Birmingham (Barczak, 1987). Swallowing problems and disabilities with eating are therefore confidently described as universal to those with HD in residential care.

5.5.1.2 Age differential a springboard for change

The results in 4.2.2.1 and Figure 4.2 demonstrated a large discrepancy between the average age of the HD residents (58.4 years) and that of other aged care residents. This finding supports a clinical impression of incongruencies with respect to the ages of all younger people in the long-term care system of people with chronic illnesses, and with respect to Huntington Disease, in particular (Figure 4.2). They do indeed constitute a very different minority group compared to those with whom they live. In response to this finding, another dimension based on the literature, is now discussed. The discussion supports a proposition that in order to reduce the existing age differential in aged care facilities, more HD specialist beds, (about 32) at least for the youngest residents currently
in aged care facilities, should be provided. This proposition hinges on the following arguments.

Firstly, the known HD affected residential care population in NSW comprises 111 people living in statewide aged care facilities (3.4.1), plus 15 in the specialist unit. This totals 126 HD affected people and represents 33% of the NSW HD population of 380 (McCusker et al, 2000). This institutionalisation rate is in line with rates elsewhere (Barczak et al, 1987; Nance and Sanders, 1996) which strengthens the case being made.

The second part of the argument relates to evidence from the literature review (Ball, 1982; Barczak et al., 1987; Bentley, 1999; Chiu & Teltscher, 1985; Gelbart, 1998; Glendinning and Skirton, 1994; Kapp, 1987; McGillicuddy, 1997; Smith, 1998) of widespread support for the view of an HD specialist residential unit being the preferred residential option for care. A major criterion for admission to the existing NSW specialist facility is that of age ≤ 50 years. According to Figure 4.1, 17 individuals, or 27% of the sample of aged care residents with HD, are less than 50 years of age. The next part of the argument is an inference based on this figure of 27% of the total, namely that 32 HD aged care residents would be eligible on the age criterion for consideration for these specialist residential unit beds. Finally according to these statistics, there will be, at any one time in NSW, approximately 32 individuals with Huntington Disease, who are under 50 years of age and who are living in an environment where they are surrounded by people the majority (65%) of whom are 80 years or older.

The importance of this finding, with serious implications for practice in aged care settings, can be described (Gardham 1982) in terms of the “Cuckoo in the nest” phenomenon. This is an example of the possible contribution of “situational relativity” features (Trexler 1996), to the likelihood of attracting deviance status. It is further
supported by the significant correlation (4.2.4.4, Appendix L), between *Age* and global *Disapproval of the facility*, which indicates dissatisfaction with the facility related to the relative youth of the HD affected residents. It is also proposed that the consequence of a rating of inappropriate for the accommodation for a particular individual might include some negative possibilities including distancing, unreasonable expectations of self-control and even efforts to have them transferred out. This "exclusionary" response, (Relocation history 4.2.2.1) was known to have occurred on at least 10 occasions. This provides further support for the tenets of this reformulated deviance theory. The other relationship noted, namely with the measure *Disapproval of the physical spaciousness of the accommodation*, reflects once again the perceived mismatch of these residents with their care environment, another possible contributing element towards their deviance status.

On the other hand, 38% of the sample, was aged over 65 years, matching the ages of their peers in the aged care facility, and was therefore not particularly obvious on this account. However, the effects of the disease, as discussed next, have been shown to represent significant predisposing factors for deviance, which will operate regardless of age.

5.5.1.3 *The influence of other aspects of the disease*

- The natural history: a chronic and incurable disease

Whilst the inhabitants of aged care facilities are known statistically to be subject to increasing levels of ill health, HD remains a rare disease, but alongside other incurable conditions such as AIDS, requires monitoring for treatable new signs and symptoms and changes to existing ones. The focus becomes one of "sickness" rather than "wellness," in contradistinction to the current underpinning philosophy of aged care in NSW. At times the needs would be better met in the acute hospital setting where active treatment is the
norm. This represents another aspect of the anomalous “Cuckoo in the nest” phenomenon.

In line with the findings of Nance & Sanders (1996) with respect to their comparison between the specialist facility and the generic nursing home, the atypical nature of the HD diagnosis in the nursing home setting, was described as being due to the progressive nature of the condition with correspondingly different care requirements.

The implications of HD residents’ different care requirements for the nurses include a need for flexibility and diversity of practice skills. In terms of comparisons with Trexler’s framework of Deviance, this could be considered as being seen as “interfering with the nurses’ work routines” (Lorber, 1975) and thereby an HD diagnosis could be included in a list of features, or Actor relativity predisposing towards attracting a label of Deviance.

- Body image

This brings up a further aspect of the signs and symptoms, namely the prominence of the visual impact of some of the physical changes particularly chorea, facial grimacing and weight loss. In a society where the dominant social values are reflected in the images of perfect and beautiful young bodies on billboards and television advertisements, the physical changes described often give the person with HD a negative prominence on this ground alone. As described by Trexler (1996, p.135), “Demographic data related to age, gender, and physical appearance have also been associated with the label of ‘problem patient’

It is interesting to note that HD is not the only condition causing physical changes which may contribute to deviance status. Narcez (1990), reports that for people with Cystic Fibrosis who have outward signs of the disease such as clubbing of fingers, pot
belly and dyspnoea, these changes are seen by patients to be a source of stigmatisation and sometimes even discrimination.

Extrapolating the idea of visual bodily changes to another sign of HD, namely the underweight status of the great majority of these residents, the resulting need for increased staff time to provide extra nutrition, is proposed as another factor to promote possible deviance status for them. On the other hand, no significant statistical relationships were found between underweight status and any of the other eleven measures of the Resident profile, including age, with which it was compared.

Therefore, in this instance, the findings do not support the notion of the deviance model of Trexler (1996). This may be because the peer group of elderly residents also belongs to a minority group with respect to the issue of prevailing views of attractive personal characteristics and so the person with HD is not as conspicuous or different with regard to this characteristic as they are on others. The evidence of the lower status associated with aged care generally includes work (Hall, 1999) linking this perceived stigmatisation to the perceived lower status of aged care nurses within the nursing profession.

- The significance of surrogate decision-makers

By definition, the legally binding appointment of a guardian or financial manager in NSW presupposes cognitive deficits in the area of judgement and other executive functions. A rate of 65% for the sample is another indicator of variation from the standard aged care norm, although not for dementia specific units. In itself, this status involves extra work for the staff who have to defer all major decisions to the guardian by means of time-consuming communication.
Nance & Sanders (1996) indicated a 29% rate of appointment of a guardian, but meaningful comparison was difficult as the figure of 66% for this NSW study included the appointment of a financial manager as well. On reflection, the legal appointment of a surrogate decision-maker can be interpreted as a strong statement of support for the notion of reduced responsibility by virtue of disease, another possible moderating factor contributing to categorising the HD affected resident as a case of accidental deviance.

- "Difficult" behaviours

Amongst others, the nurses included the following negative descriptions in their collective list (4.2.2.4) of observed clinical signs of HD: “yells, attention seeking, antisocial behaviour, loud vocal outbursts, physical and verbal aggression, inappropriate behaviour, will not wait for attention, passive aggressive behaviours, spits, throws things at people, occasionally hits other residents, and throws a tantrum.” These descriptions appear to reflect behaviours predisposing to the label of unpopular residents. It should also be noted that the literature (Kelly and May, 1982) with regard to the concept of “good and bad patients, and (Armitage 1980, Habenstein and Christ, 1963, and Spitzer and Sobel, 1962), with respect to negative labelling, indicates an increasing tendency to judge behaviours negatively which do not conform to the accepted norm for the patient role. This is particularly when they are perceived as wilful and under the control of the person (Podrasky and Sexton, 1988; Trexler, 1995). To the uninitiated regarding HD, the above comments would fall into that category.

- The challenge of multiple problems

In addition to the challenges of the movement disorder, high (≥70%) reported rates of: emotional problems, behaviour problems in addition to expressed aggression, swallowing problems, and communication problems, are all potentially individual clinical
situations requiring personal, if not unique, care planning and skilled staff input. Reported rates of more than half having the need for a modified diet and social problems, complete the picture. This last is underscored by information from the pooled responses to the open-ended questions, that 10% of all the themes represented the social mismatch coined as “the Cuckoo in the nest” phenomenon (Gardham 1982).

If these are present as a configuration, the complexity and corresponding skill requirements are multiplied and mandatory. If there is also the propensity for the affected person to refuse the help needed to manage these situations, or to be non-compliant, or “resistive” (respondent’s words), another condition towards categorising the HD affected resident as a case of deviancy is surely met. There are several examples of this described by the nurses in chapter 4.

5.5.1.4 Similarities to other aged care residents

- Family contact

A higher than expected (85%) rate of family contact was recorded which indicates less isolation than anticipated from anecdotal reports. Possible statistical links between the Family contact measure and gender showed a tendency for reduced contact for males, but this was not demonstrated at a level greater than chance. This information is augmented from the associated open-ended question revealing that over half of the nurses’ comments were positive observations of family contact.

For example, a most experienced hostel RN said of the social situation of her 71-year-old Anglo-Indian resident: “Eldest daughter and [wife] very supportive. Take resident to appointments when needed. However visit approximately once a month.”
Chapter 5: Discussion of the results

It is suggested that the substantial amount of information volunteered about the social situation of the residents, in terms of family contact, may be seen as an indicator of the holistic view of the residents these nurses have. This is in line with a view of aged care nursing as having its own specialist focus, which includes documentation regarding the social contacts of the resident.

- Gender

The 40:60, male to female proportion was unexpected and is inconsistent with the natural history of Huntington Disease as it is caused by abnormalities on an autosomal, not a gender-linked gene. The 50% chance of inheritance, thereby affecting males and females equally, is reflected in the statistics for all HD patients in NSW (McCusker et al., 2000). On the other hand, comparison with the findings from two similar studies indicates that for the specialist facility in Minnesota (Nance and Sanders, 1996) the Male : Female ratio was 53 : 47 and for the psychiatric hospital HD population in Birmingham (Barczak, et al, 1987), the ratio was 60 males : 40 females. The explanation to this apparent variation in rates of institutionalisation across differing types of institutions and for the increased rates of institutionalisation for females in NSW is not readily obvious. However, on face value it appears to indicate greater problems for male spouses in NSW in fulfilling the carer role for their HD affected wife into the more advanced stages of the disease. With reference to increasing propensity for deviance status however, this gender differential finding would not be noticeable in this setting as aged care facilities have 2.5 times as many women residents as men (A.I.H.W., 1996). The differences noted in the other two studies require local knowledge to interpret.

- Physical disability
Mobility ratings with a propensity towards immobility, and the statistically significant relationship of this measure with reported maximum numbers of staff needed for nursing interventions (the dependency rating (4.2.2.2), appear on superficial examination to be consistent with expected patterns for non-HD aged care residents, and therefore not implicated in possibly negative social judgements of the HD affected resident. Comparison with the four HD studies cited in Chapter 2, indicated a much higher rate of immobility than those quoted by Nance and Sanders (1996), which alongside a younger average age by nearly 6 years, suggests that the HD resident population of the facilities examined had less advanced disease than the NSW one. On the other hand, the nursing home residents in Somerset (Glendinning & Skirton, 1994), appear to have similar ratings with those in the Birmingham, U.K. study (Barczak et al, 1987), but who were in a psychiatric hospital. By contrast, those in this last study described as being in “residential care” were reportedly less disabled.

5.5.1.5 Links to deviance theory

These findings are now examined in the context of the search for evidence of characteristics that would predispose the residents to marginalisation as a result of being labeled deviant by staff or others where they live. In other words, “actor relativity” (Trexler, 1996), includes identifying behaviours seen as wilful, and evidence of non-modifiable or modifiable traits.

Information has been presented which clearly demonstrates that the HD affected residents in NSW aged care facilities, meet many descriptors, including: appearance, an atypical diagnosis, age, not fitting expected social criteria, and having characteristics which could be expected to interfere with nurses’ work routines; all of which have been shown to be linked with negative social judgements including being labeled as “difficult,”
“unpopular” or even “deviant” by nurses in hospitals (Johnson & Webb, 1995; Lorber, 1975; Podrasky & Sexton, 1998; and Trexler, 1996). It is argued that this resident profile (4.2.2) is noted overall to be in line with published clinical knowledge of people with HD who live in aged care institutions. It is also argued that many characteristics of this same profile potentially disadvantage them in this way. Other characteristics of the profile such as Gender as already noted, are not considered significant in this respect.

In summary then it can be said that many aspects of the HD affected resident profile meet the necessary criteria for the deviant label to be applied. The social environment in which the resident lives has been shown to produce an ambiguous context because of the age differential between the HD affected resident and the other elderly residents and due to the effects of a physically disabling, incurable disease. This increases stress levels in the nurses whose tolerance of difference is thereby reduced, even for those very characteristics over which the patient has no power. On the other hand, as per Johnson and Webb’s contention (1995) that social judgements occur as part of an ever changing dynamic scenario of social relationships, this tolerance could be further influenced by other factors such as low staffing levels or other environmental influences, which will act as additional intervening variables in this process. Other aspects of the care environment are now examined starting with those identified in the second Research Objective, The identification of aspects of providing care for HD affected residents in aged care facilities which the nurse carers perceive to be unsatisfactory.

5.5.2 Objective 2: To identify unsatisfactory aspects of care provision

The following discussion focuses on the interpretation of the results which contribute to the second research objective: to identify aspects of providing care for HD affected residents which the nurse carers perceive to be unsatisfactory. In terms of the
theoretical background, this section is an examination of the context relating to nursing performance in which potential labelling occurs. It will seek indications of negative aspects of the care provision environment that could increase or diminish the likelihood of the deviance status of the HD affected resident. These will be sought from measures of satisfaction/dissatisfaction with various aspects of the care for the residents, which will now be discussed. This is done in three sections:

First the importance of the nurses’ views on aspects which are regarded as the responsibility of the facility,

Secondly with respect to views on aspects of medical care for the residents, and then with respect to Direct care provision by the staff.

5.5.2.1 Facility care provision

The responses to questions about standards of Facility Care Provision, generally provided endorsement for positive views of this aspect of the general concept of Care provision as stated in Objective 2. However, some strongly stated exceptions will be described in the last part of the section.

Consistently high levels (>88%) of satisfaction with the performance of the employing facility were stated by the nurses. These figures relate to questions about:

- Adequacy of facility care
- Catering for essential needs and
- Catering for nonessential, higher order needs

In addition, the evidence is there (4.2.3.7) of personal involvement in what could be termed “lifestyle activities,” a characteristic found by Pearson, et al, (1992a, 1992b, 1993a, 1993b) to be a feature of the higher performing nursing homes in their study. For
the nurses in this current study (4.2.3.12) there was a close association between this parameter and the provision of individualised nursing care. This implies identification of the one with the other and provides support for the view that the respondents see lifestyle as part of the domain of their nursing role. The work by Barczak et al (1987), and Glendinning and Skirton (1994), describes a similar finding, although their numbers were too small to support generalisations.

However all these observations are in stark contrast to the role of the acute hospital based nurse, upon whom most of the labelling theories were based (Johnson & Webb 1995, Lorber 1975, Stockwell 1972).

The evidence is also there (4.2.3.7), that although there was at times a focus on difficulties in the area of lifestyle provisions, the nurses are committed to care which is more than merely meeting basic needs, and also provides for the more abstract notions such as pleasure, fun, belonging and exploring meaning of life issues.

In addition, the following results acts positively to supports the case that generally, the provision for nonessential (including lifestyle) needs counteracts the impact of the resident characteristics, in promoting deviance status for the HD affected resident. These are the moderate correlations found between the measure Ratings of meeting nonessential needs, Rated Appropriateness of the facilities (seen as an overall satisfaction measure) and Rated Spaciousness of the facility.

On the other hand, in addition to revealing the complex and dynamic nature of the whole phenomenon, the results of the analysis of an open question, The adequacy of individual care provision, gave information regarding some of the difficulties experienced in this area. Contained in one of the constituent themes, "Views on lifestyle issues," these responses highlighted one aspect of the "Cuckoo in the nest" phenomenon, namely the
carers’ responses to some behaviours of the HD affected resident that caused frustration. These provided direct evidence of the negative effects on the nurse-resident relationship caused by unfamiliar behaviour that is incongruent with their expectations of the situation. In other words, the behaviour does not easily fit the mind-set they bring to the work situation. From the nurse-respondents’ comments on the theme of difficulties regarding lifestyle issues, this mismatch of behaviour and expectation produced a variety of responses. There was sometimes increased effort to find solutions to the challenging situation through networking, research or trial and error, or the carers may have resorted to blaming the person at the centre of the mismatch. They also sometimes simplified the situation to suit their personal theory of aberrant or deviant behaviour. In line with the work of Benner (2001), Ciolfi (1997), Gardham (1982), Seidman-Carlson & Wells (1998) and Smith (1998), it is proposed that these findings highlight the need for quite advanced analytical skills in all carers of HD affected people. The challenge for the nurse is to make sense of the complexity (social, physical and psychological) of the total phenomenon they witness.

This negative view of Facility care provision is supported by information from another open question aimed at identifying unsatisfactory aspects of care provision, namely knowledge of “Essential needs that are not always adequately met.” These results provided interesting insights into dissenting views to the endorsement of care which has been expressed. The “Denial of the identity or personhood of the resident” was a theme representing one third of all the responses. As evidence of the holistic view these nurses bring to their work, this theme represents deep dissatisfaction with care. It seems to imply almost total negation of the very existence of an individual, and paradoxically, the lack of provision for higher order needs such as love, esteem and self-actualisation (Maslow,
1987). With respect to its application to the theoretical framework of deviance (Trexler 1996), the finding is also considered as evidence of differential care provision, allied even to some of the exclusionary responses quoted in the literature on deviance. This leads to a consideration of the phenomenon as discriminatory and against the basic philosophical underpinnings of the Australian Health Care System, a very serious situation indeed.

5.5.2.2 Medical matters

The views on the medical management of the HD residents are examined first, followed by a brief comment on the reported frequency of medical specialist contact.

With respect to the nurses’ views of medical care for the HD affected resident, it should be noted that although the two relevant measures were included in this, the Care Provision objective, rather than the next objective, namely the Impact of Resources, an argument could be made for their inclusion in either objective. The following discussion however, would have equal relevance for either objective.

With regard to the performance of the nurses’ medical colleagues as measured by satisfaction for firstly, The regularity of medical assessments and secondly, Medication management, the nurses’ responses indicated very high levels of satisfaction for Medication management but opinions were more equivocal regarding the Need for more regular medical assessments. Considering these findings in conjunction with the results of the associated open-ended question, it can be said that, with some strongly stated exceptions particularly by the hostel nurses, there was general satisfaction with those aspects of care, which are the responsibility of the doctors. The finding was somewhat unexpected in light of the outreach nursing clinical experience motivating the inclusion of these questions. This will now be discussed.
The nursing experience in the HD specialist team with direct access to HD specialist neurology and psychiatry, confirms the view that appropriate medication improves the lives of people with HD and thereby, their carers too. Reported difficulties of poorly managed signs and symptoms of HD have been found at times to indicate lack of confidence and knowledge on the part of the local medical officers in prescribing medications for HD. The aged care nurse-respondents appear to accept the status quo in this respect. There may be several reasons for this, but one may be that there is a differential in HD knowledge and experience between that of the specialist nurses and their generic counterparts, which limits the aged care nurses’ vision of what is possible for their HD affected resident. If this is the case, it provides an incentive to include more information about the potential value of medication in management of the signs of HD in formal education sessions and written material.

On the other hand, those who dissented expressed strong and often knowledgeable views, which reinforce this last point regarding the value of education in raising awareness of possibilities for change.

As a counterpoint to these last two points however, information related to the last objective indicated that over half of the sample was reported to have medical specialist contact. This contact should provide an opportunity for expert review of the medications, which would support an apparent confidence in the medication management of the HD affected residents. In summary, an acceptable standard of medical supervision of medications of the HD affected residents was endorsed, but an appreciable need for more regular assessments was identified. These questions also raised additional possibilities to explain the findings, which are considered a valuable research outcome.
5.5.2.3 **Self assessment of direct care provision**

The five questions (4.2.3.3 – 4.2.3.7) relating to care provision to overcome the disabilities caused by HD were all answered in the affirmative by over 75% of the nurses. This is strong endorsement for the effective provision of direct care by the staff.

With respect to ratings of the provision of direct care by staff, 90% gave a rating reflecting views of above minimum standards for *staff care*. When compared to the ratings for the measure of *nonessential facility care*, i.e. *above minimum standards*, the staff care ratings were more strongly endorsed. In other words, the nurses’ expressed greater approval of care provided by themselves and their colleagues as compared to that seen as the responsibility of the organisation in which they work. The strong correlation noted (4.2.3.12) between the last two measures, indicates that as the one varies, so does the other. This observation adds weight to the comparison previously made between them.

Information from the analysis of the nurses’ words adding depth to these findings is now given. This includes the observation that this question generated the second most prolific amount of material next to the description of the signs and symptoms of the disease. On this basis alone, the question should be considered important in providing answers to the research question as to why the nurses express dissatisfaction with regard to the HD resident.

With respect to the content of their answers regarding the two possible categories of adequate care, there was a tendency for respondents who rated the care as adequate, to use as evidence for their rating of adequate care, statements of a general nature. These relate to more standard, predictable criteria such as reporting changes in the resident’s condition to the responsible medical officer, or comments such as "*good staff who do the*
"best they can." On the other hand, examination of the 41 responses by nurses who rated the care as very adequate for the previous multiple choice question, revealed that they were more likely to make explanatory statements regarding the roles of staff attributes, environmental factors, nursing philosophy, family, and more specific aspects of the nursing role.

In addition, the group of respondents who had recorded more, rather than less, adequate care ratings but who had added the rider of barriers to even better care, had almost unanimously rated the staff care as only adequate in the multiple choice question. Their comments, as already shown (4.2.3. 2), amplify this response in quite specific ways. Thus, it can be seen that the more positive responses to this question can be divided into those of a general and those of a more specific nature.

The interpretation of this overall picture could be that the respondents who are prepared to rate the care provided by themselves and their colleagues as very adequate, by comparison with those who do not, have a clearer and more detailed perception of what constitutes good practice.

These data also highlight the important role played by environmental factors, such as time allocation (4.2.3.2, Theme 4) and the physical environment, in the eyes of the nurse-respondents. Time allocation and the nature of the cognitive deficits in HD in particular, are linked through the concept of the characteristics of the disease being a major factor in the ratings of less adequate care.

Overall, the analysis of the data generated by this question echoes the original taped interviews (3.4.5.1) with HD experienced nursing staff, which produced the detail of the questionnaire as reported in Appendix D. These findings provide strong evidence that
the questionnaire is a valid instrument and that the postulated contribution of the HD resident characteristics to the labelling process (5.5.1) is supported.

This succinctly summarises the findings related to the proposition that aspects of care provision will moderate the predisposition (which was demonstrated in the previous section) for the imposition of deviance status on the HD affected resident. Although there were clearly some negative aspects, the overall view was of facilities providing an adequate care environment in which the nurses reported they gave more than adequate individualised care.

5.5.3 Objective 3: The impact of internal resources on care provision

The following discussion highlights answers to the third objective namely to test the appropriateness and adequacy of the facility’s staffing and other resources, and whether some nominated factors represent barriers to optimal care for the HD affected resident. The impact of resources from within the facility: the testing of the appropriateness and adequacy of the facility’s staffing and other resources, and whether the lack of, or the quality of some of these represent barriers to optimal care for the HD affected resident. In terms of the theoretical background of deviance in nursing, information gleaned in meeting this objective provided guidance as to whether environmental factors affect the possibility of assigning deviance status to the HD affected resident.

In this study, the environmental factors are in the form of the staff and other resources that are provided from within the facility. The validity of suggested barriers to optimal care is also canvassed. It is postulated that the challenge of providing care for the resident who is so different to the others in the facility, would be exacerbated or ameliorated by these other factors, the detail of which is now presented. The resources
are discussed in three sections: firstly the impact of the physical environment, secondly barriers to best practice, and finally, the contribution of staff attributes as an influence in assigning deviance status to the HD affected resident.

5.5.3.1 The influence of the environment – physical, and professional

It was thought that external, or environmental, factors probably made a major contribution to the difficulties reported by the nurses in their care of HD residents. Equal numbers of nurse-respondents making positive and negative responses to the question regarding the appropriateness of the facilities (4.2.4.4), suggests ambivalence by the respondents to this issue, thereby challenging this notion. On the issue of the roominess of the accommodation (4.2.4.5), the responses were very similar.

Based on these results, the message from the nurses seems to be of tentativeness in judging the facility, which, considering that their educational preparation and practice revolves around the health of people, rather than buildings, is probably justified on one level. It may also be that at the level at which they practice, the issue of possible changes to a less than perfect work environment is not seen as their responsibility so does not receive their attention.

The strong correlation noted between the nurses’ views of the appropriateness and the roominess of the accommodation, (4.2.4.4, 4.2.4.5 and Figure 5.3) indicates the possibility of one common underlying construct, which relates to global opinions of the facilities. The moderate correlation, in a negative direction, between the appropriateness measure and the ages of the residents (a major component of the “Cuckoo in the nest phenomenon”) is thus seen as a key conceptual link to the theory of deviance for nursing (Trexler, 1996).
Chapter 5: Discussion of the results

There has already been discussion (5.5.2.1) to illuminate the notion of care provision concepts such as meeting higher order needs can minimise the impact of the affected resident characteristics. Attention is now focussed on the concept of the nurses’ characteristics in attributing deviance status. The statistical analysis undertaken did not reveal any direct links to the resident profile, but the concept of nursing experience was moderately strongly correlated with that of professional educational level attained, and more weakly, but nevertheless significantly, with that of HD nursing experience. Therefore, it is proposed to consider these three concepts as secondary influences on the possibility of deviance status being assigned to the HD affected resident. Thus it was shown that the registered nurses (with higher levels of education and more nursing experience of various sorts), are less critical (or more tolerant) of the facility’s shortcomings with respect to the HD affected residents there. The significance of the discriminating effect of educational achievement of the carer on various outcomes was reported in some of the literature reviewed (Courtney & Spencer, 2000; Feldt & Ryden, 1992), although none appears to shed light directly onto this particular finding. Taken at face value it appears that the problems encountered with HD nursing in the aged care setting are not as troubling to the more experienced RN’s as to the other nurses. There are several possible explanations for this including the possibility that the reduced number of personal interventions undertaken by the more experienced RNs in comparison with the more hands-on role of the E.N.’s and A.I.N’s, limits the opportunities for problem encounters. This is a type of “distancing” which in other contexts is seen as a deliberate defence against anxiety provoking experiences. Certainly, Feldt and Ryden (1992) linked the issue of the amount of contact with the extent of educational preparation. In view of the improvements noted by Feldt and Ryden (1992) following targeted education as well
as modelling by an advanced practice nurse, it would appear that basic educational background is not as important as education focussed on the specific problems.

On the other hand, although the impact of the environment is often the domain of a specially designated Occupational Health and Safety nurse, maintenance of standards to prevent injury has become everyone’s responsibility and focus. This may explain the discriminatory response to the question regarding the presence of hazards putting carers and residents at risk. An affirmative response to this fixed choice question was clarified by responses to the associated open-ended question represented diagrammatically in Figure 5-1 below. There were 74 examples of language that was classified in the theme of Internal factors increase risks as against only 26 examples of language which was subsumed into the theme of External factors increase risks.

Of the two themes that emerged from the analysis, “External factors which increase risks” and “Internal factors which increase risks,” the second more prolific group identified “personal and disease-based internal factors” as hazards in care giving. Thus, this analysis clearly supports the notion that elements of the nature of the disease, HD, are perceived by the nurses as increasing risks to themselves and to others.

Whilst the nature of a disease may be a neutral concept in itself, “the person” affected by a disease which is as pervasive of the whole person as is HD, could conceivably be interchanged with “the disease,” in the mind of the respondent to this question. In other words, this may be an obtuse way of saying that the HD affected resident, rather than the disease, is a danger to others and therefore should be avoided. Some of the nurses, some of the time have made the case for the isolation and stigmatisation of the resident based on their disease.
Chapter 5: Discussion of the results

FIGURE 5-1 REPORTED HAZARDS THAT INCREASE RISKS
Other information in this section, which supplements the notion of differential treatment by some nurses, is drawn from the responses to an open-ended question detailing other problems with the accommodation. A stated lack of specialist accommodation, the theme for 26% of the responses, was underpinned by the following scenario constructed from their words. The nurses identified that having an HD resident living in an aged care facility results in emotional reactions by others, including residents, their families and staff. The age gap (about 20 years) creates a situation resulting in no peers and social isolation for the HD resident, who may also be ostracised.

Evidence of particularly strong views supporting first the notion that insufficient staff support was a barrier to optimal care, and secondly that there was a need for more regular medical contact, were gleaned from the study that identified the characteristics of the hostel nurses subset (4.2.4.3). These were the majority views of the hostel nurses who represented the least educated of the nurse responders and whose work environment, by definition, was characterised by low staff to aged care facility resident ratios.

5.5.3.2 Barriers to optimal care

Approaching the issue of understanding the components of this apparently complex phenomenon from a different angle, the discussion now moves to reflect on responses denying quite strongly that insufficient staff support, fear for safety of staff or residents, or less than adequate staffing, represented such barriers. On the other hand, the admission by even 36% of 86 respondents, i.e. 30 respondents that fear compromises care, must be interpreted as evidence of negative consequences for the diseased HD resident: a case of possible discrimination based on characteristics, which cannot be modified, and for whom the affected person can never be held responsible. Likewise, other parameters, such as the roominess of the accommodation, the provision of appropriate lifestyle
activities, or the provision of HD education for staff, which can be more easily altered than the nature and course of this disease, may change the propensity for the HD affected resident to attract deviance status.

Finally, on the issue of funding, which received almost unequivocal endorsement as a barrier to best practice, a case could be mounted for an urgent financial response by Australian state governments on possible humanitarian and equal rights grounds.

These sentiments are further reinforced by acknowledgement that this last question was also the most frequently reported on category (38%), in the related qualitative data. Reference to the respondents’ words, which were coded into a theme “Funding as a barrier to care,” in, the qualitative analysis, indicated that the respondents were preoccupied with placing the responsibility for the lack of funding with the government authorities. This is exemplified by one of the nurses who said: “There is no recognition by authorities of the special needs for HD.” It is postulated that those who saw the funding issue as important felt strongly enough about it to write comments on it, and largely they held the government responsible for this situation.

5.5.3.3 The value of education and HD experience

The characteristics of the nurses is considered particularly important both as an important contributor to all “resident outcomes” (Pearson, et al., 1992a), and as a possible contributor to the negative labelling process. Whilst concepts of staffing mix and skills mix have been used (Pearson, et al., 1992a to differentiate between the impact of qualifications alone or combined with additional education experiences, and experience, this level of sophistication was not possible in this study so that professional qualification and education were treated as equivalent measures.
As has already been mentioned, the deviance literature quotes many examples of the importance of staff characteristics, including education, experience (Podrasky and Sexton (1988), cultural background, and attitudes, derived from authoritarian traditions in nursing (Boorer, 1970a and Cartwright, 1964, as cited in Kelly and May, 1982).

With this in mind, the importance of the findings regarding the amount of HD nursing experience, the nursing qualifications, and the correspondingly inferred nursing education level of the respondents, is now examined. Practical implications, comparisons with findings from other studies, and the relevance to the theoretical model of deviance proposed by Trexler (1996), are also discussed.

- Experience

Most of the nurses had some but not much, previous HD nursing experience. It could be argued that the educational value of nursing two or fewer HD affected residents previously (the experience of 61% of the sample group), might be questionable in view of the complexity of HD. This refers to the changing needs according to stage, variation in type and degree of signs and symptoms presented, (Drapo, 1981; Hardy, 1989; Harper, 1996; Hoffman, 1999; Kimball-France, 1993; Kovach & Stearns, 1993; Seidman-Carlson & Wells, 1998; van der Weyden, 1994). However, there can be no doubt of the importance of even limited exposure in increasing the levels of confidence, of the staff and better care for the HD affected resident (Ball, 1982; Barczak et al. 1987; Bentley, 1999; Hardy, 1989; Klimek & Rohs, 1997). Taken as a whole, and considering both the length of overall nursing experience and the numbers of HD affected residents nursed previously, the majority of the group was described (4.2.4.2) as having limited experience only. Perhaps they have enough experience to manage most of the HD affected resident’s physical signs and symptoms, but not necessarily for example, a more complex scenario
including difficulties with persistent refusal of personal care accompanied by aggressive responses.

The significance of education level is shown to be of even greater importance for the HD affected resident when combined with the measures of experience and global satisfaction with the facility. *The less educated nurses are also less experienced and express more dissatisfaction with the appropriateness of the facility.*

Taken in combination with knowing that most staff in aged care facilities are the least educated (AIN’s), it is clear that the frustration expressed by this group would have a significant impact on the experience of the HD affected resident and their family. When one acknowledges that the family can include some young, impressionable children, the impact of this situation is seen to extend well into the rest of the community, and well into the future.

The value of experience in nursing has received serious attention (Benner, 2001; Cioffi, 1997). The analysis by Cioffi of the use of heuristics as the basis for expert decision making, supports the view that for a nurse, confronting an unusual clinical situation would involve drawing on many personal resources including knowledge and experience. If an effective solution was unavailable, frustration, and feelings of inadequacy and loss of control would ensue which may lead to reduced tolerance and less than professional responses. At the least, there would be reluctance to have no more than the minimum amount of contact. This scenario illustrates how the response of “distancing” may ensue.

- Qualifications and education

The finding (4.2.4.2) that 85% of the sample reported their qualification to be that of RN, (reflecting the highest educational level), conforms to expectations with respect to
enrolling a group of respondents who would have the desired ability to make the
judgements required to complete the questionnaire in a manner enabling meaningful
analysis of the data to occur.

In addition, the issue of education level of nursing staff being considered as a
factor in the phenomenon of the labelling of non-conforming patients as deviant is now
raised. This characteristic of a predominantly highly educated group could bias the results
with respect to the possibility of a reduction of negative attitudes to the HD affected
resident. Several studies indicated the increased likelihood of negative labelling with
decreasing levels of education of staff. Therefore, the lack of any strong evidence of such
attitudes in all the results such as, the perception, for example, that fears for their safety
would be a barrier to optimal care, which was denied by 64%, should be interpreted with
this in mind. This possibility is supported by the outreach not essential response given by
a small group of five nurse-respondents who had received almost unanimously no formal
HD education.

In terms of the application of the reformulated deviance theory (Trexler, 1996), to
the study under discussion, it is timely to propose that this study of HD in aged care,
highlights the possibility of the redefinition or conversion of deviance status to that of
accidental deviance by virtue of the role of education and specialist input. In other words,
there is the tendency in the face of the unusual and socially unattractive characteristics of
the residents (actor relativity), as well as some responses indicating the disease (and
thereby the person) to be considered hazardous, for deviance to be declared. This is
counteracted, on the other hand, by the impact of a higher general educational level and
access to understanding the nature of the disease processes, resulting in a reframing of the
person (and their disease) as being not accountable for their antisocial characteristics.
They are “forgiven” and treated with increased tolerance as solutions to the difficulty created are sought. The solutions may move away from efforts to manipulate the resident, to efforts to change elements of the environment. This environmental change could include increasing the skill levels and HD knowledge base of the less educated staff, the provision of more flexible routines according to the preference of the HD affected resident and the provision of increased personal space for the resident.

Thus the examination of new knowledge gained from the HD research under discussion has identified the major role played by internal resources, such as physical characteristics of the environment and the nursing profile. In line with the findings of previous studies (Feldt & Ryden, 1992; Pearson et al. 1992A; Smith et al. 1982), staff skill and educational levels were linked with standards of care. The discomfort experienced by the nurses in the face of ambiguous or unclear situations was reinforced and will again be amplified by much of the discussion in the next section.

5.5.4 Objective 4: The expert nature of the HD nursing role and its support

The following discussion will highlight understandings gained with respect to objective four: The determination of views on aspects of the nursing role; namely its skill requirements, feedback on current methods of obtaining these skills, and views of the effectiveness and accessibility of the existing HD multidisciplinary services in supporting this role. The discussion will highlight new knowledge gained from the current research as compared to findings from relevant literature, including a focus on aspects of the HD nursing role and their contribution to the possibility of deviance status being conferred on the HD affected resident.

Firstly, there is a focus on HD nursing skills and their acquisition, followed by discussion on the findings regarding the contribution of medical specialists, the members
of the multidisciplinary team, the outreach service and the value of the HD specialist inpatient unit.

5.5.4.1 Acquiring adequate HD nursing skills

The overwhelming support for the notion that HD nursing requires special skills can be interpreted in at least two ways. Firstly, as a statement from a group of relatively unsupported, novice nurses with respect to HD nursing, who lack confidence in their ability to provide this specialist care, or alternatively, as a statement of the belief of these nurses in the expert nature of their skills. Although the second position is supported by the observation that their responses overwhelmingly rated their care as above average (5.5.2.3), there was a lack of compelling direct evidence for either view. Therefore, the overwhelming support for the notion of HD nursing requiring special skills will be interpreted on face value simply as a statement that special skills are needed for this work.

The finding from the next question that over half of the nurses reported contact with the HD specialist nurse (usually including formal education) and that all, with the exception of two respondents, were affirmative that “this contact was helpful in delivering better care to the patients,” endorses this as an acceptable method of promoting the acquisition of these skills. The evidence of a small, statistically significant association (Table 4-3), between the measure of contact with the HD nurse specialist and the measure of receiving HD education subsequent to the admission of the HD affected resident (4.2.5.2), indicates that contact usually included education, which strengthens the claim. On the other hand, with respect to the deviance theory of Trexler (1996), the impact of HD education as a means of reducing the potential for the HD affected resident to be
seen as deviant was not demonstrated statistically. No significant associations were demonstrated between either of the two additional education measures, or any other measures from the questionnaire. The importance of the highly educated sample in masking associations, for example, between overall satisfaction with the facility and educational attainment, remains speculative but possible.

The amplification from the associated qualitative data is interpreted as adding to the knowledge regarding the nature and preferred method of acquisition of these skills. As an alternative means of acquiring skills, the value of experience is highlighted by this nurse’s words: “Only what I gathered, by reading the Huntington Disease Booklet and information I got from visiting other Day/Care centres. I did learn a lot from experience, how to cope with H.D patients. I certainly knew a great deal more about "Huntingtons" by the time the patient went to another special accommodation to be closer to his family and specialist. I enjoyed very much caring for him, whilst in our care.”

Thus, it has been shown, in line with the findings from non-HD literature (Feldt and Ryden, 1992; Pearson et al., 1993b and Smith, Jepson, & Perloff, 1982), that the provision of in-service training sessions and other forms of education such as self education and learning from experience, made a difference to the staff. Whereas staff performance in managing aggressive behaviour (a difficult to manage dysfunctional effects of HD) was reported to have been improved (Feldt and Ryden, 1992), in the HD study, staff reported increased confidence in managing people with HD. Education provision in other studies was also positively related to resident quality of care and quality of life (Pearson, et al 1993b). Staff attitudes to their clients were also linked to the amount of basic educational preparation they had received (Smith, et al., 1982). However,
Staff education levels in the HD study were not statistically linked to the measures of individual or facility care provision.

5.5.4.2 Medical specialist contact

The evidence of a substantial amount of contact by the resident with medical specialists endorses the view of the specialist medical nature of their disease. This again emphasises the individualised nature of the care required by this person. This has been shown to be difficult for some of the nurses due to the lack of corporate knowledge of HD and the ensuing lack of collegial support (4.1.4), lack of educational preparation (4.2.5.2), and also lack of effective medical treatments for some of the signs of the disease (1.3, 4.2.2.5 and 5.7.1). It is also further evidence of referral of the resident for specialist help, arguably part of what Trexler (1996, p.5), in her reformulation of deviance theory for nursing, describes as a “Status degradation ceremony.” According to the proposed theory, the status degradation ceremony contributes to a designation of deviance for the person being referred. This claim is supported by its demonstrated statistical relationship with the problem behaviours measure (4.2.5.3), an indication that this negative resident characteristic is associated with seeking outside assistance with the care of the HD affected resident.

5.5.4.3 Evaluation of the multidisciplinary team roles

In spite of stated reservations (5.2) due to inconsistencies of phrasing of the questions for this section, the results were nevertheless considered useful in adding to the arguments made regarding the Cuckoo in the nest phenomenon, as follows. The fact was that the nurses indicated a generally high level (over 60%) of preference for the HD therapists over their generic counterparts, regardless of the amount of contact with the HD Specialist. This indicates satisfaction with the help given by these therapists. It also
could be understood as support for the notion of both their inadequacy to deal with the HD resident, and their hope that by involving an expert, the person (and their disease) will be declared in need of specialist care and removed from their ambit.

A statistically significant, although quite weak, relationship was demonstrated (4.2.2.1) between the youth of the resident and a stated preference for the HD specialist diversional therapist. This is a clear indication that there is a real problem providing for the lifestyle needs of these residents, and evidence of the social mismatch inherent in the “Cuckoo in the nest” phenomenon.

5.5.4.4 The indispensability of an outreach service

The overwhelming valuing of the outreach service was supported by mainly positive views in the nurses’ words.

The role was described clearly, with provision of support and advice as the most common functions described.

On the other hand, as described in Section 4.3.2.7, five respondents did not agree with the statement that it is essential to have available a specialist outreach (community) service. The results of that analysis of their responses did indicate however, some possibilities to illuminate what may distinguish them from their peers. They were reportedly uneducated about HD through formal avenues, although experienced with regard to caring for someone with HD. Their HD charges had advanced disease, including swallowing deficits, without a statement from the nurses of the most common strategy (modified diet) being in place to reduce the risk of aspiration. Among other possibilities, their rejection of the essential nature both of an available HD outreach and inpatient unit may be seen to indicate either a lack of awareness of the broader issues relating to HD or a confident “hands-on,” practical approach to care issues with less
evidence of critical thinking driving their practice. In terms of the framework (2.5) regarding the value of external services in redefining the deviance label to that of “accidental deviance,” this knowledge could give understanding to the barriers to be overcome in achieving this redefinition for those apparently few nurses who, it is suggested, may be less open to change.

5.5.4.5 The indispensability of a specialist inpatient facility

This question was profitable in producing rich information about the required expertise for the HD nursing role related to the role of the specialist inpatient facility. This is discussed firstly with regard to the superficial analysis of the fixed choice responses, followed by the meanings derived from the associated question. The discussion then moves on to how these compare with findings from the literature and subsequently to understanding the responses to questions associated with this one. The contribution of meaning gleaned from viewing a snapshot of a group of residents who are linked by their disease characteristics and the common characteristics of their nurse carers, follows with the final section relating these findings to the theoretical backdrop of deviance and other frameworks.

Firstly then, with regard to the question as to whether a specialist inpatient facility is essential, the nurses’ responses indicated their ambivalence.

This was augmented by reflection on the inclusion of the adjective “essential” which conveys an extreme position with regard to the inpatient unit. The nurses’ words probably explain that whilst not being perceived as indispensable, the specialist inpatient unit would certainly be desirable, particularly at certain times.
In addition, review of their words "explaining" the fixed choice responses, indicated that only 23% of the volume of the text supported the need for a specialist HD facility as being essential. The content analysis indicated that the nurses who did consider the specialist unit essential, generally described the purpose of such a facility in terms of providing above minimum standards or for non routine needs such as end stage care. Those who did not consider the availability of a specialist HD inpatient unit to be essential, likewise explained this in terms of seeing such a facility as either unnecessary or as a luxury. In terms of the rationale behind the wording of the question (4.2.5.10), the open-ended responses do not reflect extreme dissatisfaction with the status quo nor a preference for an alternative model. Those endorsing the concept did so in terms of it being desirable rather than essential.

In relating these observations to relevant findings by other authors, notice was taken of various arguments presented by Chiu (1990), Hardy (1989), Smith (1998), and particularly by Kapp (1985, 1987), as already stated (1.4), in favour of the establishment of Huntington Specific Care Units, both worldwide, and also in NSW. Other health professionals (Barczak, et al., 1987; Gardham, 1982; Klimek, et al., 1997; Skirton & Glendinning, 1997) have referred to problems with accommodation particularly in psychiatric institutions in the United Kingdom. In comparison with the findings of these authors, it is noted that this significant number of NSW aged care nurses, expressed divided opinions about whether it is essential to have a specialist inpatient unit available. However, limitations to these comparisons are noted because of the differences in the precise nature of the issues being compared.

The meaning of the findings regarding the indispensability of a specialised residential facility is now extended by suggesting that this issue also directly canvasses
the concept of the *expert nature of the HD nursing role*. From a logical standpoint, strongly stated preferences by the nurses for the idea that a specialised facility is essential, should correlate with a high score in support of the notion that *HD nursing requires special skills* i.e. requires increased, specific expertise. In this study, there was an extremely high score supporting the expert nature of the HD nursing role (4.2.5.2), and only moderate support (4.2.5.10), for a strongly stated case for the specialist facility being indispensable. However, the statistical relationship between these measures was not significant, and was therefore not seen to support this logical proposal.

Yet another comparison is made when the unrevealing views of the nurses with regard to the specialist residential facility is contrasted with the unreserved support they gave (4.2.5.11) to the indispensability of a specialist outreach service. Taken at face value this indicates strong differential support for the outreach service against the residential component of the HD service. On the other hand, the *specialist inpatient facility* was an abstract concept to most of them whereas the relevance of the *outreach service* was known to them through experience. This differential may indicate that some respondents were influenced in their positive responses for the outreach service by the duality of the roles, (namely researcher and HD nurse specialist), occupied by the main author of the questionnaire. This is akin to the “halo effect” (Skodol-Wilson, 1989, p.125) whereby research results are influenced by subtle interpersonal factors.

Deficiencies in the current care provisions include the *need for special skills*, the *presence of hazards related to the characteristics of the illness*, and the value they place on the *input of the multidisciplinary team*. Taken in conjunction with affirmative views of measures which highlight this inconclusive result regarding views of the need for a specialist facility, is not interpreted as further support for deficiencies of the current
accommodation arrangement. Neither is it viewed as evidence of lack of insight into the deficiencies, but rather it is seen as a statement of genuine belief that the specialist unit may be an ideal, rather than an achievable reality for most people.

Not only was it probably seen as an ideal, but also according to the results of the analysis of the subset of negative respondents, the shared idiosyncratic features of the group of respondents who denied the necessity of a specialist residential unit, predisposed them to have such a view (4.2.5.10). The residents these negative responders reported on also had distinguishing characteristics in common. They appeared to have more advanced disease and were therefore potentially more passive recipients of care, and easier to nurse than at an earlier stage.

In deriving additional meaning for these findings from reference to deviance and labelling theory (Kelly & May, 1982; Johnson & Webb, 1995; Narcez, 1990; Trexler, 1996), it is argued that this group of nurses represents an identified cohort who should be least likely to confer deviance status on the HD affected residents. The advanced state of the disease process and the significant degree of associated dependency might alter the dynamics of the relationship so that the power differential would be held by the staff, and attempts to change undesirable behaviour using influence, manipulation or coercion (also known as inclusionary responses by Trexler, 1996) could be more successful. It is also proposed that by the very nature of the more dependent state of these HD affected residents, they are less deviant with reference to their aged care peers and therefore less conspicuous in the aged care context. This is further supported from the field of aged care nursing with respect to the impact of the increasing frailty of their elderly population.

"Professionally, ethically and financially, the nurse must now provide multiple services
for an ailing resident who will require more intensive care in terms of physical, psychological and social support needs” (van der Hoeven 1994).

Extending the discussion of deviancy yet further, Narcez (1990), in an address to the American Sociological Society, argues on the basis of a typology based on Societal Reaction, as proposed by Friedson (1970), that the greater the deviation from normal health, the more likely that the person will not be held responsible for his condition. In other words, more extreme deviation (Narcez, 1990) and the ensuing “forgiveness” of Trexler are linked in reducing societal reactions otherwise associated with deviance.

To sum up then in terms of overall meaning, it was thought that these results indicated a tendency that, in spite of difficulties in providing care for the HD residents, and for various reasons, most aged care nurses do not favour the option of permanent transfer of an HD resident with advanced disease, from their care to a specialist unit.

5.6 Putting it all together: Viewing the whole picture

The structural framework to the results of this survey is represented in Figure 5.2.

The actors who participate in the clinical phenomenon, which gave rise to the research, include:

- the aged care facility as the stage for the unfolding drama;

- non-nursing staff in the facility who have least knowledge of the features of the disease;

- the families of the HD resident who include children from the next generation who are at risk of inheriting the disease, and may be known to be gene positive, also
affected (with HD), or gene negative with all the concomitant social and emotional consequences for each of these;

- the other residents who are the same age as the parents of this “Cuckoo,” frail and at risk of injury from the unsteady, impulsive, poorly coordinated HD resident who is still mobile and who may have signs of a dementing illness;

- the HD resident who: is young, is dying slowly, needs lots of attention because of the disease, has little in common with his/her room mates and companions, and may be irritable, noisy, a messy eater, with unattractive involuntary movements, disinhibited, and with a severe speech impediment or even is mute;

- the aged care nurses with responsibilities to all the above who are: generally well qualified, experienced nurses whose strongest views were held about the difficulties engendered by the features of the disease rather than aspects of the care environment, and who wanted to use the Huntington outreach team to improve their care of the HD resident, and finally

- the outside experts who need to understand the internal dynamics to assist all the actors involved in this complex scenario.
FIGURE 5-2 A DIAGRAM OF PARTICIPANTS IN THE "CUCKOO IN THE NEST"
PHENOMENON
Chapter 5: Discussion of the results

Explaining the findings as a whole will be done in three parts. Firstly, there is the concept of “The Cuckoo in the nest.” Next, the complexity of the situation will be highlighted, and finally, the discussion will seek to explain the whole picture through the concept of “the Cuckoo in the nest” as a case of ‘accidental’ deviance.

5.6.1 The Cuckoo in the nest phenomenon

This study has demonstrated that because of the nature of the disease and the rarity of its occurrence in the aged care context, the nurses caring for a resident with HD are presented with competing care needs that require disproportionate time and energy to meet. This supports the description (1.1) of the phenomenon under scrutiny as another case of “the Cuckoo in the nest” (Gardham, 1982). Other writers (Klimek, et al., 1997, Glendinning and Skirton, 1994) have also described this as a problematic situation.

In response to this statement, a solution is generated from a theme extracted from the responses regarding “details of other problems with the environment.” Related to staff lacking knowledge of effective management strategies, including the problem of dealing with the residents’ distorted perceptions of reality (Seidman-Carlson & Wells, 1998), is their belief in the need for HD expert staff, which would be achieved by the acquisition of appropriate knowledge and skills (5.7.4), in short, educational preparation for the job.

5.6.2 The two sides of the problem

The complexity of the situation as described by Johnson and Webb (1995) is highlighted in two separate ways. The first is in generating meaning from the content of the words of the nurses by the description of recurring or overarching Meta themes. Those themes derived from non specific open-ended questions designated as Openers and therefore available as a conduit for individual and novel views, are interpreted as being
highly significant indicators of the issues underlying the "Cuckoo in the nest" phenomenon. The second is by exemplifying the issues in the words of two particular nurses.

The two most frequently recurring or overarching meta themes are first affirmative of needs being met and staff managing, and second that the specifics of the disease and its management is the problem. These themes support the interpretation that it is the individual characteristics of the resident in terms of disease manifestation, which underlies the nurses' referral for specialist help. On the other hand, this does not necessarily imply attaching a stigmatising label (Podrasky & Sexton, 1998) or an exclusionary response (Trexler, 1996) but illustrates the importance of the complexity and changing nature of social judgement as described by Johnson and Webb (1995).

The second way the two sides to this complex situation is highlighted is through the words of two respondents. They illustrate the difficulties as well as the nurses' readiness to suggest solutions to the difficulties they observed. The NUM of a metropolitan dementia unit, a novice in terms of HD, was responsible for the care of a totally insightless man of 50 years who refused personal care daily and was therefore periodically malodorous to the point of needing continuous deodoriser sprayed into his room. She had this to say: "I think that we meet the needs of this resident in personal care, grooming. Support is given to the family who are also very supportive of him, but it would be nice to have specialists in HD give us ideas & suggestions i.e. DT but the resident usually refuses to see anyone or participate with anything."

And the words of a metropolitan registered nurse caring for her third HD affected resident, a young woman in her forties who suffers from two chronic neurological conditions, is visited regularly by her father but never sees her two young children due to
estrangement: "I feel that accommodation of a younger HD sufferer in a nursing home situation—with aged/demented residents [is] very inappropriate. Surely accommodation in a more specialised unit would be more encouraging and more practical i.e. group therapy etc."

An additional concept to be stressed is that of the nurse-patient relationship being interactive.

The total picture, as described by the HD nurse carers in the HD aged care study is seen to be that of a complex set of dynamic interactions between the HD resident, the nurse-caregivers, and the facility in which they live.

With this in mind, the emotional responses of the aged care nurses caring for the HD resident can be postulated to derive from the struggle involved in managing increasing ambiguity in the workplace. This may include the factors relating to the usual demands of ambiguous situations that are an essential part of the nursing role (Healey & McKay, 1999; Littlewood, 1991). These may come, for example, in the form of confusing messages from family regarding the exact nature of the medical condition for which the patient has been hospitalised, or may involve interpreting for a confused resident what is about to happen. So, according to the framework outlined by Littlewood (1991), nurses represent the link between doctor and patient, and attend to the needs of a person whose bodily functioning in their usual social setting might be considered unacceptable; they thereby function as a bridge between the "outside" world and the institutional world of the sick (or in this case the elderly). They also have to assist the younger resident with socially unacceptable behaviours in the form of signs and symptoms of HD, to fit in and have their unique needs met. However, their lack of expertise with this complex disease, as is reflected in their responses, reduces their
confidence and increases their stress. These factors appear to contribute to a negative attitude to experiences of the situation, which gave rise to the clinical observations, from which the study arose (1.1).

This analysis is supported by the findings from an Australian study by Healey & McKay (1999), in which nurses reported that increased stress levels were due to workload and deficiencies in knowledge of various sorts. These findings are mirrored in this study of HD residents in aged care. In this instance, the nurses nursing HD residents in the aged care sector report dissatisfaction, frustration and stress, which appear to be related to the distinctness, difference, or uniqueness of the HD person in this particular setting. These features differ from the common uncertainties (or ambiguities) that nurses accept as part of their work. This issue, quite independently of personality or cultural differences, derives from the specifics of the illness the resident suffers from. These include all the major symptoms, and the comparable youth of these people, which contributes to their social isolation within facilities focused on the aged. It also includes the hereditary nature of the condition (which causes a relative lack of extended family support by those who are potentially, or actually, also affected), and the relative rarity of HD. This rarity minimises the availability of informed peer input for carers into the situation.

5.6.3 The Cuckoo in the nest as a case of accidental deviance

Finally, the discussion seeks to explain the whole picture through the concept of “The Cuckoo in the nest” as a case of ‘accidental’ deviance.

This commences with a statement of the Reformulated theory of Deviance as a theoretical framework from which to view the total phenomenon. The concept of the Cuckoo in the nest is seen as a vital component of the theory in conjunction with the other concepts already outlined in the literature review and alluded to again above.
The application of the theory is now presented. Figure 5.3 summarises the understandings derived from the search for statistical relationships between the measures that comprised the questionnaire. These findings are supported by others derived from the statistical and qualitative analyses in the study to identify clearly some key interrelated elements in the clinical scenario that gave rise to the research. They are:

firstly the significant interplay between the relative youth of the HD affected residents in this setting and the prevailing views of this being inappropriate or unsatisfactory; and

secondly, the moderately strong correlation between this more global disapproval and the physical attributes of the facility; also

the strong link between the perceived standard of individual nursing care and the provision for higher order needs by the facility which in turn both interrelate with the opinions regarding appropriateness and roominess; and

the identification of higher educational levels being linked to increased experience for this sample of nurse-respondents, and this showing statistically significant correlation with less dissatisfaction with the situation overall; and finally,

the presence, although relatively weakly, of a statistically significant correlation between the amount of overall nursing experience and HD nursing experience, and its slightly stronger significant correlation with satisfaction with the physical attributes of the facility.
FIGURE 5-3 - DIAGRAM OF THE RELATIONSHIPS BETWEEN FACTORS RELATING TO THE DEVIANCE STATUS OF HD AFFECTED RESIDENTS IN NSW AGED CARE FACILITIES
Having viewed the graphic representation of the Cuckoo in the nest to deviance theory, the arguments to support this observation are now resumed. With regard to the concept of deviance, and the sick role, Parsons (1951), described deviance which is perceived as being wilful as being defined as a crime, but when it is viewed as not wilful, or not under the control of the individual, it tends to be defined as sickness. According to writers on the topic of deviance and labelling, the ultimate sanction in response to social judgements by the dominant group is rejection. According to Trexler (1996), this can take the form in hospitals of distancing or isolating behaviours towards the person with the deviance label (Appendix A). Allied to this and in the context of tracing the progressive medicalisation of deviance, Conrad & Schneider (1980) describe this process as using medical means with a stated health goal, to change or extinguish deviant behaviour. This then effectively becomes another means of social control.

Direct evidence of labelling by the nurse-respondents was sought from the open-ended data for the whole questionnaire. Commonly used words (Johnson & Webb, 1995; Lorber, 1975; Podrasky & Sexton, 1998), indicative of negative nurse–patient relationships and stigmatisation, including “demanding,” “manipulative,” “attention seeking” were identified and frequency of use was noted. The frequency of use of other words associated with descriptions of problems was also noted. Although examples (5.7.1.1) were found of descriptions of antisocial behaviour, the results to the search for the use of pejorative terms by the nurses for the residents, was inconclusive. From a list of 14 frequently found words, the most common ones, were “problem, behaviour”, and “difficulty.” Used about half as often was “aggressive” followed by “isolate/ion, dement,” and “resistive.” From 1114 identified phrases, this very small percentage of negative statements is clear evidence, at least in the context of this study, of a denial of
negative labelling. On the other hand, with respect to evidence of possible exclusionary responses, such as physical or psychosocial avoidance measures, denunciation or belittlement, there are two points to be made. Firstly, there is the clinical experience (which led to this HD in aged care research being undertaken), namely a referral from an aged care facility, in rather strong terms at times, for assistance in “managing the problem” with the resident with HD. This is always an indication of deteriorating relationships of some sort with some one or group and has been accompanied at times by clear evidence of not only a label of “bad patient” but also discrimination regarding allocation of resources, for example.

As has already been said in relation to the relatively high prevalence of medical specialist consultations for the HD affected residents, Trexler (1996, p. 5), describes referral to specialists as a “Status degradation ceremony.” It is therefore suggested that the observation regarding referral to the outreach nurses might be evidence in support of the “Cuckoo in the nest” phenomenon as it is an example of deviance with all its theoretical connotations.

Secondly, evidence of possible exclusionary responses is gleaned from responses to the questionnaire (4.2.2.1) which were corroborated from the outreach records, that 10 of the 20 residents (16% of the whole sample) who had lived in more than one facility, moved due to problems. The total relocation figure for the sample was 33%, although it was known that a minimum 16% had moved due to problems. By contrast, Nance & Sanders (1996) noted that 59% of the patients in their sample had moved to the specialist unit from an aged care facility, and three had had to be transferred out due to inability to contain the aggression they displayed. Thus it seems evident that exclusionary responses are present towards HD affected residents in aged care facilities and the rate in NSW was
demonstrated to be at least 16%. Transfer to the specialist facility in NSW prior to the establishment of the Outreach Service was reported by the Medical director (personal communication) to be high. This trend has been reversed and since 1995 transfer in due to insoluble problems in the aged care facility have totalled only about three or four individuals.

Evidence from aged care literature (Nay, 1995) that this can be a move with serious consequences, such as premature death, increases the importance of these findings.

This supports the evidence already presented in this chapter that the “Cuckoo in the nest” phenomenon, through the interaction with firstly all types of care provision, secondly all the resources of the facility, as well as the aged care nurses supported by the specialist team, represents a case of accidental deviance. This ensures that the HD affected resident can be fully understood and cared for with tolerance and the expertise they deserve.
APPENDIXES
Appendix A – HD in aged care facilities—guidelines for care

This is a double sided, single page education handout designed for carers in aged care facilities with an HD resident.

The story of Huntington Disease (side one)

These simple notes have been written to help you give the best care to the person with Huntington Disease. If you need more information please ask others where you work. They can also contact us at Huntington Outreach for more information. Angela Lownie / Kerry Watson 9804 5863

Huntington Disease is inherited. Your patient had a parent with it and may pass it onto their children. There is a 50% chance for each child. This means they have a faulty gene in every cell of their body. The faulty gene causes brain cells in a part called the basal ganglia to die. The front part of the brain is also damaged. The disease is incurable and this brain damage causes many changes to the body functioning which get gradually worse over about 20 years. The changes are usually noticed from about 35–55 years of age.

The following are some of the changes you will need to help them with—

- Uncontrolled movements of various parts of the body

- Poor co-ordination leading to unsteady walking and inability to use their hands

- Speech problems causing difficulty knowing what words they want to say and their ability to say them
• Difficulty eating and swallowing food leading to a danger of coughing and choking on the food

• Tendency to lose weight unless provided with at least twice the normal calories

• Quick temper due to frustration and changes in their ability to reason and remember

• Poor concentration

• Inability to read as the eyes are unable to follow the words properly

The aim of nursing care is to keep the person functioning as well as possible and to give them a good quality of life.
A B C of good nursing care in HD (Side 2)

Attitude - remember that although they cannot communicate well, they understand a lot, so don’t treat them like a child or as though they are unintelligent

Constipation is prevented by bulk forming laxatives, plenty of fluids and occasional suppositories

Environment – affects us all. A clean, cheerful, calm and personal space is everyone’s right

Exercise - providing regular exercise maintains muscle tone and strength, improves morale and prevents constipation

Family contact is important and should be encouraged

Fatigue is prevented by a daytime nap

Injury—the uncontrollable movements increase the risk of injury to you and to them. — follow recommendations from risk assessments

- make space during transferring by moving furniture

- prevent injury to yourself by careful planning of interventions and getting assistance in time

- use suitable equipment

Mealtimes—a focal point—they require help with meals—sitting upright, food cut up, correct texture, reminders to keep eating and assistance in putting it into their mouths at times

Occupation—they require a lifestyle programme—including regular social activities, choice of entertainment and 1:1 talks
Oral hygiene is very important—they cannot clean their own teeth

Problems—if they are upset—they will tell you what the trouble is if you make the time to try and understand

Routine—a well planned routine that everyone sticks to prevents agitation and outbursts

Spiritual matters—personal faith, beliefs and religious practices should be provided for

Urinary incontinence is prevented by regular toileting
Appendix B – Introductory letter to the D.O.N’s re the survey

Huntington Outreach Service,
Lottie Stewart Hospital,
Ph: 9804 5863,
23/5/99

Re - Participation in nursing research in Huntington Disease

Background

It is the experience of the Huntington Outreach staff situated at Lottie Stewart Hospital, that caring for people with Huntington Disease (HD) in the standard aged care facility can be extremely difficult and frustrating for both the staff and the resident. Evidence from nursing staff in these facilities suggest that they are sometimes dissatisfied with the outcomes both from their professional point of view, that of the person with HD, and that of their family. This is in spite of the fact that the institutions are carefully chosen and that the staff in them are caring, aware, and appropriate for the patient.

A probable explanation is that the symptoms of the condition create care needs which are different from those of most of the other residents and therefore not easily met in the standard aged care facility.

The Study

The NSW Huntington Outreach Service is undertaking an ongoing study to investigate the key elements in the care and facilities currently being provided in the standard aged care facility for the resident with Huntington Disease. Information is being sought from the Nurse Caregivers in these facilities. The primary purpose of the study is
to provide reliable evidence and data to assist in the planning for the needs of the over 400 known people with symptoms of HD in N.S.W. The Outreach Co-ordinator / Clinical Nurse Consultant, Angela Lownie, is the principal researcher. Research assistance with developing the questionnaire was provided by Brett Mathison, UWS, Nepean. Supervision and statistical assistance is being provided from the School of Health and Nursing, UWS, Nepean.

Your Participation

The evaluation survey tool is the enclosed questionnaire which was designed from previous face to face interviews. As you currently have, or previously have had, a resident with a major diagnosis of Huntington Disease, we are hoping you will assist us. We would like you to arrange for the completion of these questionnaires by yourself and/ or other relevant staff. We would like at least one questionnaire to be completed per resident, but as it is essentially a staff survey, more than one would be even better i.e. different staff for same patient. Choose the person/s with the most knowledge of the resident.

Even if it is a while since you had a person with HD we would appreciate any information you can give us about your experience of caring for them.

In order to facilitate the early analysis of the data, we would appreciate it if the survey could be completed and returned as soon as possible. We have assisted you by including a stamped, addressed envelope.

Your co-operation in regard to this study would be greatly appreciated. If you have any queries regarding the research, please do not hesitate to contact me.

If you would like a copy of the results please indicate YES/NO on the returned questionnaire.

All information will remain strictly confidential
Appendixes


Angela Lownie, Huntington Outreach Co-ordinator / CNC,

Lottie Stewart Hospital,

40 Stewart Street,
Appendix C– Research proposal

The Lottie Stewart Hospital
Huntington Outreach Service
Huntington
5/1/98

RESEARCH PROPOSAL
INSTITUTIONAL CARE OF PEOPLE WITH MODERATE TO ADVANCED
HUNTINGTON DISEASE—A COMPARISON OF THE SPECIALIST FACILITY
WITH THE STANDARD AGED CARE FACILITY

THE PROBLEM

It is the experience of the Huntington Outreach staff that caring for people with Huntington Disease in the standard aged care facility can be extremely difficult at times for the staff and frustrating for the resident. Anecdotal evidence from nursing staff in these facilities suggests that they are often dissatisfied with the outcomes both from their professional point of view, that of the person with H.D., and that of their family. This is in spite of the fact that the institutions are carefully chosen and that the staff in them are dedicated and caring and also that education and support are provided by nursing and social work staff on the Outreach Team. A probable explanation is that symptoms of the condition create care needs which are different from those of most of the other residents and therefore not easily met in the standard Aged Care Facility. These symptoms include, swallowing difficulties, communication difficulties, unpredictable and involuntary movements of arms and legs, irritability and metabolic changes requiring increased caloric intake about twice the normal. Finally, these disabilities occur frequently before the age of
50 years so their interests and social situations are quite different from most of the other residents.

With the assistance of the Nepean Summer Awards Scheme it is proposed to undertake a study to highlight the key differences in the care and facilities provided in the specialist unit which is devoted entirely to the provision of care for residents with Huntington Disease.

THE PURPOSE

The broad purpose of this study is to provide reliable data to be made available to the Authorities to assist in planning for the needs of the 400 known people with symptoms of HD in NSW.

The more specific objectives of the study are—

1. To confirm or challenge the notion that it is essential to have available a Specialist Inpatient Unit for people with Huntington Disease

2. To confirm or challenge the notion that there is a need for an increased number of Specialist Beds for people with H.D. in NSW

3. To identify most/some of the essential elements which are provided by the specialist unit and not by the standard Aged Care Facility.

4. To identify the major deficiencies in the care available in the standard Aged Care Facilities in NSW today.

BACKGROUND

Due to the short notice given of the attainment of the Summer Awards, only a brief internet search has so far been conducted and has not identified any similar studies. Recent attendance at the International H.D. Association Conference also indicated little current research into Care Provision for those with H.D. However, further investigation
into the details of related research is planned prior to and during the course of conducting the study.

THE DESIGN

The design will be that of an evaluation survey.

The survey tool will be a questionnaire which will be designed following face to face interviews with 4 nursing staff from institutions who have recently (in the last 6 months), or who are currently, caring for a resident with H.D. There will be 2 from the specialist Unit at Lottie Stewart Hospital and 2 from selected Aged Care Nursing Homes. The interviews will be semi-structured and taped and content analysed to provide categories of significance to the topics outlined.

The questionnaire will be trialled prior to distribution.

Tests of validity and reliability will be conducted. The precise details have yet to be decided.

The questionnaire will be mailed out to all relevant Nursing Homes with the reply-paid envelope enclosed. A covering letter will be included giving details of the aims of the research and the credentials of the researchers. A follow up phone call two weeks later to non respondents will be made by a researcher.

An attempt will be made to include Nursing Homes not known to the Outreach Service by publicising the study in a Geriatric journal as well as through the Australian Huntington Disease Association (NSW).

Each question will be coded and the results will be collated and scored. The scores will be examined statistically to compare the data relating to the specialist unit and that relating to the standard Aged Care Nursing Homes. The data will be subjected to tests of significance which will indicate the strength of the differences (or lack of).
Appendix D – Agreement with assistants

Huntington Outreach,

Lottie Stewart Hospital,

Dundas 2117

15/6/99

To whom it May Concern

Introduction

The research you are assisting with is a study being conducted from the Huntington Outreach Service at Lottie Stewart Hospital. It relates to the care of people with Huntington Disease in institutions in NSW. The information you will have access to has been given by nurses in these institutions for the purpose of gathering data which, it is hoped will eventually improve the quality of life of people with Huntington Disease needing this form of care. The information has been given with an assurance that it will be kept strictly confidential which means that none may be disclosed to anyone not authorised by the researcher, Angela Lownie. The data must furthermore be stored securely in a locked container at all times when not being directly used, and this container must be kept secure.

Please indicate by signing below that you understand the above and are willing to abide by the requirements. If you have any concerns regarding any of this, please contact the researcher, Angela Lownie on 9476 4521 or (work) 9804 5863.

____________________________________________________________________ (Signature)

____________________________________________________________________ (Name)
Appendix E –for Custom designing the questionnaire : letter to interviewees

Huntington Outreach Service,
Lottie Stewart Hospital,
Ph: 9804 5863,
23/1/98
To Whom it may concern

It is the experience of the Huntington Outreach staff situated at Lottie Stewart Hospital, that caring for people with Huntington Disease (HD) in the standard aged care facility can periodically be extremely difficult and frustrating for both the staff and the resident. Evidence from nursing staff in these facilities suggest that they are sometimes dissatisfied with the outcomes both from their professional point of view, that of the person with HD, and that of their family. This is of course in spite of the fact that the institutions are carefully chosen and that the staff in them are caring, aware, and appropriate for the patient.

A probable explanation is that the symptoms of the condition create care needs which are different from those of most of the other residents and therefore not easily met in the standard aged care facility.

The Huntington Outreach Service has proposed to undertake an ongoing study to highlight the key differences in the care and facilities provided in the specialist unit which is devoted entirely to the provision of care for the residents with HD, and the standard
aged care facility. The primary purpose of the study is to provide reliable evidence and data to assist in the planning for the needs of the over 400 known people with symptoms of HD in N.S.W. The evaluation survey will be a questionnaire which will be designed following face to face interviews with four nursing staff. The four nursing staff will be from institutions who have, or who are currently caring for a resident with HD. There will be two selected from Lottie Stewart Hospital and from selected aged care facilities. The interviews will be semi-structured taped then analysed to provide categories to formulate the questionnaire.

The Outreach Co-ordinator / Clinical Nurse Consultant, Angela Lownie, will be the principal researcher. Research assistance with developing the questionnaire was provided by Brett Mathison, B. Health Sc. UWS Nepean. We are both hoping that you will assist us in our study by agreeing to provide data in this taped interview format.

The confidentiality of all information you provide is assured.

Your co-operation in regard to this study would be greatly appreciated. If you have any queries regarding the research, please do not hesitate in contacting us.

Angela Lownie, and Brett Mathison
Appendix F – Copy of the Questionnaire

INSTITUTIONAL CARE OF PEOPLE WITH MODERATE TO ADVANCED HUNTINGTON'S DISEASE

The Essentials In The Components Of Care
Feedback on results requested Y / N

This is a survey being conducted by the staff of the Huntington Outreach Service at Lottie Stewart Hospital. We hope you will assist us in our investigation into the quality of care for people with Huntington Disease (H.D) living in institutions. Through this staff survey we will identify any special needs which the standard aged care facility may have difficulty meeting. In turn we will also identify whether the specialist facility is considered to be able to meet these needs.

We will be using the information to assist us in planning for ways we can help to improve the quality of life for people with HD wherever it is given.

ALL INFORMATION YOU GIVE WILL REMAIN STRICTLY CONFIDENTIAL.

Thank you very much for your help.

GUIDELINES:

1. Please answer all questions and / or add as much detail as possible.
2. Please answer all questions as honestly and accurately as possible.
3. Throughout the survey, the terms “patients” and “residents” are used interchangeably and only refer to the resident/patient with H.D.
4. If more than one patient is involved please complete one questionnaire per patient/resident.
5. Residents who are no longer with you may also be included in the survey.
6. If you need more information please contact Angela Lownie on 9804 5863.

<table>
<thead>
<tr>
<th>PART A:</th>
<th>YOUR DETAILS (Please circle)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.0</td>
<td>Your name?.............................(Optional)</td>
</tr>
<tr>
<td>2.0</td>
<td>How long have you been nursing? ............................. 0-5 years, 5-10 years, 10-15 years, 15+ years</td>
</tr>
<tr>
<td>3.0</td>
<td>What qualifications do you have? .............................(Registered Nurse, Enrolled Nurse, Assistant in Nursing)</td>
</tr>
</tbody>
</table>

How many patients with Huntington Disease -

4.1 have you cared for in the past?..............................................
4.2 are you currently caring for?..............................................
4.3 approximately how long, in total, have you cared for residents with HD?
PART B: RESIDENT DETAILS

1.0 Please indicate the age of the resident.

2.0 Please indicate the sex of the resident.

3.0 Please indicate the mobility of the resident?

          Very mobile,      Mobile,  Slightly mobile,    Immobile

4.0 Please briefly note what symptoms of H.D this resident has?

5.0 Has this resident previously been in another aged care institution?  Yes/No

6.0 Has this resident an appointed Guardian and/or Financial Manager  Yes/No

7.0 Does the patient ever become aggressive?  Yes/No

8.0 Does the patient have other behavioural problems?  Yes/No

9.0 Does this patient have contact with their family?  Yes/No

Please comment

10.0 What would be the most number of staff needed for any nursing activity with this patient?

          1,       2,       3,       4,       More

PART C: Your assessment of:

1.0 Accommodation/Physical Environment:

1.1 How appropriate do you feel the facilities are for the H.D patient living here? Very appropriate,       Appropriate, Somewhat appropriate, Inappropriate

1.2 Are there are obvious or potential hazards which can put the patient or carers at risk?  Yes/No.

1.3 If Yes, could you please indicate them.

1.4 How adequate is the accommodation in providing sufficient room to cater for the patient with Huntington Disease?

          Very adequate,  Adequate,  Somewhat adequate,  Inadequate.

1.5 Could you please comment on any other problems you have noted with this present accommodation for H.D residents?
PART D: Your assessment of care provided

1.0 The facility: Adequacy of care provision by the facility  
1.1 Do you find this facility adequate in providing care for it's resident/s?  Yes/No  
1.2 Do you believe that this facility caters for all the essential needs of the resident/s?  
   i.e. meet minimum standards?  Yes/No


Please explain any essential needs of the resident/s that are not adequately catered for by  
this facility

1.4 Do you believe that this facility caters for non-essential but, nevertheless important,  
needs of the patient?  
   ......  Y /N

1.5 How well are the needs catered for?  
   Very adequate,  Adequate,  Somewhat adequate,  Inadequate.

2.0 Adequacy of care given by staff to the H.D resident  
2.1 How adequate do you feel the care that is given to residents in this facility?  
   Very adequate,  Adequate,  Somewhat adequate,  Inadequate.  
2.11 Please explain

2.2 Please indicate if the following make it harder for the resident to receive optimal  
care?  

2.2.1 Fear for the safety of staff or the other residents in this facility  
   Yes/No

2.2.2 Less than adequate staffing  
   Yes/No

2.2.3 Insufficient staff support e.g. debriefing following incidents  
   Yes/No

2.2.4 Insufficient funding for patient care needs  
   Yes/No

2.2.5 Comments

3.0 Nursing Role:
3.1 Do you feel that nursing a person with H.D requires special nursing skills? Yes/No
3.2 Have you had contact with an H.D nursing specialist? Yes/No
3.3 Was this helpful in delivering better nursing care to the patient? Yes/No
3.4 Before caring for the patient did this facility give you any training or education to assist you and the patient to adjust? Yes/No
3.5 Have you had any education on H.D since then? Yes/No
3.6 Comments

PART E: INFORMATION ABOUT THE CONTRIBUTION OF OTHER HEALTH CARE PROFESSIONS

1.0 Medical supervision:

Huntington Disease is an inherited disease of the nervous system that causes many changes, which generally benefit from medical supervision.

1.1 Do you feel that there should be more regular assessment of the HD patient/s by a Doctor? Yes/No
1.2 Does the patient have contact with specialist Doctors e.g. neurologist, psychiatrist? Yes/No
1.3 Do you feel that the patient/s medications are appropriately managed? Yes/No
1.3.1 If ‘No’, please explain

2.0 Physiotherapy:

The H.D patients can benefit from physiotherapy by improvement in mobility, the maintenance/improvement of disabilities, maintenance of posture when seating or in wheel chairs or learning effective coughing techniques.

2.1 Do you and the patient have access to a physiotherapist? Yes/No
2.2 Do you and the patient have access to a H.D specialist physiotherapist? Yes/No
2.3 Is this situation satisfactory? Yes/No

3.0 Speech pathology:

Due to HD patients being prone to speech and swallowing difficulties, use of speech pathology can be helpful in preventing choking episodes or chest infections and promoting quality of life.

3.1 Does the patient/s suffer from any communication difficulties? Yes/No
3.1.1 Are there strategies in place to manage these? Yes/No
3.2 Does the patient suffer from any swallowing difficulties? Yes/No

3.3 Has a speech pathology service been used by your facility for this patient? Yes/No

3.4 Do you feel that you and the patient/s would/do benefit more from the H.D specialist speech pathologist? Yes/No

4.0 Dietician:

Huntington patients, generally have dietary and weight problems.

4.1 Is the patient’s weight measured regularly? Yes/No

4.2 Is their weight usually normal /underweight / overweight Please circle

4.2.1 If underweight is there a plan in place to improve this? Yes/No

4.3 Can the resident only a modified diet? Yes/No

4.4 Have you and the patient/s had contact with a dietician? Yes/No

4.5 Do you believe that you and the patient/s would/do benefit more from a specialist dietician? Yes/No

5.0 Diversional Therapy:

5.1 Does the patient have any hobbies or interests? Yes/No

5.2 Do you, or any other staff member spend time with the patient in activities, hobbies or any such diversional therapy? Yes/No

5.3 Do you think that a H.D specialist diversional therapist would be beneficial for the patient here with HD? Yes/No

5.4 Comments........................................................................................................................................

........................................................................................................................................................

6.0 Social Work

6.1 Does the patient / family have any emotional problems? Yes/No

6.2 Does the patient / family have any social problems? Yes/No

6.3 Do you attempt to deal with any of these? Yes/No

6.4 Do you and the patient / family have access to a social worker? Yes/No

6.5 Do you feel that you and the patient / family would/do benefit more from the specialist social worker? Yes/No

6.6 Comments........................................................................................................................................

........................................................................................................................................................
7.0 Occupational Therapy

7.1 Does the patient have many difficulties with activities of daily living?
   e.g. walking, sitting, sleeping, dressing, eating, showering etc.
   Yes/No

7.1.1 Is there a strategy in place to overcome these difficulties?   Yes/No

7.2 Have you and the patient had contact with an Occupational therapist?  Yes/No

7.2.1 Do you feel that you and the patient would/do benefit more from the H.D specialist Occupational therapist?
   Yes/No

PART F:

Please explain whether, it is essential to have available

- a specialist Inpatient unit?
   Yes/No...........................................................................................................

...........................................................................................................

- a specialist Outreach (community) service, for H.D sufferers?
   Yes/No.................................

...........................................................................................................

Please feel free to make any other comments..............................................................

...........................................................................................................

...........................................................................................................

Thank you very much for participating in this survey.
### Appendix G – Inter-respondent congruency study

<table>
<thead>
<tr>
<th>Variable</th>
<th>Congruency scores for pairs of raters per named group</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>a b c d e g h j k l m n o p r t u</td>
<td></td>
</tr>
<tr>
<td>Rating of how well needs are catered for by institution</td>
<td>X</td>
<td>N N X X N X N X X</td>
</tr>
<tr>
<td>Rating of adequacy of care given by staff</td>
<td>X</td>
<td>X X</td>
</tr>
<tr>
<td>Fear is a barrier to optimal care</td>
<td>X N X</td>
<td>N X X</td>
</tr>
<tr>
<td>Less than adequate staffing is a barrier to optimal care</td>
<td>X</td>
<td>X X X</td>
</tr>
<tr>
<td>Insufficient staff support is a barrier to optimal care</td>
<td>N X X N</td>
<td>M</td>
</tr>
<tr>
<td>Insufficient funding for patient care needs a barrier to care</td>
<td>N X N N</td>
<td>M</td>
</tr>
<tr>
<td>HD nursing requires special skills</td>
<td>X</td>
<td>N</td>
</tr>
<tr>
<td>Report need for more regular medical assessment</td>
<td>X X X X N X</td>
<td>N X X</td>
</tr>
<tr>
<td>Appropriate management of medications</td>
<td>N N X</td>
<td>X X</td>
</tr>
<tr>
<td>The situation is satisfactory</td>
<td>N</td>
<td>X N X</td>
</tr>
<tr>
<td>Resident has communication difficulties</td>
<td>N</td>
<td>X X</td>
</tr>
<tr>
<td>Strategies exist to manage these</td>
<td>N</td>
<td>X X</td>
</tr>
<tr>
<td>Patient has swallowing problems</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>Believe staff and resident benefit more from HD specialist speech path</td>
<td>X X X</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>4 2 2 1 3 0 1 4 5 3 3 3 1 0 0 4 0 37 178 23</td>
<td></td>
</tr>
</tbody>
</table>

**Note:** Number of variables = 14  Number of groups of pairs of raters = 17  Number of possible congruent pair ratings for sheet = 238  M = missing data, X = noncongruent ratings, Shaded groups = congruent ratings for all variables for this pair of raters
# Appendix H – Nurse-respondent accuracy study

Table H 1 Frequency distribution of accuracy of reporting by nurses of HD specialist nurse contact

<table>
<thead>
<tr>
<th>Details of rated accuracy of statements regarding contact by nurses with HD nurse specialist</th>
<th>No of nurses</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agreement regarding contact</td>
<td>47</td>
<td>70</td>
</tr>
<tr>
<td>Error that &quot;contact&quot; occurred</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Error that &quot;no contact&quot; occurred</td>
<td>13</td>
<td>19</td>
</tr>
<tr>
<td>Nurses in facility disagree</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Total</td>
<td>67</td>
<td>100</td>
</tr>
</tbody>
</table>
Appendix I – Description of content analysis method used

To enable the data to be inspected as far as possible as a whole, the text was modified by reducing the font size to eight point and the line spacing to single. The language units consisted of phrases or sentences judged to contain a single idea and were identified as such by the use of a “+” symbol, by underlining, bolding or by italicizing. To collate multiple identical units into a category, the duplicates were represented by a “+” symbol for each additional unit. Safeguards were instituted to avoid losing text when placing sentence components into multiple categories.

Method 1 (Figure 3.2). This was a “one-stage code and collate” method, whereby these processes were done concurrently and manually, collating the unit by placing it (“cut and paste”) into a text box on the computer screen with other units judged to be of similar meaning. On the basis of critical reflection, the heading was revised during subsequent sorts with a focus again on the words in the context of the question, and altered if not considered to represent the meanings accurately.
### Appendix J – Summary of results of content analysis of qualitative data

<table>
<thead>
<tr>
<th>Details of the question inviting comments. In most cases this followed a fixed response question which is also stated.</th>
<th>Number of respondents</th>
<th>Number of language units</th>
<th>Component themes &amp; categories identified by the content analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>B4 Please briefly note what symptoms of HD this resident has</td>
<td>62</td>
<td>309</td>
<td>Statements describing: Movement disorder Cognitive &amp; emotional disorder Perceived handicap, alterations to personal safety, other signs of HD</td>
</tr>
<tr>
<td>B9 Re Q. 5, 6, 7, 8, 9—Does the patient have contact with their family? Y/N Please comment</td>
<td>51</td>
<td>102</td>
<td>Family contact details Comments re other problem behaviours Social &amp; accommodation history Regarding becoming aggressive Regarding substitute decision-maker</td>
</tr>
<tr>
<td>C1.3 Are there obvious or potential hazards which can put the patient or carers at risk? Y/N If Yes could you please indicate them</td>
<td>53</td>
<td>72</td>
<td>Disease characteristics &amp; other internal factors External factors: Physical, Social, and Staffing environments</td>
</tr>
<tr>
<td>C1.5 Could you please comment on any other problems you have noted with this present accommodation for HD residents.</td>
<td>55</td>
<td>102</td>
<td>Lack of personal space Lack of specialist accommodation Need for specialist equipment Disease characteristics Ineffective symptom management</td>
</tr>
<tr>
<td>D1.2 Do you believe this facility caters for all the essential needs of the resident/s? Y/N (explain)</td>
<td>14</td>
<td>16</td>
<td>The meeting of disease related needs, environmental and government standards. Reservations in terms of lack of time and constraint of the environment</td>
</tr>
<tr>
<td>D1.3 Please explain any essential needs of the resident/s that are not adequately catered for by this facility</td>
<td>44</td>
<td>64</td>
<td>Denial of identity Physical needs Need for specialist care Affirmative statements Needs not met due to disease characteristics</td>
</tr>
<tr>
<td>D1.4 Do you believe that this facility caters for non-essential but, nevertheless important, needs of the patient? Y/N (explain)</td>
<td>36</td>
<td>43</td>
<td>Affirmative statements in terms of meeting lifestyle, disease related and social needs, and positive staff characteristics Reservations with respect to lack of time for individual attention and in meeting special needs</td>
</tr>
<tr>
<td>Details of the question inviting comments.</td>
<td>Number of respondents</td>
<td>Number of language units</td>
<td>Component themes &amp; categories identified by the content analysis</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-----------------------</td>
<td>--------------------------</td>
<td>---------------------------------------------------------------</td>
</tr>
<tr>
<td>In most cases this followed a fixed response question which is also stated.</td>
<td>46</td>
<td>80</td>
<td>Themes described by those who had rated the care as more, rather than less, adequate nurse’s role</td>
</tr>
<tr>
<td>D 2.1.1 How adequate do you feel the care is that is given to residents in this facility? Please explain</td>
<td></td>
<td></td>
<td>role of staff attributes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>environmental factors</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>medical officer</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>nursing philosophy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>role of family</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Barriers to better care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>environmental factors</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>problems in nurse’s role</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>disease characteristics</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>staff attributes (jack of experience)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Less adequate care</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Environment</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>disease characteristics</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>staff attributes</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>nurse’s role</td>
</tr>
<tr>
<td>D2.2.5 Please indicate if the following make it harder for the resident to receive optimal care. Comments</td>
<td>35</td>
<td>40</td>
<td>Funding for patient care needs</td>
</tr>
<tr>
<td>Comparison made with quantitative data— NB of funding, Dismissal of staff support as an issue</td>
<td></td>
<td></td>
<td>Fear due to safety issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Staffing issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No barriers noted</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Facility considered totally inappropriate</td>
</tr>
<tr>
<td>D3.6 Nursing. Comments re education for nursing role 41 respondents generated 74 statements</td>
<td>41</td>
<td>74</td>
<td>Details of education from specialist sources</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>self education</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>general statements regarding HD education needs—formal, ongoing, specialist education by experience</td>
</tr>
<tr>
<td>E 1.3.1 Do you feel that the patient/s medications are appropriately managed? Y/N If “no” please explain</td>
<td>17</td>
<td>31</td>
<td>Satisfaction with medical management including medications</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Details of view of medications not being managed appropriately</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Support for increased medical input</td>
</tr>
<tr>
<td>E.5.4 Diversional therapy Comments</td>
<td>22</td>
<td>65</td>
<td>Difficulties with lifestyle issues</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Successful lifestyle interventions</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Specialist DT role</td>
</tr>
<tr>
<td>E.6.6 Social Work. Comments re emotional, social and HD social work contact needs of resident, their family and the staff</td>
<td>23</td>
<td>29</td>
<td>Need met; Unmet social, emotional &amp; contact need; no need identified</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Details of the question inviting comments.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In most cases this followed a fixed response</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>question which is also stated.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of respondents</td>
<td>Number of language units</td>
<td>Component themes &amp; categories identified by the content analysis</td>
<td></td>
</tr>
<tr>
<td>-----------------------</td>
<td>--------------------------</td>
<td>---------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>F1 Essential to have a specialist inpatient unit</td>
<td>23</td>
<td>30</td>
<td>Detail regarding positive response: quality of life, periodical need, end stage Reasons for negative response: numbers, no current problems, other</td>
</tr>
<tr>
<td>F2 Essential to have a specialist Outreach (community) service, for HD sufferers?</td>
<td>27</td>
<td>27</td>
<td>Describe ideal outreach service One negative respondent</td>
</tr>
<tr>
<td>F3 Please feel free to make any other comments</td>
<td>45</td>
<td>110</td>
<td>Negative statements needs Cuckoo in the nest phenomenon Positive statements needs are met situation is satisfactory Other—information may be of limited use</td>
</tr>
<tr>
<td>Total</td>
<td>594</td>
<td>1194</td>
<td></td>
</tr>
</tbody>
</table>
Appendix K – Comparison of ages of HD and non-HD affected residents

**TABLE K 1 - NSW AGED CARE RESIDENTS BY DIAGNOSIS, AGE AND GENDER**

| Population group details | Females | | | Males | | | | M. & F. | | | | All ages | | |
|--------------------------|---------|--|-----|-------|--|-----|-----|---------|-----|-----|-----|-------|-----|
|                          | 65+     | -65 | All ages | 65+ | -65 | All ages | All ages |         |         |         |         |         |         |
| a Sample of NSW aged care residents with HD | 15 | 23 | 38 | 9 | 16 | 25 | 63 |         |         |         |         |         |         |
| b Sample of NSW nursing home residents with HD | 13 | 21 | 34 | 7 | 13 | 20 | 54 |         |         |         |         |         |         |
| All NSW nursing home residents | 19,703 | 773 | 20,476 | 7,459 | 827 | 8,286 | 28708 |         |         |         |         |         |         |
| NSW population |         |     |         |         |         |         | 6,203,894 |         |         |         |         |         |         |

*a This includes accommodation in both nursing homes and aged care hostels

b N = 54
Appendix L – Correlations between measures.

**TABLE L – CORRELATION MATRIX**

<table>
<thead>
<tr>
<th></th>
<th>Age of resident</th>
<th>Immobility of resident</th>
<th>Dependency of resident</th>
<th>Experience level of nurses</th>
<th>Education level of nurses</th>
<th>HD nursing experience</th>
<th>Rated inappropriateness</th>
<th>Rated adequacy of space</th>
<th>Meeting higher order needs</th>
<th>Staff care ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of resident</td>
<td>1.000</td>
<td>- .050</td>
<td>.175</td>
<td>-.061</td>
<td>-.175</td>
<td>.021</td>
<td>- .515*</td>
<td>-.267</td>
<td>-.185</td>
<td>-.132</td>
</tr>
<tr>
<td>Immobility of resident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(low – high)</td>
<td>-.050</td>
<td>1.000</td>
<td>.632*</td>
<td>-.150</td>
<td>-.136</td>
<td>.045</td>
<td>- .023</td>
<td>.117</td>
<td>-.003</td>
<td>-.048</td>
</tr>
<tr>
<td>Dependency of resident</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(low – high)</td>
<td>.175</td>
<td>.632*</td>
<td>1.000</td>
<td>-.026</td>
<td>-.215</td>
<td>.093</td>
<td>-.137</td>
<td>.209</td>
<td>.088</td>
<td>.050</td>
</tr>
<tr>
<td>Nursing experience level</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>of nurses (low – high)</td>
<td>.061</td>
<td>-.150</td>
<td>-.026</td>
<td>p = 1.00</td>
<td>-.501*</td>
<td>.317*</td>
<td>-.224</td>
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Note: Pearson Product Moment test; Casewise deletion of missing data; n = 46; * indicates significant result
Appendix M: Figure of Sequence of the labelling process in nursing practice


Fig M: Sequence of the labelling process in nursing practice

(30/3/03 Permission to use this figure has been sought and an answer is awaited.)
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"THE CUCKOO IN THE NEST" : Understanding Huntington Disease, and the nursing of people with HD, in aged care facilities in NSW

Emma Vans-Collima

A. P. Lownie

Master of Nursing (Honours)

University of Western Sydney

2003
"THE CUCKOO IN THE NEST": Understanding Huntington Disease, and the nursing of people with HD, in aged care facilities in NSW

Angela P. Lownie

Master of Nursing (Honours)

March, 2003
PLEASE NOTE

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

and the best possible result has been obtained.
PREFACE

I, Angela Lownie, do hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person nor material which to a substantial extent has been accepted for the award of any other degree or diploma of a university or other institute of higher learning, except where due acknowledgement is made in the text.

Date: 31st March 2003

Signature
ACKNOWLEDGEMENTS

This document is the result of five years’ work. The history begins with the establishment of the position of Outreach Coordinator / Clinical Nurse Consultant in the NSW Huntington Disease Service in November 1995, and the disturbing initial contacts with HD affected residents, often in their 50’s or 60’s, living in aged care facilities. It continues with the introduction of problem based education sessions for the staff (mainly nurses), giving them the opportunity to describe the problems and frustrations for them and the relatively small group of distinctly different people they cared for.

These insights motivated utilisation of funding through the University of Western Sydney, Nepean Summer Awards Scheme for the employment for three months of Brett Mathison, research assistant. With supervision, he undertook the work of designing the research tool, ‘The institutional care of people with moderate to advanced Huntington Disease—the essentials in the components of care’.

Reflecting on the process involved in this undertaking has made me conscious of the contributions of so many in bringing it to fulfilment. I am warmed by a sense of being part of a collective endeavour and I would now like to focus on the contributions of the others.

Firstly and most importantly, I would like to acknowledge the vital contribution of those ninety nurses from aged care facilities in NSW who took the time and trouble to complete the questionnaire. They did this so that the issues concerning them and the sixty four residents with Huntington Disease they collectively care for, could be raised. Their directors of nursing or managers must also be included as they caught the vision of the project and enabled their staff to participate.
Then the role of Lottie Stewart Hospital, Dundas, Sydney and the foresight of the then Director of Nursing Ms Jenny Coutts, must be acknowledged. In addition to contributing to the Nepean Summer Awards Scheme, the hospital also granted an amount of $4000 for the purchase of Statsoft Statistica software, secure record storage equipment and the word processing assistance of Kathleen Davey, who transcribed the qualitative data. Other hospital resources in the form of clerical support by Melissa Hogan, volunteer support with the questionnaire preparation and mailout by Cath Woodward, and the input of nurse educator Jan Sayers and registered nurses Anne Buxton and Winnie Sue, is also gratefully acknowledged.

Volunteer assistance by Kerryn Lownie with the trial of a method of sorting the printed qualitative data on cardboard posters, is noted with appreciation. The hospital also made a contribution to support the cost of a trip to the Hague to present a poster on the work in progress at the 18th International Meeting of the World Federation of Neurology Research Interest Group on Huntington Disease. The bulk of the funding for this, however, was provided by a scholarship from the NSW Nurses’ Registration Board, which is acknowledged, with thanks.

In addition, the input, support and interest of the Executive, the Board, and other colleagues at Lottie Stewart Hospital at the time, is acknowledged with sincere appreciation. This also applies to the members of the Huntington Disease Service, including nurse unit manager Anne Buxton, and especially Medical Director Dr Elizabeth McCusker who, by example, has encouraged me to persevere.

John Conaghan, social worker with Hunter Genetics kindly provided information on aged care facilities in the Hunter region of NSW, and Robyn Kapp of the Australian Huntington Disease Association, NSW (Inc) was most helpful in supplying reference material from their library.
At a later stage the contribution of members of the School of Nursing, Family and Community Health of the University of Western Sydney Nepean, (as it then was), and in particular, statistician John Bidewell, Professor Jennie Greenwood of the Professorial Unit at Westmead Hospital, and Sally Candlin, were vital in motivating, challenging and supporting me to maintain momentum to see the project through.

In addition, the awarding by the University of an Establishment Grant of $1000 to be used for the purchase of a new computer, made the practical tasks of the research undertaking so much more efficient and rewarding. Further funding of $4000 was also provided to pay for the editorial work of Judy Waters.

The assistance of Richard Ramsden and my sister Lynette Faragher-Sinclair with the final editing is also noted with much gratitude. The input of my co-supervisor, Dr Lydia Tan is also gratefully acknowledged.

However, most thanks must go to my supervisor, Associate Professor Helen Ledwidge, to whom I would like to express my heartfelt gratitude for her encouragement, patience and tactful, but honest, input at every stage of the research process. Her assistance in preparing the final draft and for her knowledgeable comments at all stages are valued beyond words.

Finally, I would like to thank my husband, Kevin and children James and Kerryn for supporting me in so many ways, including the undertaking of extra household tasks in order to free up my time for this work. Their tolerance of my need for space and the opportunity to think and reflect has been of enormous assistance to my achieving the goals I have set myself.

To all of these people I dedicate this work. It is also respectfully dedicated to the memory of all HD affected people, their families and their friends, who so eagerly await
the advent of curative and preventative treatments which will joyously make a work like this, and professionals like me, of primarily historic interest.
TABLE OF CONTENTS

PREFACE ................................................ III

ACKNOWLEDGEMENTS ................................. IV

TABLE OF CONTENTS ................................. VIII

LIST OF TABLES ........................................ XVI

TABLE OF FIGURES ................................. XVII

ABSTRACT ........................................ XVIII

ABBREVIATIONS .................................... XIX

CHAPTER 1 – HUNTINGTON DISEASE: SOLUTIONS AND CHALLENGES .......................... 20

1.1 INTRODUCTION .................................... 20

1.2 DEMOGRAPHY, PATHOLOGY AND NATURAL HISTORY OF HD ............... 21

1.3 CLINICAL BACKGROUND .......................... 24

1.4 HD CARE PROVISION IN NSW .................. 27

1.5 SUMMARY ........................................ 32

viii
CHAPTER 2 – THE LITERATURE REVIEW

2.1 INTRODUCTION

2.2 HD BEST PRACTICE

2.3 MODELS OF CARE

2.4 THE INFLUENCE OF INSTITUTIONAL CARE PARAMETERS

2.5 DEVIANCE AND ALLIED CONCEPTS

2.6 CONCEPTS AND QUESTIONS THAT EMERGED

2.7 SUMMARY

CHAPTER 3 – METHODOLOGY

3.1 INTRODUCTION

3.1.1 Contextual constraints

3.2 MAINTENANCE OF ETHICAL STANDARDS

3.3 THEORETICAL FRAMEWORK OF THE STUDY

3.3.1 Key Concepts

3.3.2 The Objectives of the study

3.4 RESEARCH DESIGN

3.4.1 Setting

3.4.2 Participants

3.4.3 Sample

3.4.4 Treatment
CHAPTER 4 THE RESULTS

4.1 SURVEY RESPONSES

4.1.1 Aged care facilities

4.1.2 HD affected residents

4.1.3 Nurse-respondents

4.1.4 HD clusters

4.1.5 Multiple reporting figures
Table of contents

4.2 RESPONSES TO THE QUESTIONNAIRE

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.2.1 Introduction</td>
<td>96</td>
</tr>
<tr>
<td>4.2.1.1 Responses to the open-ended questions</td>
<td>98</td>
</tr>
<tr>
<td>4.2.2 Objective 1: The affected resident profile</td>
<td>98</td>
</tr>
<tr>
<td>4.2.2.1 The demographic profile</td>
<td>99</td>
</tr>
<tr>
<td>4.2.2.2 Physical profile</td>
<td>105</td>
</tr>
<tr>
<td>4.2.2.3 Psychosocial profile</td>
<td>107</td>
</tr>
<tr>
<td>4.2.2.4 Other resident characteristics</td>
<td>110</td>
</tr>
<tr>
<td>4.2.2.5 Objective 1: The affected resident profile – a summary</td>
<td>112</td>
</tr>
<tr>
<td>4.2.3 Objective 2: Unsatisfactory aspects of care provision</td>
<td>113</td>
</tr>
<tr>
<td>4.2.3.1 Introduction</td>
<td>113</td>
</tr>
<tr>
<td>4.2.3.2 The Adequacy of direct staff care: nurses' self-assessment:</td>
<td>113</td>
</tr>
<tr>
<td>4.2.3.3 Managing difficulties with activities of daily living (ADL)</td>
<td>119</td>
</tr>
<tr>
<td>4.2.3.4 Management of communication problems</td>
<td>120</td>
</tr>
<tr>
<td>4.2.3.5 Managing weight loss</td>
<td>120</td>
</tr>
<tr>
<td>4.2.3.6 Dealing with the emotional and social problems</td>
<td>121</td>
</tr>
<tr>
<td>4.2.3.7 Participation in lifestyle activities</td>
<td>121</td>
</tr>
<tr>
<td>4.2.3.8 Satisfaction with medication management</td>
<td>121</td>
</tr>
<tr>
<td>4.2.3.9 Satisfaction with medical assessments</td>
<td>121</td>
</tr>
<tr>
<td>4.2.3.10 The adequacy of care provided by the facility</td>
<td>123</td>
</tr>
<tr>
<td>4.2.3.11 Providing for essential needs</td>
<td>125</td>
</tr>
<tr>
<td>4.2.3.12 Catering for nonessential needs</td>
<td>127</td>
</tr>
<tr>
<td>4.2.3.13 More evidence of divided opinions of care standards</td>
<td>129</td>
</tr>
<tr>
<td>4.2.3.14 Objective 2: Unsatisfactory aspects of care provision – a summary</td>
<td>129</td>
</tr>
<tr>
<td>4.2.4 Objective 3: The impact of internal resources</td>
<td>131</td>
</tr>
<tr>
<td>4.2.4.1 Introduction</td>
<td>131</td>
</tr>
<tr>
<td>4.2.4.2 Nursing profile.</td>
<td>132</td>
</tr>
<tr>
<td>4.2.4.3 Impact of variation in Staff: Resident ratio</td>
<td>135</td>
</tr>
</tbody>
</table>
CHAPTER 5 - DISCUSSION OF THE RESULTS 164

5.1 SOME LIMITATIONS OF THE RESEARCH 164

5.2 AN EFFECTIVE RESEARCH DESIGN 169

5.3 RESULTS OF THE SURVEY 172

5.3.1 Introduction 172
**Table of contents**

5.3.2 Response rates.  
5.3.2.1 Nurse-respondent rates  
5.3.2.2 Facilities response rates  
5.3.2.3 Resident response rates  
5.3.2.4 Implications

5.4 RESPONSES TO THE QUESTIONNAIRES

5.4.1 General impressions
5.4.2 Reliability
5.4.3 The value of a triangulated approach

5.5 RESULTS OF THE DATA ANALYSIS

5.5.1 Objective 1: The profile of HD affected aged care residents in NSW.  
5.5.1.1 Signs and Symptoms of HD  
5.5.1.2 Age differential a springboard for change  
5.5.1.3 The influence of other aspects of the disease  
5.5.1.4 Similarities to other aged care residents  
5.5.1.5 Links to deviance theory

5.5.2 Objective 2: To identify unsatisfactory aspects of care provision
5.5.2.1 Facility care provision  
5.5.2.2 Medical matters  
5.5.2.3 Self-assessment of direct care provision

5.5.3 Objective 3: The impact of internal resources on care provision
5.5.3.1 The influence of the environment – physical, and professional  
5.5.3.2 Barriers to optimal care  
5.5.3.3 The value of education and HD experience

5.5.4 Objective 4: The expert nature of the HD nursing role and its support
5.5.4.1 Acquiring adequate HD nursing skills
5.5.4.2 Medical specialist contact 212
5.5.4.3 Evaluation of the multidisciplinary team roles 212
5.5.4.4 The indispensability of an outreach service 213
5.5.4.5 The indispensability of a specialist inpatient facility 214

PUTTING IT ALL TOGETHER: VIEWING THE WHOLE PICTURE 218

5.5.5 The Cuckoo in the nest phenomenon 221
5.5.6 The two sides of the problem 221
5.5.7 The Cuckoo in the nest as a case of accidental deviance 224

CHAPTER 6 – LOOKING AHEAD: RESEARCH, PRACTICE AND POLICY IMPlications 230

6.1 THE NEED FOR FURTHER RESEARCH 230

6.1.1 The importance of the skills mix of the nurses 231

6.1.2 Education for the job 232

6.1.3 Which model is best? 232

6.2 PRACTICAL IMPLICATIONS 232

6.2.1 An ideal-type HD nurse 232

6.2.2 Focus groups: shared knowledge to guide change 234

6.2.3 Making a difference 235

6.2.3.1 Making a difference through increased resources 235

6.2.3.2 Making a difference through education 235

6.3 SUMMING UP 236

6.4 NEW KNOWLEDGE FOR A BETTER WORLD 239
LIST OF TABLES

TABLE 4-1  AGE RELATED INFORMATION ON NSW AGED CARE RESIDENTS 100

TABLE 4-2 RELATIONSHIPS BETWEEN PREFERENCE FOR HD DIVERSIONAL THERAPIST AND YOUTH OF RESIDENT 102

TABLE 4-3 THE ASSOCIATION BETWEEN HD SPECIALIST CONTACT AND HAVING HD EDUCATION 148

TABLE 4-4 RELATIONSHIPS BETWEEN CONSULTING A MEDICAL SPECIALIST AND THE RESIDENT PROBLEM BEHAVIOUR MEASURE 150

TABLE 4-5 RELATIONSHIPS BETWEEN VIEWS OF A SPECIALIST INPATIENT UNIT BEING ESSENTIAL & OF HD NURSING REQUIRING SPECIAL SKILLS 158
# TABLE OF FIGURES

<table>
<thead>
<tr>
<th>FIGURE</th>
<th>DESCRIPTION</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>FIGURE 1-1</td>
<td>SERVICE PROVISION FOR PEOPLE WITH HD IN NSW</td>
<td>29</td>
</tr>
<tr>
<td>FIGURE 3-1</td>
<td>COMPONENTS OF THE RESEARCH DESIGN</td>
<td>81</td>
</tr>
<tr>
<td>FIGURE 3-2</td>
<td>ILLUSTRATION OF CONTENT ANALYSIS: THE USE OF TEXT BOXES</td>
<td>90</td>
</tr>
<tr>
<td>FIGURE 4-1</td>
<td>AGES OF HD AFFECTED RESIDENTS IN YEARS</td>
<td>99</td>
</tr>
<tr>
<td>FIGURE 4-2</td>
<td>HD AFFECTED AGED CARE RESIDENTS ARE YOUNGER THAN OTHER AGED CARE RESIDENTS</td>
<td>101</td>
</tr>
<tr>
<td>FIGURE 5-1</td>
<td>REPORTED HAZARDS THAT INCREASE RISKS</td>
<td>203</td>
</tr>
<tr>
<td>FIGURE 5-2</td>
<td>DIAGRAM OF THOSE INVOLVED WITH THE &quot;CUCKOO IN THE NEST&quot; PHENOMENON</td>
<td>220</td>
</tr>
<tr>
<td>FIGURE 5-3</td>
<td>DIAGRAM OF THE RELATIONSHIPS BETWEEN FACTORS RELATING TO THE DEVIANCE STATUS OF HD AFFECTED RESIDENTS IN NSW AGED CARE FACILITIES</td>
<td>226</td>
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Abstract

ABSTRACT

This mailed survey of nurses in all (111) NSW aged care facilities with HD affected residents, used a custom designed questionnaire in a triangulated, exploratory design. It was undertaken by an HD specialist nurse into the previously un-researched field of the nursing challenges in that setting. Knowledge was sought, through descriptive and correlational analysis of fixed choice and open-ended questions, of the facts of the affected resident profile (N=63). Similarly, nursing opinions were obtained on the following: unsatisfactory aspects of care provision, the impact of internal resources and the HD nursing role and its support.

High return rates (57%) from experienced (77%>15 yrs), mainly registered nurses (85%), indicated contributing factors to their dissatisfaction included their lesser HD experience and insufficient knowledge of this rare condition, in spite of specialist education (58%) and multidisciplinary support. The accommodation was considered especially inappropriate for the younger HD affected residents (M =58yrs) and by the less qualified nurses (AIN’s) in hostels as well as the more experienced nurses. However, it was the age differential of HD affected residents (64%<65yrs) with their very elderly companions (6%<65yrs), and the unattractive and time consuming characteristics of the disease (especially ill-understood “antisocial” behaviours) that were seen to predispose them to attract deviance status. Although in the minority, and a “Cuckoo in the Nest,” overt evidence of stigmatisation was not evident. Reformulated Deviance theory for nursing, (Trexler, 1996 ) suggests the possibility of redefinition as “accidental deviant” by education should increase tolerance of carers, other residents and their families. Approximately 32 additional long stay HD beds are needed plus more equipment and education for the aged care facilities. The outreach model of support was strongly endorsed.
## ABBREVIATIONS

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<td>Enrolled nurse</td>
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<td>Director of Nursing</td>
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<td>Diversional therapist</td>
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<td>Huntington Disease</td>
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