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CONSTRUCTIONS OF SELF-NEGLECT

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ABSTRACT

Self-neglect can be understood as the failure to engage in those activities which a given culture deems necessary to maintain a socially accepted standard of personal and household hygiene and carry out activities needed to maintain health status. This failure to care for one's self can be diagnosed as a medical syndrome. A synthesis of the Medical Model and Orem's Theory of Self-Care provided the framework for stage one. This stage comprised a comparative survey of a group of self-neglecters and a comparison group identified by and drawn from the caseload of District Nurses. Many participating nurses practised in remote and rural settings. This geographical and cultural context may have influenced the relationships between nurses and patients and the way in which care was delivered. Self-neglecters had lower levels of self-care agency, were more likely to have a psychiatric disorder and have the nursing diagnoses of non-compliance and ineffective management of therapeutic regime. The self-neglect and comparison groups showed similar levels of independence and dependence in Activities of Daily Life functioning.

The medical construction of self-neglect has come to dominate the discourse. The medicalisation of self-neglect obscures the fact that patients and professionals may have different ideas on what is and what is not self-neglect. The notion of self-neglect as a social construction was the theoretical perspective which provided the framework for stages two and three of the main study. This challenged the assumption implicit in the medicalisation of self-neglect that self-neglect is an objective *a priori* category.

In stage two multiple-case study methods were employed to investigate other constructions of self-neglect. It was found that there were divergent views on self-neglect both between cases and across cases. A wide range of behaviours were classified as constituting self-neglect. It was concluded that self-neglect is a

constructed phenomenon which is the product of social and individual normative judgements, which are themselves rooted in the dominant discourse on cleanliness, hygiene and self-care.

These social judgements were investigated in a systematic way in stage three. Judgements regarding self-neglect and the degree to which individuals were perceived to have chosen to lead a neglecting lifestyle were proposed to be social judgements influenced by professional socialisation and cultural values. Stage three was a factorial survey investigating which variables or combination of variables influenced nurses' judgements of self-neglect and choice in lifestyle. The variables investigated in the factorial survey were self-care status, functional status, gender, psychiatric illness, stated preference for lifestyle, and socio-economic status.

Self-care status was the most important variable in judgements of self-neglect and a combination of functional status, stated preference for lifestyle and psychiatric status were the most important variables in judgements of choice of lifestyle. Psychiatric, general and student nurses had very similar patterns of judgements about self-neglect but general nurses were more likely to believe that self-neglect was an active lifestyle choice.

The findings of the three stages challenge the existence of an objective medical diagnosis of self-neglect. The evidence suggests that self-neglect is a label applied to a wide range of behaviours and that there is disagreement between professionals and between professionals and patients about the existence of self-neglect in specific cases. It has also been shown that self-neglect is defined by the methods which are used to study this phenomenon. Different research methods produce a seemingly contradictory picture of self-neglect.

INTRODUCTION

The notion of self-neglect is one which is frequently found in nursing and allied health literature and the picture portrayed of the severely self-neglecting individual in the literature is one which is instantly recognisable to all clinicians (Fabian and Rathbone-McCuan 1992). In fact the set of rather bizarre and puzzling hygiene and household squalor behaviours attributed to severe self-neglect appear to be of much interest to the general public. The case of the Polish gentleman in the BBC documentary A Life of Grime whose squalid lifestyle presented a public health problem for neighbours is an illustration of the public fascination with this phenomenon. Nevertheless in-spite of this interest Fabian and Rathbone-McCuan argue that self-neglect is a vague construct which is plagued by poor conceptualisation.

The phenomenon of self-neglect became the focus for this thesis as a consequence of the author's interest in the seemingly contradictory descriptions of self-neglect found in the literature and also the rejection of this label by people labelled as self-neglecting. These often contradictory constructions allied to the increasing medicalisation of aspects of everyday life, such as hygiene and cleanliness, sensitised the author to the very tenuous nature of the professional construction of self-neglect.

The Medical Model is the dominant construction of self-neglect in Europe, whilst in the USA self-neglect as a type of abuse is the dominant construction. A construction of self-neglect refers to a set of

ideas, values and behaviours which people, groups, or cultures have judged to be a true representation of self-neglect.

The Medical Model construction has portrayed self-neglect as a medical syndrome, the symptoms of which include household squalor, very poor personal hygiene, and an aloof and suspicious personality. This medical syndrome has a variety of labels which are used synonymously; the most well known of which is the Diogenes Syndrome. This label, rather inaccurately, draws parallels with self-neglect and the classical Greek character Diogenes. Diogenes lived in a barrel, promoted self-sufficiency and disowned possession of the type of material goods much prized by others.

It has been suggested above that the dominant construction of self-neglect in USA views self-neglect as a form of abuse. In many states self-neglect is often defined within a legal context and is dealt with by the State Ombudsman as a type of abuse.

These very different constructions of self-neglect illustrate the fact that this phenomenon may be understood in dramatically different ways by different groups in different contexts.

The medicalisation of self-neglect, as the only legitimate construction of self-neglect, can be challenged on the basis that it is in fact the product of normative social judgements. Self-neglect may also be understood from other theoretical perspectives. For example that in which judgements of self-neglect are seen to be rooted in contemporary

values regarding hygiene and cleanliness. This point is graphically illustrated in a number of case studies of self-neglect which indicate that the individual labelled as self-neglecting may reject this label in the belief that they are exercising their right to live the way they choose. One of the main aims of this thesis is to explicate the various constructions of self-neglect, both professional and lay.

Although self-neglect is likely to be a problem which nurses frequently encounter there is little to be found in the nursing literature on this phenomenon. Two of the handful of articles published in nursing journals, which describe how nurses deal with self-neglecters, use Orem's theories to reconstruct self-neglect in order that nurses can best care for the self-neglecter. There is an implicit suggestion here, one which finds support in the wider literature, that self-care and self-neglect are related. It is therefore proposed to explore the relationship between the capacity for self-care and self-neglect. In Orem's Theory of Self-Care the ability of an individual to engage in appropriate self-care behaviours is dependent on self-care agency. Self-care agency was operationally defined through the Appraisal of Self-Care Agency Scale (ASA-B).

The three stages of this study provide a critical examination of the construction of self-neglect as a medical syndrome and describe the implications of the medicalisation of self-neglect for both patients and nurses. This study does not restrict its focus to mental health nurses, but takes the position that all nurses deal with phenomena such as self-neglect which cannot easily fit into the medical nosology of

physical or mental problems. Self-neglect is a complex phenomenon which can be understood from a variety of perspectives and thus the corollary position is that self-neglect requires to be studied from a variety of methodological perspectives. As a consequence therefore the study design in this thesis employs both qualitative and quantitative methods.

The general design of the study is a sequential design. A sequential design refers to a research design in which a study comprises of a number of phases, with each phase building on the preceding phase with the aim of providing a comprehensive account of the phenomenon under investigation. The main study comprises of three distinct but interlinked phases.

The broad aim of the first phase study is to provide a greater understanding of the functional ability, self-care status, medical and nursing diagnostic status of self-neglecters. Functional ability is operationally defined through the Index of Independence in Activities of Daily Living Scale. Nursing diagnoses and medical diagnoses are operationally defined by the NANDA diagnostic typology and the International Classification of Disease typology respectively.

In phase two this broad understanding is complemented by focusing on a few cases in more depth. This multiple-case study facilitates the explication of self-neglect as understood by patients, professional carers and relatives. In phase three the process of social judgements of self-neglect is investigated by means of a factorial survey. This phase

investigates the specific patient characteristics which influence nurses' judgements of self-neglect and their perception as to whether patients exercise choice in the lifestyle they lead.

The study sample includes District Nurses, Community Psychiatric Nurses and GPs practising in the Scottish Highlands, many of whom work in remote and rural settings. Likewise self-neglecters, as defined by District Nurses, live in similar geographical settings and it is likely that this presented particular problems in care delivery which are related to distance and access to services. Also included in the study sample are Registered General Nurses, Registered Psychiatric Nurses (both groups were practising in secondary care) and a number of Diploma in Higher Education (Nursing) students from a single university campus.

The explication of the various constructions of self-neglect and the problems these present for effective nursing intervention will contribute to the development of nursing practice. Findings will identify the patient characteristics which influence nurses when they make judgements regarding the severity of self-neglect. The thesis challenges the view that self-neglect is a discrete self-neglect medical syndrome. The literature review will describe the process by which the medical model has come to dominate nursing and medical literature in Europe and will discuss other theoretical approaches to understanding self-neglect.

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CHAPTER 1: THE LITERATURE REVIEW

CONSTRUCTIONS OF SELF-NEGLECT

1. **INTRODUCTION**

> *Mental health nursing practice is strongly influenced by the process of psychiatric diagnosis. It is frequently incorporated into nursing discourse often without critical examination of its implications for mental health nursing practice and, more significantly, the implications for those who receive a diagnosis (Crowe and Alavi 1999).*

Crowe and Alavi (1999) succinctly articulate the essence of this thesis when they argue that medical diagnoses require to be critically examined. The three stages of the study provide a critical examination of the construction of self-neglect as a medical syndrome and describe the implications of this process for both patients and nurses. This study does not restrict its focus to mental health nurses but takes the position that all nurses deal with phenomenon such as self-neglect which cannot easily fit into the medical nosology of physical or mental problems.

The fundamental proposition posited in the thesis, one which is shared by Crowe and Alavi, is that the Medical Model is only one way in which we can understand and respond to self-neglect. There are many other ways in which we can understand this phenomenon, most notably from the perspective of people identified as being self-neglecting. The three stages in the study explicate the various constructions of self-neglect provided by a synthesis of the Medical Model and Orem's Theory of Self-Care and the constructions of

patients, nurses and other health care professionals. In the literature review therefore a large and wide range of literature will be reviewed. This literature is drawn from nursing and medical sources and also from the fields of sociology, psychology and philosophy. This breadth of literature is necessary in order that self-neglect can be understood from the broadest perspective possible.

1.1 **Self-Neglect: Conceptual Issues**

Hudson (1989) suggests that many researchers have given a typology of behaviours characteristic of self-neglect but have failed to provide a theoretical or conceptual definition. Those which do provide conceptual definitions tend to be vague, fail to distinguish between closely related concepts and mix conceptual definitions and behavioural typologies.

Self-neglect is a concept used in a variety of ways including as a symptom of some other disorder such as substance abuse in old age (Thibault and Maly 1993), as a failure to maintain one's physical health (Chan and Beard 1993) and as a risk factor for re-admission to in-patient psychiatric services (Swett 1995). Those who support the notion of a self-neglect syndrome may concede that it remains unclear whether self-neglect is related to age, specific disease states or functional status. In addition there is no consensus as to whether self-neglect is a continuum or whether there is a well-defined cut off point between self-neglect and non self-neglect.

The problem of who defines self-neglect is another conceptual and practical issue of some importance. Johnson and Adams (1996) argue that objective and subjective perceptions of self-neglect may vary between different professional groups and between professional groups and those who they categorise as self-neglecting. Possibly an even more fundamental challenge is the claim that there is little evidence to support the very existence of a self-neglect syndrome (Johnson and Adams 1996, Reifler 1996). It appears that there are a number of theoretical and empirical issues which need addressed if an understanding of self-neglect is to be furthered. These issues and others to be outlined in the literature review form the background for any discussion of the concept self-neglect.

Adaptive Compensation Theory of Self-Neglect

Rathbone-McCuan and Bricker-Jenkins (1992) suggest that self-neglect is a continuum of functioning which ranges from poor grooming to self-neglect behaviours which promote disease or can lead to death. These authors provide a general framework for understanding self-neglect, one of the few examples of a theoretical perspective on self-neglect. They refer to this framework as the Adaptive Compensation Process for Self-Care. In this Adaptive Compensatory Framework the major concepts are identified as self-care, personal care, well-being and self-interest. The Adaptive Compensatory Process has a number of processes involving a sense of self, a sense of will, awareness of capacity and potential, options in environment and acceptance of assistance. The concepts of sense of will (intentionally),

options in the environment, and acceptance of assistance will be discussed in more detail in later sections. Rathbone-McCuan and Bricker-Jenkins (1992) believe that a number of factors contribute to self-neglect including loss of interest in self, environmental factors such as social networks and formal service networks.

Rathbone-McCuan and Bricker-Jenkins do not offer any empirical support for their theory and do not place this theory in the context of existing literature by acknowledging extant literature. The theory is framed in a very general way and concepts are not clearly specified, a fact acknowledged by the authors themselves. This framework is not developed nor described in sufficient detail and clarity to be used as a framework for this study, but nevertheless some central ideas, such as intentionality, will be investigated.

Self-Neglect and Age

Self-neglect syndromes are frequently regarded as disorders of old age (Post 1985, Redfern 1994). Hudson (1989) is critical of the claims that neglect and age are linked. This claim, she argues, is based on the false premise that the old and young are powerless and unable to protect themselves. Moore (1989) takes the opposite position when suggesting that self-neglect is to be found in the age range of 60-90 years old. Moore does not provide any empirical evidence for a relationship between age and self-neglect.

Johnson and Adams (1996) suggest that although previous studies have in general focused on older people young people also exhibit

features associated with the self-neglect syndrome referred to as Diogenes Syndrome. They conclude that there is no evidence to support or reject the hypothesised relationship between severe self-neglect and age.

Self-Neglect and Abuse

Neglect and abuse have frequently been used in an interchangeable manner (Beachler 1979). In USA the notions of elder neglect and elder abuse are used as synonyms. Elder neglect is used in a different sense to the use of the term in UK inasmuch as the literature in USA seldom distinguishes between self-neglect and neglect by a significant other. Hudson (1989) believes this is evident in the following definition of elder neglect provided by Jacobs (1984)

> *the failure of an adult (60 or over) to provide for himself/herself goods or services necessary to avoid physical harm, mental anguish, or mental illness, or failure of others to provide such goods or services (p10).*

In Connecticut self-neglect has been placed within a legal framework (Lachs et al 1996) and the statutory definition of self-neglect in this state is

> *an elderly person alone who is not able to provide for himself or herself the services necessary to maintain physical and mental health (p 450).*

Self-neglect, abuse, neglect, exploitation and abandonment problems can be referred by social workers and physicians to the state ombudsman on ageing for protective services. Self-neglect accounts for 73% of all referrals to the ombudsman. In Iowa self-neglect is also placed in a legal framework in which it is regarded as a category of abuse (Weiler and Buckwalter 1992). The person with self neglect is seen as a 'victim' who fails to eat, becomes dehydrated, maintains a filthy infested home, fails to heat the home during cold weather and fails to take prescribed medicine. Hudson (1989) argues that a lack of precise definitions of abuse and neglect makes a systematic comparison of research findings very difficult. This may be especially problematic when comparing USA and UK data.

Self-Neglect and Self-Care

Self-Care has been identified as an important concept in any understanding of self-neglect (Fabian and Rathbone-McCuan 1992, Shah 1992). Hindelang (1987) states that self-care is a major determinant of health and social fitness. In two of the limited number of articles on self-neglect found in the nursing literature Orem's Theory of Self-Care was used to explain self-neglect and to determine the correct nursing intervention (O`Rawe 1982, Moore 1989). Although these nurses do not provide a detailed rationale for their use of Orem's theory it may be the case that there is an intuitive recognition that self-care and self-neglect are inextricably linked. Alternatively it could be claimed that few nursing theories were well known to nurses in the 1980s and of those Orem's was possibly the most visible. Thus Orem may have been chosen on the basis of high visibility. Nevertheless it

remains the case that the relationship between self-neglect and self-care is frequently taken as self-evident.

Self-Care has been defined as

> *actions deliberately performed by persons to regulate their own functioning ...performed actions supply and ensure the supply of materials (air, water, food) needed for continued life....actions, at times, focus on the prevention, alleviation, cure, or control of untoward human conditions that are affecting or can affect life, health or well-being* (Orem 1995, p106).

Persons who do not regulate their own functioning and supply of materials needed for continued life or take action to prevent, alleviate, cure or control conditions which affect life, health and well-being are not providing optimum levels of self-care (Orem 1995).

Self-neglect can therefore be defined as the failure to engage in acts which adequately regulate functioning, supply adequate levels of food, take actions to prevent, alleviate, cure or control conditions which affect life, health and well-being (MacMillan and Shaw 1966, Clark et al 1975, Gannon and O'Boyle 1992, Ungvari and Hantz 1991a, Shah 1992). It can therefore be suggested that persons described as self-neglecting do not provide optimum levels of self-care. In other words in terms of Orem's Theory of Self-Care (1991) they have a self-care deficit.

Self-Neglect and Intentionality

Intentionality describes the process of exercising choice in the way we behave or think. The extent to which people with self-neglect have responsibility, either through acts of commission or acts of omission, for their own self-neglect is an interesting question. The question is 'to what extent do people who are categorised as self-neglecting choose to adopt a particular lifestyle?' Reed and Leonard (1989) clearly believe that individuals are responsible for their own self-neglect when they define self-neglect as intentionally neglecting oneself despite the availability of resources and the possession of knowledge.

Stevenson (1974) considers the issues of choice and intentionality as ontological issues. Ontological issues refer to the nature of person. Stevenson regards both Freudian psychoanalytical and behavioural approaches to disease and behaviour in general as denying the existence, or imposing limits on the individual's capacity to act intentionally. Much of the literature on severe self-neglect, whilst not operating from a Freudian or Behavioural theoretical perspective, do share a similar position with respect to an individual's perceived ability or lack of ability to choose to engage in intentional acts.

The notion of intentionally can also be found in the self-care literature (Orem 1985, Cavanagh 1991, Orem 1991, Gast 1996). Intentionality and self-care are linked by Sullivan and Munroe (1986) when they argue that self-care is a self-initiated, deliberate and purposeful behaviour linked to health and well-being. Cavanagh (1991) also explicitly links self-care to intentionality when claiming that, for

whatever reason, individuals at any given time may choose not to engage in self-care even when they have the functional ability to do so. Therefore Orem's theories or any other theory purporting to deal with self-care and/or self-neglect must necessarily give an account of the relationship between self-neglect and choice.

Orem (1991), in her propositional statements on self-care, opens up the possibility that self-care ability may be limited because of factors which are outwith the control of the individual. Thus Orem's theory suggests that individual behaviour is rational and open to choice except in circumstances in which the individual's ability to reason is externally constrained. Orem does not make is clear under what conditions and for what reasons people may make a conscious and possibly rational choice not to engage in self-care. Although she does offer the following propositions

> *Engagement in self-care or dependent care is affected by persons' valuation of care measures with respect to life, development, health and well being* (p 70).

and

> *engagement in self-care and dependent-care are affected, as is engagement in all forms of practical endeavour, by persons' limitations in knowing what to do under existent conditions and circumstance or how to do it* (p 71)

and

Adults may choose or may not choose to engage themselves in specific self-care actions (p 120)

and

Disease, injury and mental or physical malfunctioning may limit what a person can do for himself, since such states may limit his ability to reason, to make decisions and to engage in activity to accomplish self-care goals (p 120).

This aspect of Orem's work can be argued to be under-developed and little reference to the existing literature on the philosophical issues underpinning these propositions is evident in her work. The philosophical notions of choice and responsibility are specific examples of ideas which are not well developed in Orem's work.

Gast (1996) suggests that self-care comprises of behaviours that individuals perform for themselves and which are learned, deliberately chosen, intentional and may or may not produce the intended affect. Gast (1996) supports Orem's notion of self-care as a rational process when stating that

as action, self-care proceeds through three phases or the three sequential operations described previously: estimative, transitional and

productive. In other words, in a self-care event the person assesses the need for self-care, decides on a course of action, and then plans, executes, and evaluates the course of action (p 118).

The literature on self-neglect does not provide a satisfactory explanation as to whether individuals intentionally neglect themselves (Johnson and Adams 1996). It can be suggested that it is an implicit assumption in Orem's theories that individuals who have an illness, especially a psychiatric or psychological illness, have a reduced or non-existent capacity for intentionally engaging in self-care acts. Byers and Zeller (1995) found that judgements of responsibility in elder self-neglect made by adult protective workers were influenced by perceptions of the disability status of patients. They conclude that judgements of responsibility are unidimensional. The relationship between intentionality and self-neglect will be investigated in the multiple-case element of this study.

1.1.1 **Summary**

There is a lack of conceptual clarity regarding self-neglect and there are few extant theoretical frameworks. It is suggested that the issues of choice, intentionality and self-neglect require to be explored and clarified. The questions which need to be addressed include 'What is meant by self-neglect?', and 'Do people actively choose to lead a self-neglecting lifestyle or is this forced on them by other factors such as disease and what are the implications of this?'

1.2. **Self-Neglect Categorised As A Medical Syndrome**

Self-neglect literature within the medical domain has generally worked on the assumption that there is a discrete self-neglect medical syndrome which can be objectified, described and measured. Self-neglect as a medical syndrome has many apparent synonyms including Diogenes Syndrome, senile squalor, senile self-neglect and Social Breakdown Syndrome (Reifler 1996). Cases of the Diogenes Syndrome have been documented in Canada (Roberge 1998), Israel (Rosenthal et al 1999), Australia (Little 1996), Ireland (O'Shea and Falvey 1997), UK (MacMillan and Shaw 1966), USA (Reifler 1996) and Germany (Kummer and Gundel 1995). The various terms used to describe self-neglect seem to describe a broadly similar picture. Nevertheless it will be suggested in this section that this superficial similarity may obscure differences in the way in which self-neglect is conceptualised. There is some debate within the medical literature as to what is the most appropriate term for this phenomenon (Snowdon 1997). The generic term self-neglect will be used as an umbrella label

except where it is necessary to refer to a specific label in this review. It is hoped that this will prevent confusion for the reader but nevertheless it is acknowledged that this should not be taken to suggest that all conceptions of self-neglect as a medical syndrome are the same.

Senile Breakdown and other Self-Neglect Syndromes

The first reported empirical study of self-neglect was undertaken by MacMillan and Shaw (1966). This study arose from these researchers' intuitive recognition that a group of patients existed whose symptoms were sufficiently similar to see them grouped together as suffering the same illness. MacMillan and Shaw provide a description of the putative syndrome, which they tentatively labelled Senile Breakdown

> *The usual picture is that of an old woman living alone, though men and married couples suffering the condition are also found. She, her garments, her possessions, and her house are filthy. She may be verminous and there may be faeces and pools of urine on the floor* (p 1032).

The design of this study can be criticised, specifically the sampling method limits generalisation, and the claims that the incidence of self-neglect can be determined by this study is inappropriate. The study sample was recruited by asking practitioners to report cases known to them. The validity of the self-neglect severity scoring system is not described and some of the conclusions drawn by the authors go beyond the data. Nevertheless in-spite of the methodological limitations

in the design of MacMillan and Shaw's study it is clear that the picture they paint of self-neglect is remarkably similar in many respects to the case studies of self-neglect published over the next 30 years. The process by which MacMillan and Shaw's description of self-neglect may have influenced the ways in which self-neglect has been constructed over the last 30 years will be discussed later (Section 1.4.2). The extent to which this is an accurate representation of self-neglect will be investigated in the multiple-case study stage (Chapter 4).

The next well known study into self-neglect was not undertaken till the 1970s (Clark et al 1975). This descriptive study investigated 30 patients who were diagnosed as suffering self-neglect. The defining features of a self-neglect syndrome given by Clark et al were very similar to that provided by MacMillan and Shaw (1966). Clark et al (1975) claim that patients with self-neglect have aloof, detached, shrewd and suspicious personalities, although how they arrived at this conclusion is not clear in the published report. The same criticisms levelled at MacMillan and Shaw's research design can be made with respect to the Clark et al study. The influence of the powerful imagery of self-neglect portrayed by MacMillan and Shaw (1966) is evident in a later description provided by Clark

...the patient may present after a fall or a collapse and sudden illness, or because of persistent complaints by relatives or neighbours that "something must be done". They are unwashed, sometimes verminous, their hair is unkempt and matted and their nails are long and filthy.....Small physical precipitants and illnesses such as

respiratory infection or a fall with bruising can convert this precarious domestic situation into a critical one and rapid deterioration may follow in a setting where proper care is impossible (Clark 1980, p 65).

Ungvari and Hantz (1991a,b), in another study, use the term Social Breakdown in the Elderly (SBE) when describing a collection of behaviours and symptoms which are in essence those previously described as the Diogenes Syndrome. The principle feature of SBE is given as profound social isolation. Whilst Ungvari and Hantz (1991a) suggest that the label SBE is more appropriate than Diogenes Syndrome they do not present a convincing argument in support of this suggestion. They do though add to the debate by specifying exclusion criteria for self-neglect. These criteria are the presence of economic factors such as extreme poverty, social and cultural deprivation such as seen in ghettos, acute transient episodes such as may be found in grief response, and socially sanctioned withdrawal as seen in hermits. This can be viewed as an attempt to clarify the concept of self-neglect whilst assuming that it exists *a priori.*

Radeburg et al (1987) present a somewhat different conception of self-neglect when they argue that the SBE is a failure of social and self-care. This contrasts with the essentially individualistic model presented in earlier constructions of self-neglect in which the problem is to be seen in the context of the individual self-neglecter who has been abstracted from their social and cultural setting. Radeburg et al (1987) also suggest that severe self-neglect is not qualitatively different from other forms of self-neglect. They believe that self-neglect is a

continuum of behaviours and that self-neglect as manifest in the various medical syndromes represents one extreme end of this continuum.

Gunter (1980), in an editorial comment, offers a conception of SBE which differs significantly from any other conception of this phenomenon. She suggests that many people who have been diagnosed as senile may in fact have SBE. Gunter illustrates this in a vignette of a woman who was hospitalised as a result of senility and who will not sit and talk with anyone. This she regards as SBE which has been caused by institutional forces. Gunter's conception of SBE resembles the problems of institutional life rather than self-neglect.

Shah (1990) in a short review of extant knowledge highlights the increased prevalence of physical disease found in Diogenes patients, although no comparative data with non-Diogenes Syndrome sufferers is presented. Shah also suggests that the literature indicates that patients come from all walks of life, most live alone and deafness is common.

Cybulska and Rucinski (1986) believe that women and men are equally at risk and that there is a preponderance of widowed subjects. This article is another which simply refashions existing knowledge and adds little new to the extant knowledge. Cole, Gillet and Fairbairn (1992) describe Diogenes patients as having a "shameless attitude to the resulting squalor". These authors present yet another case study of two

people living together who are self-neglecting. They label this variation as "Diogenes A Deux".

Johnson and Adams (1996) suggest that there is insufficient evidence to accept or reject the hypothesis that a discrete self-neglect syndrome exists. Reifler (1996) disagrees when, on the basis of his clinical experience, he rejects the existence of a discrete syndrome

> *It is tempting to look for common elements among cases, as many reports have done, including the one in this issue that states that Diogenes Syndrome patients are usually professionals with successful careers, high intelligence, and no financial deprivation. I could not find convincing evidence of such a pattern, and the only thread that seems to run through many (but not all) of the cases is some pre-existing personality disorder* (p 1484).

There are clearly a number of different constructions of self-neglect to be found in the literature. These differ on a number of dimensions including whether the focus is on the individual or the individual in a cultural context; whether self-neglect is a discrete syndrome which one suffers from or does not, or whether it lies on a continuum. Nevertheless the most pervasive view, although not a universally accepted view, is that a self-neglect syndrome exists.

1.2.1 **Functional Ability and Self-Neglect**

Gruman et al (1997) suggest that functional ability and its relationship to self-neglect is to be understood within the theoretical perspective of

Dependency Theory. Dependency Theory appears to stem from the basic proposition that if one has a functional impairment one becomes less independent. Lowered independence places one at risk of developing self-neglect. Functional ability refers to the capacity to engage in Activities of Daily Living (ADL) such as dressing, bathing and eating. Independent Activities of Daily Living refer to more complex avtivities such as shopping and answering the telephone. Self-neglect is frequently defined in terms of failure to satisfactorily carry out functions such as those which promote good hygiene (Clark et al 1975). Reyes-Ortiz and Mulligan (1996) describe a case of Diogenes Syndrome in a 77 year old man who had no history of psychiatric illness, had an independent personality and was happy with his condition. In this case the subject was independent in ADL functioning. Patients with severe self-neglect have been found to be more likely than a control group to have a longer hospital admission and be discharged to more dependent accommodation (Shaw and Shah 1996). Whilst it is not stated that this was a consequence of lower levels of ADL functioning this is one possible explanation for these findings.

The relationship between impaired functional ability and self-neglect is assumed rather than confirmed. This is an important gap in our understanding of self-neglect, as self-neglect is usually described in terms of impaired or deficient performance of ADLs (MacMillan and Shaw 1966, Clark et al 1975, Shah 1992). Thus self-neglect, whatever the proposed causal mechanism, almost by definition, is thought to manifest itself in terms of the consequences of the

individual's impaired functional ability. It is proposed that the functional ability of people described as self-neglecting is worthy of further study.

1.2.2 **Pathology and Self-Neglect**

The relationship between self-neglect and the presence of pathology is often assumed to be a causal-relationship. The complexity of the relationship between pathology and psychopathology and self-neglect is illustrated in the study carried out by Wrigley and Cooney (1992). They found that in a sample of 29 patients, 13 had senile dementia, 3 had schizophrenia, 3 were alcohol-dependent, and 10 had no psychiatric diagnoses.

Cooney and Hamid (1995) believe that there remains some confusion as to whether patients with psychiatric illness should be categorised as having a self-neglect syndrome. Their review of the literature suggests that the two earliest and most often cited studies (MacMillan and Shaw 1966, Clark et al 1975) found a high proportion of psychiatric illness in their samples. Wrigley and Cooney (1992) found that of 29 patients with Diogenes Syndrome approximately a third of cases had no psychiatric illness. Cooney and Hamid (1995) claim that there is a consensus that "at least" 50% of all Diogenes Syndrome cases have a psychiatric illness. The commonest psychiatric illnesses, they suggest, are dementia, alcohol abuse, affective disorder and paraphrenia. Radeburg et al (1987) found that dementia was the most common psychiatric illness in moderate/severe self-neglect, but in contrast to other studies Radeburg et al found that the incidence of

other psychiatric illnesses was less than would have been expected. The fact that many patients who are described as self-neglecting do not have a psychiatric illness must raise some doubts as to the validity of the claim that self-neglect is caused by a mental illness.

Clark (1980) argues that 50% of self-neglecters have normal personalities but appear less able to form relationships. Thompson (1981) also proposes that personality is a factor in the development of self-neglect. Orrel and Sahakian (1991) claim that the Diogenes Syndrome is a manifestation of frontal lode dementia. Cooney and Hamid (1995) refute this hypothesis when arguing that little evidence exists to support it. Cooney and Hamid (1995) argue that there is no single causal model which explains Diogenes Syndrome. These authors then, in what some may regard as somewhat contradictory position, argue that self-neglect is caused by an interaction between a vulnerable personality, the presence of disease and a social life change. This view, they claim, is supported by Radeburg et al (1987) who state self-neglect is the consequence of an interaction of dementing disorders, chronic and debilitating physical conditions and certain personality traits such as hostility and withdrawal. Drummond et al (1997) suggest that people with Diogenes Syndrome may be suffering from undiagnosed obsessive-compulsive disorder.

Snowdon (1987) investigated 83 patients receiving treatment at a community health centre in Australia. Patients included in the study had previously been identified as living in unclean conditions. This study, by recruiting from a community-based sample, may include a

wider range of self-neglect behaviours than previous studies. It was found that 53 out of 83 patients showed evidence of memory impairment, 31 out of 77 were, or had been, heavy drinkers, and 24 were suffering from hallucinations. Snowdon implies that mental illness and alcohol abuse are causally-related to self-neglect. He does, though, acknowledge that social and economic factors may play a part. Shah (1992) cites the cardinal features of the Diogenes Syndrome as extreme self-neglect, domestic squalor, social withdrawal, apathy, a tendency to hoard rubbish and often a lack of shame. Shah clearly implies that there is a causal-relationship between psychiatric illness and Diogenes Syndrome. This article is weakened by Shah's failure to mention the limitations in generalising to populations from a few cases.

Ungvari and Hantz (1991b) offer what is arguably the clearest conception of the causal processes underlying self-neglect, although they do qualify this by adding that the clinical validity of this conception has not been tested. Ungvari and Hantz categorise self-neglect as being either primary or secondary. Secondary self-neglect is symptomatic of the existence of a major psychiatric illness. Primary self-neglect, on the other hand, is a more complex and nebulous phenomenon. Primary or "pure" self-neglect as they refer to it

> *does not constitute a newly occurring and qualitatively distinct psychopathological entity. It could best be understood as a slow development of the personality in response to a difficult life situation, which was becoming increasingly complex and overwhelming to the individual* (p 447).

If Ungvari and Hantz's claim is true we should be able to trace the development of a self-neglect pattern over a relatively long time-span. Possibly the main contribution of Ungvari and Hantz (1991a,b) to a greater understanding of self-neglect lies in the fact that a psychopathological explanation has been identified and has been placed in a theoretical context. These authors suggest that self-neglect is causally-related to an Atypical Adjustment Disorder (Jaspers 1963). The Jasperian notion of Atypical Adjustment Disorder implies that the personality profile of the self-neglecting individual is an "extreme accentuation" of the premorbid personality. Thus it is claimed that an individual with a particular personality type, when faced with a stressful life event, develops primary self-neglect.

1.2.3 **Personality and Self-Neglect**

It has been proposed that self-neglect is causally-related to the presence of an underlying personality disorder (Post 1985). This personality disorder is characterised by aloofness, unfriendliness, obstinacy, aggressiveness, secretiveness, suspicion and eccentricity (Reyes-Ortiz and Mulligan 1996). Cooney and Hamid (1995) seem to imply that it may be more obvious why people with mental illness have Diogenes Syndrome whilst it is less clear why those without mental illness have Diogenes Syndrome. They believe that Post (1985) may be correct when he argues that Diogenes Syndrome may be the end result of an underlying personality problem. Ungvari and Hantz (1991a,b) claim the literature and their own case studies suggest that severe self-neglect is characterised by the presence of a pre-morbid

personality disorder. They make this claim in-spite of the fact that they also state that the differing objectives, study design, inclusion criteria and terminological confusion makes these studies incomparable.

Although there is a widespread belief that personality types are causally-related to self-neglect there is little empirical evidence to support this claim. The issue of personality and self-neglect needs to be considered at a number of levels including an examination of the evidence supporting the existence of personality types and personality disorders and finally whether these are related to self-neglect.

Powell (1984) defines personality theory as

> *personality theory attempts a global definition of the individual in a manner that is stable across context and time, to provide a broad and causative account of behaviour* (p 409).

The proposition that personality is a stable set of traits has been criticised by Mischel (1993). Mischel demonstrated that individual behaviour is characterised by inconsistency rather than consistency. Powell (1984) outlines the three main attacks to trait theory as being the fact that correlations of scores of personality scales from one situation to another are low; studies using analysis of variance which set out to apportion variance in personality scores to persons, situations, person-situation interactions demonstrate that person (factors unique to the individual) accounts for only around 12% of

variance; and there is a lack of predicative validity of personality measures.

In response to some of the perceived limitations in trait theories of personality, situational theories of personality have been developed (Powell 1984, Mischel 1993). Essentially situational personality theories emphasise the idiosyncratic nature of behaviours. Behaviours are responsive to a particular context and the individual's interpretation of that context. It is implied that behaviour is a consequence of the interaction between the individual and context (Powell 1984).

Mischel (1993) identifies the shared idea underpinning personality theories as the belief that individuals both construct meaning of situations but also select and create these same situations. Thus in the context of self-neglect individuals may see themselves as an independent person who is well and does not need any outside help. When offered help by professional health or social carers they forcefully reject help. In turn this leads to the individual being regarded as aloof, suspicious and aggressive. This, in the eyes of the professionals, is further evidence that the person is unwell and they were right in the first place. Thus the application of the label self-neglect is a dynamic and interactive process. This suggests that the perspectives of professionals and patients and the way in which these interact must be explicated and therefore these various constructions of self-neglect will be described within the multiple-case study design (Chapter 4).

Tyrer (1991) believes that the notion of personality disorder has an important role to play in health care. Nevertheless this notion is amongst the most contentious and controversial issues in mental health (Ironbar and Hooper 1989). The controversy revolves around the question of whether individuals who are thought to have a personality disorder are to be seen as being mentally ill or whether they have been labelled as deviant and non-conforming to group norms.

Powell (1984) rejects the whole notion of personality disorders. He is critical of the International Classification of Diseases (ICD) diagnostic category of personality disorder which he regards as lacking inter-rater reliability, test-retest reliability, factorial stability, content validity and construct validity. Powell claims that personality disorder as constructed in this system is atheoretical. Tyrer (1991), although accepting the validity of personality disorders, also agrees that they are atheoretical. Tyrer (1991) implies that the other classification system used in medicine, the Diagnostic and Statistics Manual (DSM-IV), has overcome some of the limitations in the ICD system principally by providing an operational definition of personality disorder (DSM 1995).

It can be seen from the preceding brief discussion of personality theory and personality disorders that those who support the claim that self-neglect is caused by a particular personality or personality disorder can have these claims challenged on the basis that the assumption of the existence of personality traits and or personality disorders is open to doubt. Even if their existence can be supported there remains little

evidence that people described as self-neglecting have a particular personality trait or personality disorder. Clark et al (1975) illustrate the confused picture on this issue when on the one hand they claim that such a personality trait exists in self-neglect but also report that on testing self-neglecters had no personality problems.

1.2.4 **Self-Neglect and Therapeutic Interventions**

There is a recognition that caring for individuals who self-neglect presents many difficulties for practitioners (Cooney and Hamid 1995). Such a view may stem from the belief that individuals who are self-neglecting are reluctant to seek help and are resistant to offers of help when these are forthcoming (Cybulska and Rucinski 1986, Ungvari and Hantz 1991a, Cooney and Hamid 1995). Johnson and Adams (1996) suggest that the questions as to 'whether we should intervene or not?', and 'if intervention is necessary what is the most effective treatment?' are essentially ethical questions. They sum up the ethical dilemma as "*how to balance the individual's right to autonomy and self-determination against risks to themselves or others*" (p 231).

Pidgeon and Bates (1990) and Cutler and Tisdale (1992) identify the ethical dimension as central to the response of professional groups. Pidgeon and Bates (1990) and Longres (1994) highlight the tensions between the individual's right to self-determination and the doctrine of *parens patriae* (the function of the state in protecting vulnerable members). Parens patriae as a legal principle is retained in Scotland but is not part of English legislation. Cutler and Tisdale suggest that the key to the practical application of ethical arguments revolves

around professional judgements on the self-neglecting person's capacity to make decisions about their own health and lifestyle. The extent to which self-neglecters choose to lead a particular lifestyle has important practical implications for nurses and this will be investigated in stage two (Chapter 4) and stage three (Chapter 5).

In practice ethical judgements may result in another making decisions about an individual's lifestyle and health rather than allowing the individual to make such decisions themselves. This is a consequence of arriving at a judgement that the individual self-neglecter is not competent and that their behaviour is likely to result in adverse outcomes for themselves or for others. This may result in the use of statutory legislation to forcibly hospitalise and treat self-neglect. Treatment for individuals with severe self-neglect is frequently seen in terms of the use of statutory instruments which can compel individuals, who would otherwise be unwilling, to accept treatment in a place of safety (Pidgeon and Bates 1990, Gannon and O`Boyle 1992, Cooney and Hamid 1995, Johnson and Adams 1996). Gannon and O`Boyle (1992) and Clark (1980) believe that statutory legislation should not be used with self-neglecting individuals who do not have a diagnosed psychiatric disorder.

These statutory instruments permit compulsory remand to a place of safety, police to forcibly gain access to an individual's home in order that a formal assessment can take place, Environmental Health Departments to enforce clearing of faecal matter and also bathing and disinfection (Pidgeon and Bates 1990). Clark (1980) makes the point

that the decision when to remove the self-neglecter to a place of care is not clear-cut and should not be used to improve cleanliness or enforce conformity. Clark fails to realise that the legislation is expressly designed for this very purpose.

In terms of specific therapeutic interventions Pidgeon and Bates (1990) ponder whether there are adequate support services available, whether services are flexible and comprehensive and whether services are proactive in monitoring people who self-neglect. Trends in wider service provision, against which specific interventions must be understood, include the closure of psychiatric hospitals and the corresponding pressure to care for people at home, normalisation theory and its emphasis on the principles of dignity, privacy, autonomy and choice, and finally case management initiatives (Pigeon and Bates 1990).

Cooney and Hamid (1995) advocate a co-ordinated response to treatment and suggest a proactive outreach approach which involves identified key workers developing a rapport with the self-neglecting person as the treatment of choice. Reifler (1996) strikes a positive note when he argues that day centre care and community-based low-tech services have "great potential" in the treatment of self-neglect. Reifler cites Ungvari and Hantz (1991a) and MacMillan and Shaw (1966) as evidence that success is not only possible but on this evidence it is "easy to see". Reifler's optimism may be warranted but the empirical basis for his claim that such interventions are successful is limited. Ungvari and Hantz (1991a) and MacMillan and Shaw (1966) do not

provide convincing evidence to support such optimism. Reyes-Ortiz and Mulligan (1996) take a diametrically opposing view when they claim that the prognosis for severe self-neglect is poor and the mortality rate is 50% within one year.

Ungvari and Hantz (1991a,b) provide a detailed picture of the treatment offered to a small number of self-neglecting individuals. In the first case drug treatment consisted of Methylphenidate and Desipramine which produced in one patient increased aggressive and sexually provocative behaviour. Drug therapy was supplemented by a simple behavioural modification programme. This consisted of a structured time-table, compliance with which was reinforced with a bottle of beer or encouraging comments from staff. It was reported that this combination of drug treatment and behavioural modification was successful within 2-3 weeks. Indicators of success included "*placid groaning, coupled with quiet acceptance*" (p441) and only occasional reminders to attend to personal hygiene. One year later this individual was in a nursing home. In the second case drug treatment consisted of Methyphenidate and Nortriptyline which resulted in increased aggression and disinhibited behaviour. Drug therapy was also supplemented with a simple behavioural modification programme. It was reported that eight months after treatment the patient was living in the same rest home, withdrawn, content and smoothly fitting into the new environment when he died from acute cardiac failure. The criteria of success used by Unvari and Hantz are minimal to say the least. Whether these patients also considered treatment a success would be interesting to know.

Ungvari and Hantz (1991a,b) describe drug therapy as non-specific stimulation. The rationale for employing drug therapy was to "shake up" the apathetic patient in the hope that this would improve communication. Such potential benefits, they argue, outweigh potential adverse side-effects such as increased disinhibition and aggression. Warner et al (1996) describe two patients with schizophrenia characterised by delusions, thought disorder and self-neglect all of which improved after treatment with Risperidone. Kummer and Gundel (1995) describe the case of a 72 year old man with Diogenes Syndrome with no other pathology apart from disruption of the normal sleep-wake cycle. Treatment with Zolpidem resulted in an improved sleep pattern and a course of behavioural psychotherapy resulted in "partial reintegration" of the patient. It is not clear what is meant by partial reintegration. The effectiveness of drug treatment is yet another issue which does not receive unequivocal support from existing research, in fact the rationale for prescribing drugs in the first place is not clearly explicated.

1.2.5 **Summary**

Research studies investigating self-neglect as a medical syndrome are limited in a number of ways. Previous methods have relied heavily on case studies consisting of one or two cases. It can be questioned whether these case studies are in fact case studies in the sense that they follow a rigorous research methodology or whether they are really reports of interesting cases that serve some form of educational purpose for physicians. The conduct of case studies can be criticised

as a consequence of the poor research design, notably in relation to selection of cases, data collection and analysis. It also appears that many authors attempt to move from individual cases to statements about populations. This form of generalisation is not appropriate in case study research (Eisenhardt 1989). Rather generalisation should be analytical, in which findings from individual cases are linked to theoretical propositions. This has in the past proved difficult in the case of self-neglect as there are few well formulated theories for this purpose.

A second limitation in self-neglect research has been the sampling methods used by researchers. Previous studies into self-neglect have usually recruited patients for the study who have presented to in-patient services. Cooney and Hamid (1995) suggest that this method of sampling means that these patients may not be representative of patients with self-neglect as a whole and therefore results should be generalised with some degree of caution.

The literature on self-neglect can also be criticised for its self-sustaining quality. There are nearly as many reviews of the literature as there are research studies. The self-sustaining quality of the literature, in UK at least, can be seen in the fact that many reviews cite the same literature, and having cited this literature, find themselves cited in future articles. This is problematic as ideas become established as facts rather than as tentative and provisional, as most must be regarded in the light of the lack of empirical data. This process is evident in the recycling of the Clark et al (1975) suggestion that self-

neglect is related to an underling personality disorder. Gannon and O'Boyle (1992) claim that personality problems do exist in serious self-neglect, and they cite Cybulska and Rucinski (1986) as support for this claim. In the Cybulska and Rucinski (1986) article no new evidence on the relationship between personality and self-neglect is presented. In fact Cybulska and Rucinski cite the original Clark et al (1975) article as evidence of such a relationship. This somewhat incestuous and circular process in which authors cite a small number of articles, and find themselves cited in future articles, is clearly evident in the self-neglect literature. Thus tentative, intuitive ideas become received wisdom and are regarded as givens.

Research in this area is also hampered by a lack of valid and reliable operational definitions of self-neglect. Therefore researchers may find methodological problems when sampling self-neglecting populations. Not only are there problems with operational definitions which would allow such patients to be identified there are also conceptual and theoretical problems with respect to any consensus on what constitutes self-neglect. The lack of theoretical perspectives has hampered research. Most extant research has been grounded in the Medical Model and has assumed that self-neglect is caused by some form of underlying medical disorder. Furthermore self-neglect as seen from the patient' s perspective has not been articulated to any great extent.

1.3. **Self-Care Theory and Self-Neglect**

Self-care has been proposed as a central concept in understanding self-neglect (Rathbone-McCuan 1992, Fabian and Rathbone-McCuan 1992, Shah 1992). In two case studies found in the nursing literature the use of Orem's Theory of Self-Care to conceptualise self-neglect and provide direction for nursing interventions to these patients would lend support to the notion that self-care is an important element in nurses' conceptualisation of self-neglect (O'Rawe 1982, Moore 1989). Although these nurses do not provide a detailed rationale for their use of Orem's theory it may be the case that there is an intuitive recognition that self-care and self-neglect are inextricably linked.

1.3.1 **Self-Care**

The need to care for one's own personal hygiene, household cleanliness and nutrition are examples of factors which affect health and well-being. Poor personal hygiene, poor household cleanliness and poor nutrition are frequently cited symptoms of self-neglect (MacMillan and Shaw 1966, Clark et al 1975).

Self-neglect can therefore be defined as the failure to engage in acts which adequately regulate functioning, supply adequate levels of food, take actions to prevent, alleviate, cure or control conditions which affect life, health and well-being (MacMillan and Shaw 1966, Clark et al 1975, Ungvari and Hantz 1991a,b, Gannon and O'Boyle 1992, Shah 1992). It can be suggested that persons described as self-neglecting do not provide optimum levels of self-care.

Evers (1989) places self-care in an historical/cultural context when he suggests that modern society places emphasis on self-reliance and the responsibility for caring on the individual and their family. Evers acknowledges that the under-conceptualisation of self-care presents obstacles for self-care research when he claims that there is no consensus about what self-care means across the many disciplines involved in health and social care. Self-care may be the guiding concept for much primary care practice but there also remains a paucity of empirical data in this area, especially with regards to the elderly (Padula 1992). Padula supports Evers' contention on the under-conceptualisation of self-care and the contrasting and sometimes conflicting operationalisations of the concept and goes on to argue that the development of universal constructs and definitions of terms may be an important research aim. Easton (1993), by contrast, suggests that self-care is in fact one of the most developed concepts in nursing theory.

1.3.2 **Orem's Theory of Self-Care**

Orem's theories are arguably some of the most widely known theories of self-care in nursing. Orem's Self-Care Deficit Theory of Nursing comprises of the three interlinked theories 1) Theory of Self-Care; 2) The Self-Care Deficit Theory; 3) Theory of Nursing Systems (Foster and Bennett 1991) (Figure 1.1).

Figure 1.1 The Theories Of Self-Care, Self-Care Deficit And Nursing Systems

	Self-care	**Self-care deficit**	**Nursing systems**
Focus	persons performing operations to know and to meet their own self-care	persons not able to to know and meet their own self-care deficit	nurses, patients
People	self-management, self-care agency	health-related self-care deficit	nursing agency
Change	no performance to complete perfor-mance of self-care	self or another seeking assistance	change in patients self-care agency

Adapted from Orem (1991, p 68)

The Theory of Self-Care is concerned with answers to the question -what is self-care?- (Hartweg 1991, Orem 1997). Foster and Bennett (1991) identify the key concepts of the Theory of Self-Care as self-care; therapeutic self-care demand and self-care requisites; self-care agency; and basic conditioning factors.

Therapeutic Self-Care Demand

Therapeutic self-care demand is defined as

> *The totality of self-care actions to be performed for some duration in order to meet self-care requisites by using valid methods and related sets of operations and actions* (Orem 1991, p 92).

Therapeutic self-care demands must be met using knowledge and skills which an individual possesses in order that self-care requisites or requirements which are needed for health and well-being are met. Self-care demands vary throughout the course of one's life such as when social circumstances change or when disease is present. Thus the presence of disease or altered social circumstances may place additional demands on self-care abilities which overwhelm the individual's capacity to cope.

Self-Care Requisites

Self-care requisites are the processes and substances which are necessary for health and well-being. These range from basics such as oxygen and food to more complex factors such as social interaction (Orem 1991). Self-care requisites can be either universal, developmental or health deviation. Universal self-care requisites include: The maintenance of a sufficient intake of air; The maintenance of a sufficient intake of water; The maintenance of a sufficient intake of food; The provision of care associated with elimination processes and excrement; The maintenance of a balance between activity and rest; and The maintenance of a balance between solitude and social interaction.

Developmental self-care requisites show some overlap with universal self-care requisites but are directly related to developmental processes. Health deviation self-care requisites include seeking medical attention, carrying out medication regimes and other activities required to respond to illness, injury and/or disease.

Self-Care Agency

Self-Care Agency (SCA) first appeared in the second edition of Orem's basic text (Orem 1985). Orem describes SCA as the power and capability to engage in self-care. She proposed that SCA is an acquired ability which is influenced by internal and environmental variables. Hartweg (1991) gives education and the ability to work as examples of environmental variables which influence SCA. Gast et al (1989) employ a broad definition of SCA when they define it as

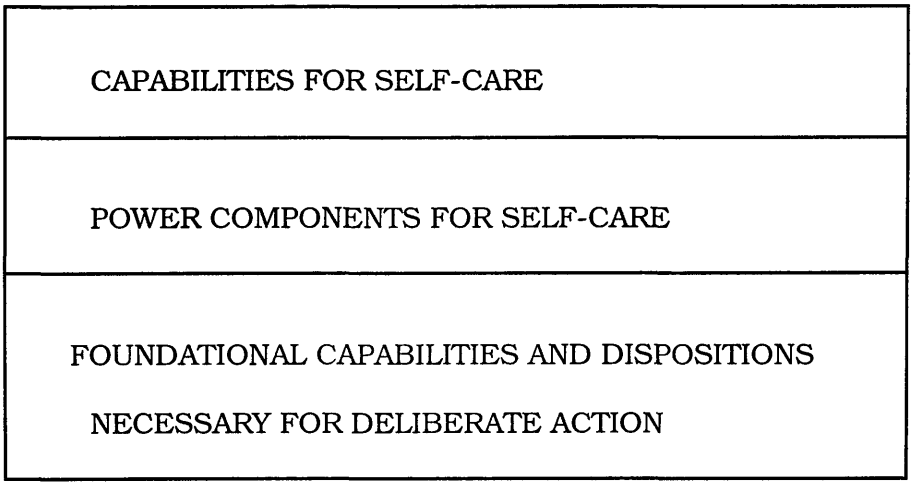
> *self-care agency refers to the capabilities of individuals that enable them to engage in self-care* (p 27).

Evers et al (1993) extend this definition when they describe SCA as

> *these operations include to investigate, to decide and to perform specific psychomotor actions. The aim of these investigations, decisions and actions is to meet self-care requisites or needs* (p 307).

Aish and Isenberg (1996) describe SCA as the capability for self-care which all human beings possess. The latest conception of SCA is of a complex phenomena comprising of three hierarchically arranged types of ability (Figure 1.2).

Figure 1.2. The Conceptual Structure Of Self-Care Agency



Adapted from Gast et al (1989)

Gast et al (1989) believe that foundational capabilities apply to all deliberate actions not just self-care. Foundational capabilities include sensation, perception, memory and orientation. Foundational capabilities are general factors which are not specific to self-care. The second level are the ten power components. Power components of SCA are capabilities which relate specifically to self-care. Orem (1991) summarises power capabilities as knowledge, attitudes and skills which allow engagement in self-care. The third level consists of another set of essential capabilities which are needed to perform self-care. These third level capabilities involve the recognition of the need for self-care, deciding to engage in a specific self-care action and actually engaging in the chosen action. A combination of power and

performance capabilities are measured in the ASA-B Scale to be used in stage one (Chapter 3).

Self-Care Agency, Health and Disease

SCA may be a useful concept in explaining why individuals neglect themselves. SCA capabilities have been conceptualised as being related to a range of factors, such as disease, functional ability and social support. Thus when these factors adversely affect an individual they experience a concomitant reduction in SCA capability. This in turn results in a failure to care for oneself adequately and may, in some cases, result in self-neglect.

Stonebraker (1991), in a study investigating SCA, self-care and health in pregnant adolescents, found a significant positive relationship between SCA and self-care ($r = .7648$, $P < .001$) and self-care and health ($r = .7648$, $P < .001$). Self-care and SCA accounted for 61% of variance in health state in this group. Gast (1996) points out that it is self-evident that self-care abilities develop over time and within particular social contexts. It would follow that in a medical syndrome of self-neglect there would be a reduction in levels of SCA in comparison to non self-neglecters. This hypothesis will be tested during stage one (Chapter 3).

Nursing care is directed towards activating and/or maintaining an individual's SCA with the aim of improving health (Sullivan 1979). Ewing (1989) conceptualised the aim of a nurse administered educational programme for stoma patients as increasing SCA levels.

Aish and Isenberg (1996) found that a nursing intervention with MI patients increased SCA levels in a study group but not in a control group. This indicates that nursing interventions can directly influence SCA and through this self-care actions. Orem (1985) argues that an individual's capacity to engage in self-care during the rehabilitation process is dependent on SCA. The notion that SCA functioning can be improved directly through nursing interventions offers up the possibility that a theoretically and empirically derived nursing intervention in self-neglect is possible.

Basic Conditioning Factors

Basic Conditioning Factors (BCF) are factors which influence the development and operation of SCA (Orem 1991). A large number of BCF have been proposed and many studies have focused on different BCF and their impact on SCA. The ability to perform and operate self-care agency is proposed to be influenced by BCF such as sex, age, developmental state, health state, sociocultural orientation, family influences, patterns of living and elements of the health care system (Orem 1991).

Jirovec and Kosmo (1993) found support for Orem's proposition that BCF influence self-care abilities. Vannoy (1989) carried out a descriptive correlational study looking at the relationship between BCF and self-care capabilities of people undertaking a weight reduction programme. Vannoy found that age, percentage overweight, previous weight loss (BCF) were all negatively associated with the ability to engage in self-care. James (1991) found that BCF (perceived health

status, perceived self-efficacy, family satisfaction, life events) explained 32% of the variance in SCA levels in obese adolescents.

Disease has been conceptualised as a BCF (Orem 1991). This provides the conceptual link between SCA, BCF and self-care. Frey and Deynes (1989) make this point when stating that people suffering from an illness or disability must take additional self-care actions in order to satisfy health-deviation self-care requisites. These are directly or indirectly related to underlying pathology.

Frey and Deynes (1989) argue that although Orem has conceptualised disease as a BCF she has not identified the relationship between BCF and health deviation self-care. In the context of self-neglect a range of possible BCF can be identified. These factors include age, marital status, functional status, occupation, household circumstances and pathology.

1.3.3 **Limitations of Self-Care Theory in Relation to Self-Neglect**

Riehl-Sisca (1989) claims that although Orem indicates that nurses can care for families the basic unit of care remains the individual. This, Riehl-Sisca asserts, may create problems for community nurses who must care for family systems. Gast (1996) describes Orem's position as one which stems from the ideology of individualism. Gast states that

> *Fundamentally, the sense of self is constructed differently in individual-versus group-orientated cultures, as are attributes regarding*

the locus of responsibility for health outcomes, to the degree that the theory cannot accommodate these differences, it is culturally biased (p 130)

Gast (1996) in her analysis of the internal consistency of Orem's theories highlights a number of logical inconsistencies. The first inconsistency is the lack of clarity regarding the fact that some person-related characteristics are conceptualised as BCF and others are foundational capabilities of SCA. Smith (1987) agrees and suggests that SCA, self-care, self-care deficit and self-care demand all refer to a single concept. This possible conceptual confusion makes the use of Orem as a theoretical framework for self-neglect research problematic.

The second limitation identified by Gast is the lack of objective and observable correlates for self-care requisites and self-care demands. Gast believes that these apparently objective phenomena are in fact normative judgements of what constitutes an adequate level of self-care. This problem lies at the very root of the notion of self-neglect. What objective and observable hygiene behaviours or absence of those behaviours can be stated to be acceptable, or unacceptable but non-pathological, or indeed pathological? It is not entirely obvious whether there are any cut-off points to make such a judgement and even if these were available they might vary from culture to culture and from sub-culture to sub-culture. This objectification of normative values may have led to the medicalisation of personal health-related self-care activities. This criticism represents a fundamental philosophical and theoretical challenge to Orem as a framework for understanding self-

neglect and also to the Medical Model construction of self-neglect: the problem being that self-neglect may not be an objective medical syndrome but a value judgement of behaviours which do not conform to social norms in a given culture in a particular historical period. In the following sections other theoretical perspectives will be discussed which directly address this fundamental limitation in the use of Orem, and for that matter the Medical Model, to contribute to an understanding of self-neglect.

1.4. **Self-Neglect: Sociological And Psychological Theories**

The case study described by Reyes-Ortiz and Mulligan (1996) presents a problem for those who claim self-neglect is a medical syndrome. The problem being that different perspectives of behaviour may be held by patients and professional carers. The case study describes a man who is categorised as being self-neglectful and who rejected this label and suggested that he was in fact happy and contented with his lifestyle. This is an issue will be explored directly in the multiple-case studies (Chpater 4).

The related problems of different constructions of self-neglect and which construction is to be regarded as true need to investigated. In concrete terms if an individual, who has been diagnosed as self-neglecting, claims that his way of life is an active choice and one which he is happy with, can he still be regarded as self-neglectful? In this section sociological and psychological explanations of disease and health will be discussed in the context of how they might present alternative constructions of self-neglect.

1.4.1 **Post-Modern Perspectives Of Self-Neglect**

Post-modernism explicitly rejects the idea of grand narratives, such as the Medical Model and Orem's Theory of Self-Care (Orem 1985). Post-modernism is a school of philosophical thought which offers a radical challenge to the truth claims of any theory or theorist. Post-modernism proposes that understanding a phenomenon is the process of making explicit a number of explanatory systems (Rogers 1991). Lupton (1994) believes that post-modernism

> *is essentially an approach which questions claims to the existence of essential truth. What is asserted to be the `truth` should be considered the product of power relations, and as such, is never neutral, but always acting in the interest of someone* (p 1).

Post-modernism proposes that there is nothing other than interpretations of reality, facts do not exist (Foucault 1980). Rabinow (1984) asserts that the purpose of post-modernism is to expose the truth claims of any discourse. Dzuric (1995) claims that this forces nurses to consider whether phenomena of interest to them, such as disease categories, are what it is claimed they are. This dictum, if applied to self-neglect, would suggest that claims of the Medical Model and Orem's theories to having access to the truth about self-neglect must be rejected. In fact post-modernists would argue that these explanatory systems are no more true than the perspectives of people who are thought to self-neglect.

Turner (1995) contrasts post-modernism and the Medical Model perspectives when stating

> *To regard illness as a text open to a variety of perspectives is a radical approach to sickness, because it points to some of the problems in the Medical Model....Modern medicine, treating the body as a sort of machine, regards illness and disease as malfunctions of the body's mechanics. All `real` diseases have specific causal mechanisms which can be ultimately identified and treated* (p 206).

The limitations of the Medical Model alluded to by Turner include the facts that many diseases do not have a known causal basis in body mechanics, there is evidence of cross-cultural variations in pathologies, and many contemporary disorders are not reducible to physiological changes. Welland (1998) argues that the dominant discourse of chronic illness has given normalisation, individualism and science a privileged place in nursing; the implication being that the Medical Model and Orem's Theory of Self-Care must be understood in the context of this wider discourse and the impact of normalisation, individualism and science on constructions of self-neglect must be, and indeed will now be, considered.

1.4.2 **Social Constructionism**

Social constructionism is a way of understanding disease which has been linked to the development of post-modernism (Rogers 1991, Armstrong 1994, Turner 1995). Social constructionism shares the

same postmodern position that reality does not exist independently of perception and that furthermore the Medical Model has created its own objects of concern and its own version of reality (Armstrong 1994). Foucault (1980) coined the term `clinical gaze` to describe the practices by which medicine exercises power by defining reality and categorising disease. Jones (1994) describes post-modern conceptions of disease as suggesting that modern medicine has created a new reality by an epistemological shift in which knowledge and the meaning of language were reconceptualised.

According to Turner (1995) post-modernism proposes that constructions of disease are products of an historically and culturally located discourse. He gives the example of homosexuality which was regarded as a sin in Victorian religous-based conceptions of behaviour, a neurosis in early 20th century medicine, and a sexual preference in contemporary medicine.

The possibility of different constructions of `disease` is graphically illustrated in the case of deafness (Gregory and Hartley 1991). Gregory and Hartley identify a number of very different constructions of deafness which have a direct impact on how deafness is understood in contemporary culture;

1. The clinical psychological construction which views deafness as a sensory impairment. Thus deafness is seen as the defining feature of a deaf person in contrast to the fact that hearing is not regarded as the defining feature of the hearing person;

2. The disease model which views deafness as a pathological state which must be overcome. This construction objectifies deafness by its reliance on audiometric measurement and the subsequent classification of deafness, which in children especially has a dramatic impact on their lives;

3. Deafness as constructed from the deaf person's perspective. Deaf people are seen as a cultural minority who have had to construct their experience within the language of the dominant discourse.

Padden and Humphries (1991) illustrate the different constructions of deafness in a vignette involving a child from a predominantly deaf family and community living in Martha's Vineyard, USA. This child came to recognise that his new friend was different but he could not figure out exactly in what way she was different from him. One day he communicated to his mother about this friend and described to her how one day his friend's mother came out and made motions with her mouth and the friend seemed to understand and was able to respond to these motions. The boy asked his mother what sort of strange people they could be and asked what they were doing. His mother told the `deaf` boy that his friend and her family were hearing people. It was only then that he began to realise he was different from others. It may be suggested that this vignette illustrates how we come to define ourselves and in turn come to be defined by others through a process of social interaction. This begs the question whether self-neglecters

recognise that their behaviour is `abnormal` and what influence health care workers have played in the development of this construction.

The notion of disease as a social construction has been used to understand a wide range of other physical disorders, ranging from Drummond and Mason's (1990) research showing how GPs and diabetic patients operated different constructions of diabetes, through to Sontag's (1991) claim that AIDS is a clinical construction comprising of an open-ended list of presenting and contributing illnesses. Sontag describes how AIDS came to be understood within the constraints of the metaphors of war, conflict, technology which are used to portray disease.

Mulhall (1996) argues that diseases are as much the product of society as they are of any pathological substrate. Rogers (1991) makes a similar point when arguing that

> *..when we label ourselves or other people as `ill`, what is happening is a process of social definition in human terms. Illness-any illness- is meaningful as illness only to the extent that it has particular implications for us, as people, and not just as biological organisms* (p 31).

Self-neglect from this perspective is thus a socially constructed phenomenon. It is necessary therefore to explore how particular constructions come to be seen as true. In their work Berger and Luckman (1967) argued that legitimation was a key process in the

social construction of reality. Legitimation of disease occurs through the linked processes of language and symbols; the impact of everyday explanations; explicit theories; and in the worldviews which underpin these theories and practices.

Legitimation Of Disease Through Language And Symbols

This level of legitimation involves the use of words to reify constructs as meaningful and real. Reification refers to the process of turning tentative abstract ideas into real concrete things. Coulter (1973) suggests that language plays an important role in framing events. Language is embedded in a discourse and it does not exist in a social vacuum (Lupton 1994). The way disease is represented by language influences both professional and lay constructions of that disease. The terms self-neglect, social breakdown and Diogenes Syndrome are not neutral but convey a set of meanings. These meanings reflect the values of those who employ such language, namely health and social care professionals. For example language used to describe self-neglect such as the "lack of shame" conveys a sense of moral judgement as much as it describes some clinical symptom.

RD Laing (1969) argues that the technical language of psychiatry splits people into compartments and cannot begin to explain the existential-phenomenological experience of mental illness

> *The words of the current technical vocabulary either refer to man in isolation from the other and the world, that is, as an entity not essentially `in relation to` the other and in a world, or they refer falsely*

substantiated aspects of this isolated entity. Such words are : mind and body, psyche and soma, psychological and physical, personality, the self and organism. All of these terms are abstracts (Laing 1969, p 19)

Laing adopts a position articulated by philosophers such as Wittgenstein inasmuch as he proposes that words can disclose or conceal reality. The language of self-neglect as seen in the variety of labels applied to this phenomenon (Diogenes Syndrome; Social Breakdown; Senile Squalor) and its symptoms (syllogomania; desperate state of domestic disorder; troublesome behaviour; refusal of treatment) gives the impression of revealing some underlying reality. In fact such language may actually define and create a reality which does not exist outside the language used to create it (Foucault 1980). Foucault explores how language is rooted in the dominant ideas within a discourse. Turner (1995) believes that a Foucaultian analysis would claim that we know, or see, only what our language permits us to know or see, because we can never understand a reality which exists outside our language.

Lupton (1994) also describes how the social construction of disease involves the use of visual images. Gilman (1988), in his notion of iconography of disease, describes how representations of disease in visual and written texts influence the way this disease is conceptualised. He argues that such representations eventually become the disease anthropomorphisised. This process may be seen in the self-neglect literature when MacMillan and Shaw's (1966) original

description of `self-neglect` came to be seen as the syndrome itself. This description has been further entrenched through visual representations of self-neglect published in the literature (Clark 1980, Thompson 1981). Lupton (1994) suggests that images and language influence the way in which the illness is constructed and the way in which patients are treated by others.

Foucault (1980) describes how knowledge/power is exercised to limit and control through hierarchical observation. Hierarchical observation is the process of sustaining power by institutionalising a particular branch of knowledge. This is achieved through professional journals playing a key role in reinforcing a particular construction. Thus professional journals may play a part in defining and legitimising a particular construction of self-neglect. This may in part explain the self-sustaining and mutually reinforcing style of the literature on self-neglect.

Legitimation of Disease: The Impact of Everyday Experience

Foucault (1980) has explored the way in which medicine has increasingly exercised power over many aspects of our daily lives. Jones (1994) believes that diagnoses are a key part of this process. He suggests that diagnoses do not simply concern pathophysiological status but these judgements go beyond the diagnosis of diseases to influence the daily lives of people, including aspects such as working, eating, sleeping and eating.

Events and behaviours which were in the past personal, religious and moral issues have now come under the gaze of medicine. This process may have had, and continues to have, a relevance to behaviours thought central to self-neglect. Thus everyday phenomena such as cleanliness and hygiene have come to be regarded as medical problems.

The Impact of Everyday Experience: Cleanliness and Self-Neglect

Two relevant examples of the medicalisation of everyday life are the related concepts of cleanliness and hygiene. Self-neglect is inextricably bound up with notions of cleanliness and hygiene. de Swaan (1996) argues that the distinction between clean and dirty corresponds to the medical distinction between healthy and unhealthy. Lupton (1994) makes a similar point when claiming that cleanliness of the body is a central discourse in contemporary notions of disease and hygiene.

Modern day attitudes to cleanliness have become more pervasive and visible (Lupton 1994). These attitudes, in the opinion of Lupton, border on the obsessive and we are bombarded nightly with television images of bright blue chemicals being released into the lavatory each time we flush. The metaphors of war and conflict are commonly used to describe the battle between cleanliness and dirt. Douglas (1980) illustrates the importance of cleanliness in contemporary medical discourse

..dirt is essentially disorder. There is no such thing as absolute dirt; it exists in the eyes of the beholder. If we shun dirt, it is not because of craven fear, still less dread of holy terror. Nor do our ideas about disease account for the range of our behaviours in cleaning or avoiding dirt. Dirt offends against order, eliminating it is not a negative movement, but a positive effort to organise our environment (p 2).

Foucault (1980) places this debate in an historical context when describing how in the 18th century medicine and specifically matters of hygiene became enmeshed in systems of social control. Thus medicine came to have power over matters of personal hygiene and was given authority to control and dominate hygiene practises and engage in "*authoritarian medical intervention(s)*" (p 175).

The concerns of nurses, such as Nightingale, physicians, politicians and social reformers regarding the relationship between dirt, squalor and disease heralded a major breakthrough in public health in the 19th and 20th centuries. To this extent cleanliness is an important health issue and should rightly be of interest to those concerned with the promotion of health and the prevention of disease. Nevertheless it may be the case that ideas on cleanliness and dirt, as understood by disciplines such as nursing and medicine, come to be used to define an increasing range of behaviours as abnormal and thus diseased.

One consequence of placing self-neglect within this discourse is that people who are `dirty`, `unclean`, and `unhygienic` are to be regarded as disordered and unhealthy. Cleanliness and dirt appear to be almost

pathognomic of self-neglect. Thus a post-modern analysis of self-neglect involves ideas of power, professional knowledge and the medicalisation of everyday life.

The type of authoritarian medical intervention described by Foucault (1980) has its modern day manifestation in the statutory legislation which allows physicians to forcibly hospitalise people who are self-neglecting. Foucault's comments on 19th century medicine may still hold true about present day responses to self-neglect, especially when he states

> *and there is likewise constituted a politico-medical hold on a population hedged in by a whole series of prescriptions relating not only to disease but to general forms of behaviour (food and drink, sexuality and fecundity, clothing and the layout of living space)*
> (p 176).

Foucault also makes a more general point regarding the discourse on disease and hygiene when asking who is served by constructing a debate in terms of the medicalisation of self-neglect? The social constructionist perspective suggests that the dominant construction of self-neglect is the disease construction promoted by professional health care workers. The question of who is best served by the dominance of the Medical Model is problematic and unclear. In one sense it can be argued that the health care professional, whose very existence as a professional may depend on the acceptance of this construction, is best served in the sense that this validates their social role and its

related material rewards. On the other hand it can be argued that if people categorised as having a self-neglect syndrome experience a self-reported increase in the quality of their lives as a direct result of this construction it may be that they are best served. Thus the answer to who is best served by a particular construction may depend on who asks and who answers the question.

Legitimation Through Explicit Theory: The Medical Model and Medical Diagnoses

The fourth type of legitimation identified by Berger and Luckman (1967) is the use of explicit theoretical frameworks and the processes and procedures which emerge from these. Johnstone and Adams (1996) believe that the Medical Model is the dominant construction of self-neglect. The key features of the Medical Model have been described by Jones (1994) (Figure 1. 3).

Figure 1.3 The Medical Model (Adapted from Jones 1994)

The Medical Model
*Health is viewed as the absence of disease and as functional fitness
*Health services are geared towards treating sick and disabled people
*Doctors and other health personnel diagnose illness and disease
*The main function of treatment is remedial or curative
*Disease and illness are explained within a biological framework
*It establishes abnormality and normality
*A high value of placed on the scientific method
*Qualitative evidence given by lay people is given lower status than quantitative evidence

Within a discourse bounded by the Medical Model, self-neglect will inevitably be constructed within the parameters set by this model. The principle method by which the Medical Model manifests itself is the diagnostic process. Turner (1995) claims diagnoses are the most important source of professional legitimation and can be seen as an attempt by professionals to sell their agenda to the public.

Rogers (1991) describes how many medical diagnoses are not made by reference to objective operational definitions but by reference to value judgements. He illustrates this point by arguing that personality disorders are no more than value judgements cloaked in the guise of psychological theory and medical nomenclature. Mulhall (1996) makes the following comments on the diagnostic process

> *A clinician tends to establish his diagnosis by making a clinical judgement of the extent to which the picture presented by the patients conforms with his concept of a specific disease. In making this judgement he seldom uses rigid diagnostic rules. That is, his diagnosis tends to be based on a conceptual rather than on an operational definition* (p 109).

Current debates within practice-based healthcare professions are usually framed in terms of clinical reasoning (Higgs and Jones 1995). There are a number of theoretical frameworks for understanding how clinical reasoning takes place including the empirico-rational and

critical theory models (Higgs and Jones 1995). Nevertheless there is general agreement that whatever theory is proposed clinical reasoning is not an exact science, is error prone, and may be influenced by characteristics of the reasoner and the context within which judgements take place (Eddy 1988, Higgs and Jones 1995, Elstein 1995, Ogden 1996).

The early 20th century dispute on disease classification between Kraeplin and Hoche is an obvious manifestation of the tensions between very different philosophical positions (Kendell 1991). Kraeplin is associated with the popularisation of diagnoses as a form of disease classification for mental illness (Horsfall 1997). Horsfall suggests that diagnostic process is rooted in the positivist position that mental illness is a disorder of brain physiology. Kendell (1991) states

> *(positivists) maintain that such things exist and are usually bent on identifying them; [constructionists] regard them as man-made abstractions, justified only by their convenience and sometimes a dangerous source of misconceptions* (p 2).

Kendell summarises the constructionist position by citing Rousseau's remark "Il n'y a pas de maladie, il n'y a que des malades" [there are no illnesses, there are only sick people]. Kendal assumes a constructionist position when proposing that mental illness is a human construction. The only questions that he thinks need to be addressed are whether diagnosis are useful, to whom and in what context? Mulhall (1996) argues that diagnoses are a manifestation of the medical professions'

need to label and classify individuals. Jones (1994) argues that nurses are not passive actors in the medicalisation of illness but they support and extend medical power. It may be the case that this is evidenced in the growth of the nursing diagnosis movement.

The most wide ranging attack on medicine and medical diagnoses has been made by the anti-psychiatry movement (Szasz 1961, Laing 1969) and other radical theorists such as Illich (1977). Szasz (1961) suggests that mental illness, as constructed by psychiatry, does not exist. Illich (1977) takes the radical position that the medical profession itself is pathogenic to humans. Illich uses the term social iatrogenesis to refer to areas of human life which have increasingly come under the domain of medicine. Cultural iatrogenesis refers to the way in which people gradually give up responsibility and control of their own lives to doctors.

Laing's (1969) rejection of a wholly biomedical construction of disease was specifically aimed at mental illness. Laing argues that madness is not an irrational disease state but an understandable and comprehensible response to a particular experience. Laing exposes and attacks the presuppositions of the medicalisation of mental illness. These presuppositions which he rejects include the very existence of the psyche.

In a similar vein Rogers (1991) informs us how medicine turns ideas and constructions into `real` things by a process of reification

Reification is the process of taking a complex and amorphous mixture of observed events, experiences, accounts and ideas, conceptually turning them (or having them turned) into a `thing` and then giving that `thing` a name (e.g. anorexia, pre-menstrual tension and post-traumatic shock syndrome) (p 19)

Turner (1995) takes a pragmatic and constructionist approach to diagnoses when suggesting that diagnoses are no more than useful concepts when he argues that disease categories are simply expressions of one contemporary form of understanding. He further suggests that they have no material existence of their own but must instead be regarded as explanatory models. Mulhall (1996) articulates the theoretical challenge to medical diagnoses when she asserts that for nurses, other non-medical health-care disciplines and the general public a different set of beliefs and assumptions about disease may inform the way in which health and ill health are constructed.

Hall (1996), in a critical analysis of the Medical Model, describes how the labelling process inherent in this model leads to a cycle of effects which result in detrimental consequences for the individual being labelled. Hall outlines a number of specific criticisms of the Medical Model. These criticisms include diagnoses which are arrived at from a restricted understanding of the patient's life, and when only factors which correspond to a disease or syndrome are taken into account. Hall also believes that other issues such as culture, social status and

personal and family beliefs about disease are discounted. Hall comments that

> *Finally, research that flows from the psychiatric Medical Model considers a minimum of factors and disregards much of the rich data that could be included, and as a result this research produces, for application to practice, nomothetic knowledge more applicable to populations instead of ideographic knowledge applicable to individuals* (p 17).

Positive aspects and strengths of the individual are not part of the diagnostic equation. One final criticism is the fact that behaviour is objectified and there is an over-reliance on problems identified by the professional. This has important implications for self-neglect as in an earlier section it has been suggested that self-neglect has been conceptualised from the professional perspective and the perspective of the self-neglecting individual has been obscured.

Thus, in terms of self-neglect, the diagnosis is made within the parameters of the Medical Model and specifically the construction of self-neglect that most clinicians are familiar with. In addition if Johnson and Adams (1996) are correct in their assertion that different groups may operate different constructions of self-neglect it would follow that different diagnostic criteria are used by each group and consequently different people may find themselves diagnosed as self-neglecting or not depending on which group is making the diagnosis.

The question of different constructions of self-neglect and the factors which lead professionals to judge self-neglect will be investigated in stages two and three.

Worldviews as a Source of Legitimation

The fifth and final way in which the social construction of reality is legitimised is through the worldview that underpins any particular theory or explanation of disease (Berger and Luckman 1967). The Medical Model and Orem's theories may be dependent on the positivist and post-positivist worldviews for their legitimation. Many authors and theorists do not fully explicate or even acknowledge the philosophical assumptions underpinning their position with respect to self-neglect. Nevertheless the literature on self-neglect and self-care, although to a lesser extent the latter, are almost exclusively rooted in the positivist tradition and therefore any discussion of self-neglect must explore the consequences of a debate which is framed within this worldview.

The Positivist Worldview

Laurin (1994) identifies the ontological basis of Orem's theories as being rooted in the Aristotelian-Christian positivist tradition. This positivist ontology is the dominant tradition in Western nursing and medical thinking. Ashworth (1997) identifies the belief in an unequivocal reality which is comprised of a set of relationships between specific variables and scientific theories, all of which are amenable to empirical testing, as the essence of positivism. Laurin suggests that this tradition proposes that phenomena have an

existence independent of the observer. A second proposition is that individuals are rational. These two propositions are central to Orem's theories, although it may be argued that only the latter is explicitly acknowledged.

A variation of positivism is the post-postivist perspective. The post-positivist perspective differs from the positivist perspective inasmuch as it does not believe that truth can be known for certain. Ford-Gilboe et al (1995) state that

> *The post-positivist paradigm focuses on the discovery of a reality characterised by patterns and regularities that may be used to describe explain and predict phenomena. Based on the ontologic stance of critical realism, truth can be discovered only imperfectly and in a probabilistic sense.....* (p 16).

If positivism or post-positivism is to be the basis for our understanding of self-neglect it follows that when self-neglecters believe that their lifestyle is deliberately chosen and is to their liking they can still be diagnosed as suffering from a medical syndrome. This is justified on the basis that the individual displays a number of behaviours which match a pre-defined list of behaviours characteristic of a category of disease. These categories have been prescribed by professional groups, most notably the medical profession. Thus self-neglect in this view exists *a priori* and can be known and objectively measured.

The Constructionist Worldview

In contrast to the positivist worldview the constructionist paradigm asserts that there are multiple truths and these are socially constructed (Penticuff 1996, Sandelowski 1996). Ford-Gilboe et al (1995) state that

> *Stemming from the ontologic position of relativism, reality in the interpretative (constructionist) paradigm exists as multiple, sometimes conflicting, mental constructions of everyday life experiences that are situational and context dependent. Thus, truth is both complex and alterable based on on-going experiences and their meanings to the person* (p 17).

Guba and Lincoln (1989) argue that the philosophical underpinnings of constructionism are radically different from those of positivism. The major differences are the rejection of an objective reality and acceptance of multiple realities which are "*social constructions of the mind*". Guba and Lincoln identify a number of assumptions accepted by constructionism which include:

*Truth is a matter of consensus among informed constructors, not of correspondence with an objective reality.

*Facts have no meaning except within a value framework; therefore there are no objective assessments of any propositions.

*Cause and effect do not exist except by imputation.

The positivist-constructionist debate raises very important questions as to whether self-neglect is to be considered a disease, a manifestation of a range of other medical problems, or a value judgement of a particular lifestyle. Clark (1980) and Thompson (1981) allude to the subjectivity of patients' views, as opposed to the objectivity of the professional view, when they claim that individuals who self-neglect have a propensity to distort reality. The presumption is that reality is not defined by the self-neglecter but by others.

Social constructionism proposes that professionals' judgements of an individual's lifestyle are not to be seen as any more truthful than that individual's judgements of their own lifestyle (Rogers 1991). In a nutshell if an individual says they are not self-neglecting then they are not, in their terms, self-neglecting but have a lifestyle somewhat different from any perceived norm. Consequently it can be seen that the constructionist tradition raises fundamental questions regarding the very existence of self-neglect as a behaviour category or as a medical syndrome.

Lupton (1994) outlines a number of criticisms which have been levelled at social constructionism the most important of which, he suggests, is its relativist epistemology. The issue at dispute is, if we are to accept the relativist position that all constructions are equally valid, how are the claims of each perspective to be judged as having access to truth about self-neglect. Lupton suggests that not only does this criticism

not weaken the relativist standpoint it actually highlights a strength. He argues that only by articulating the various constructions can we fully compare, contrast and evaluate them. Dingwall (1976) suggests that even if we accept that all constructions are equally valid it does not necessarily follow that all are equally useful. This view is consistent with the pragmatic school of philosophy of science (James 1972). The pragmatic view suggests that *a priori* claims to truth are less important than the consequence of any position. Therefore if the Medical Model construction of self-neglect can be shown to produce more effective treatment, however this may be defined and measured, it has a higher value than other competing constructions. If on the other hand the claim is that self-neglect is simply a lifestyle choice which requires no treatment and consequently results in no adverse effects on others and increases the personal happiness of the individual, this may be the most useful construction.

1.4.3 **Lay Beliefs And Lay Health Systems**

The articulation of health beliefs and health practises of people in different cultures has been the focus of medical anthropology. This branch of medical sociology focuses on how the beliefs of a particular culture influence constructions of health and disease. Rogers (1991) claims that lay beliefs and medical knowledge are not very different. Lay beliefs have been marginalised in medical discourse as they were not seen as being scientifically sound, and in fact were often regarded as evidence of pathology (Williams and Popay 1994). Williams and Popay summarise the most important research findings in the area of lay beliefs (Figure 1.4)

Figure 1.4 Major Themes In Lay Beliefs Research

LAY BELIEFS
1.Lay beliefs are varied and do not mimic science
2.Lay beliefs are logical and consistent even when they are at odds with scientific evidence
3.People try to make sense of disease in the context of their own experience
4.Lay beliefs are biographical narratives which are reconstructions of the life and history of each individual
5.Lay beliefs are culturally framed

Jones (1994) identifies how individuals operate at least two broad explanatory systems of disease. Individuals have a private construction which they use when discussing disease with friends and relatives. In addition they also have a public construction which they use when relating to health professionals. The beliefs and views of self-neglecting individuals and their families have been largely missing from the literature. What little is known strongly suggests that those categorised as being self-neglecting may reject this label (Clark 1980, Johnson and Adams 1996). It is not known why they reject this label and how they perceive their circumstances. This is an issue which requires further empirical study and will be explored in multiple-case studies (Chapter 4).

1.4.4 **Structuralist-Functionalist Explanatory Systems**

Structuralist-functionalist perspectives draw on the biological notion of systems and the anthropological notions of social structures and the homeostasis of cultures (Gerhardt 1989). Structuralism refers to the way in which language and the rules/structures which govern language-use influence our communication. The basic premise of functionalism is that roles have the function of facilitating the smooth functioning of social operations (Wolinsky 1988). Parsons (1960), possibly the most well known functionalist, proposed that roles and the capacity of individuals to fulfil these roles are important in the understanding of illness and disease. The specific role identified by Parsons was the sick role. In this role a number of expectations and obligations are identified. Wolinsky (1988) identifies the four aspects of the sick role as the expectations of exemptions from normal obligations and the expectation of non-responsibility, and the obligations to get well as soon as possible and to seek competent medical help. Freidson (1970) extends the sick role by asserting that issues of responsibility determine whether the individual is to be offered the privileges implicit in the sick role. Those held responsible for their condition cannot expect the same level of privilege as those held non-responsible. Thus the issues of intentionality and choice discussed in an earlier section of this review may have other important implications for the self-neglecting individual. If held responsible for their actions value judgements such as blame may be directed towards them. One possible benefit of the medicalisation of self-neglect is that individuals

are absolved of blame for self-neglect and thus do not find themselves caught up in a cycle of conflict with health care professionals.

Gerhardt (1989) suggests that Parsons equates health with normality and illness with deviance. Deviance is said to be a relative concept in relation to social ideas about health and thus there is a large degree of variability in the boundaries between health and illness. Caring and curing in the Parsonian construction of illness are regarded as forms of social control (Gerhardt 1989). Gerhardt argues that the political dimension of Parsons' work is frequently overlooked. This political background is that in capitalist societies there is an all pervasive drive to achieve. Illness is a disruption in the normal capacity to fulfil roles which allow achievement. Illness is thus characterised as a passive, helpless and emotionally disturbed state. Turner (1995) argues that the Parsonian sick role is a functionalist view. Sickness in this sense thus serves the purpose of maintaining the integrity of a social system. In essence sickness is necessary to the effective functioning of society

> *The consequence is that in Western Societies general practitioners are concerned with clinical situations where they are professionally obliged to certify illness in order to explain the patient's failure to comply with social expectation* (Turner 1995, p 38).

In the context of self-neglect, practitioners are faced with people who do not fulfil social expectations regarding self-care and may also exhibit very bizarre and intractable problems. Therefore, in terms of the sick role, the practitioner is obligated to judge and categorise these

behaviours as abnormal. This provides what is essentially a value judgement with a measure of social validation and legitimacy in the form of a medical diagnosis.

1.4.5 **Interactionist Perspectives**

Interactionist perspectives of disease and illness include both labelling and anti-psychiatry theories (Gerhardt 1989). Self-neglect from this perspective can be seen as a label applied by health and social care professionals. Disease and illness are seen as both biological and social realities which are not fixed structural categories but are fluid and dynamic

> *rejecting psychodynamic interpretations, focusing on structural environmental factors determining the origin and course of illness and treatment, the labelling theorists and anti-psychiatrists adopt a nominalist perspective. What matters is not the symptom which the individual develops but, rather, that it is perceived and categorised by the environment* (Gehardt 1989, p 82).

Thus in terms of the labelling perspective it is not the signs and symptoms which are displayed by an individual which cause an illness to be regarded as such but illness is conceptualised by reference to a normative standard. Self-neglect from this perspective is not a property of the individual but a category arrived at through a dialectical process of meaning-giving.

Gerhardt (1989) suggests that the interactionist perspective moves from the Parsonian belief that medicine legitimises illness to the view that medicine actually defines illness. In terms of social reality what may be defined as disease is potentially limitless. Gerhardt believes that the knowledge which is used to put someone in a particular role vis a viz disease is the point of departure of the interactionist perspective from medical perspectives. This approach suggests that self-neglect would need to be understood within a particular cultural context rather than being regarded as an objective reality which exists independent of the individual within a given culture.

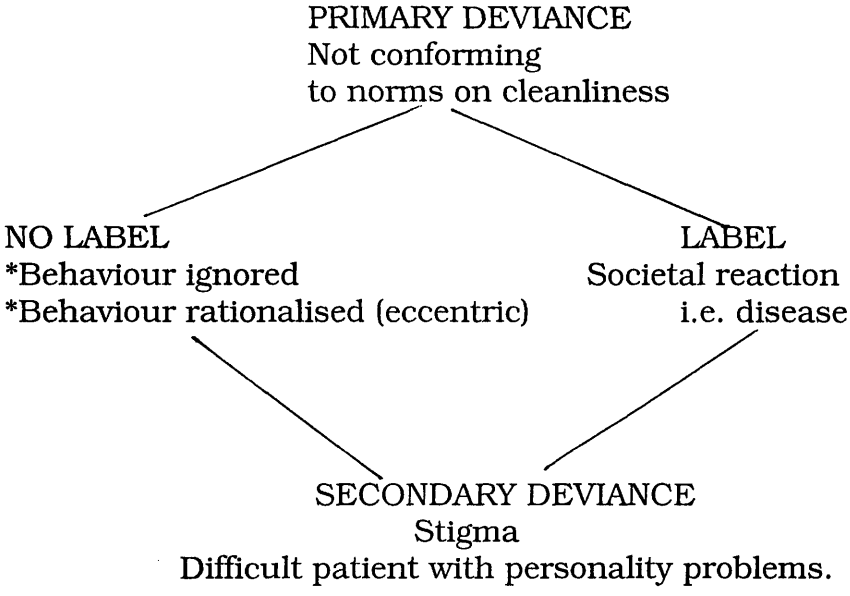
A variant of the interactionist perspective is negotiated interactionism (Gerhardt 1989). Gerhardt argues that negotiated interactionism proposes that deviant roles are not the consequence of fixed structural forces, and thus deviance is not simply imposed by others. Deviance is a fluid and dynamic process of negotiation between individuals. Schelling (1956) describes the negotiation of the deviant role thus

> *the subject includes both specific bargaining and the tacit kind in which adversaries watch and interpret each other's behaviour, each aware that his own actions are being interpreted and anticipated, each acting with a view to the expectation he creates...*(p 125).

The patient-deviant is no longer to be seen as a passive actor but actively participates in the creation of the deviant role. This is in direct contrast to the Parsonian notion of structural stability explicit in the sick role (Gerhardt 1989).

The labelling perspective is one example of an interactionist theory. Scheff (1966) advocates labelling theory and develops a view of labelling from the perspective of patients. Lemert (1972) another advocate of labelling theory, believes that illness is an example of a deviance. Deviance is manufactured by society when it makes rules the breaking of which constitutes deviance. Lemert (1972) distinguishes between primary and secondary deviance. Primary deviance is the process of people not conforming to social norms. Secondary deviance occurs when primary deviance is labelled and the person becomes stigmatised (Figure 1.5). Lemert suggests that the deviant person (i.e. the self-neglecter) is then unconsciously committed to fulfilling the deviant role. The act of labelling self-neglect sets in motion a circular process in which the self-neglecter's response to the label becomes further evidence to support the original label.

Figure 1.5 Labelling Theory And Self-Neglect (adapted from Jones 1994, p408)



It is possible that groups with their own sub-cultural values, such as travelling people and so-called `new age` people, may have an alternative construction of cleanliness and hygiene which may result in a different set of norms and a concomitant shift in how they define self-neglect.

The application of a diagnosis is not simply a one-sided, technical and non-problematical procedure. Tuckett et al (1985) describe the diagnostic meeting as follows

We conceive of the consultation as a meeting between one person who has, by his training and experience, access to science and specialised

knowledge and another person who has, by experience, immersion in his culture and post-discussion, a set of ideas about what is happening to him. Both parties form models of what is wrong and what should be done, what are the consequences of the problem, its treatment and so on, based on their own reasoning and background knowledge (p 48).

The problem of disagreement between lay and professional constructions has been addressed by Pilowsky (1978) and Turner (1995). Pilowsky (1978) has developed the label Abnormal Illness Behaviour (AIB) that he applies to patients who adopt an inappropriate way of perceiving or acting towards their health in a way which is in opposition to the doctor's view. This is an important issue and is one that is seen in the self-neglect literature which documents the frequent disagreements between doctors and patients as to whether the patient's behaviour is self-neglecting or not. Consequently the questions which arise are 'what happens when patients, nurses and medical practitioners operate constructions of self-neglect which appear mutually exclusive?' and 'Are competing constructions accommodated in the therapeutic context or are they a source of misunderstanding and conflict?'. These issues will be explored during stage two (Chapter 4).

1.4.6 **Attribution Theory**

The process of categorising an individual as self-neglecting can also be explained by reference to Attribution Theory (Kelley 1973). Attribution Theory describes how we infer traits and characteristics on the basis of another's behaviour. Jones and Davis (1965) suggest that we categorise

people as having a particular trait or characteristic by selectively emphasising and focusing on certain types of behaviour, especially those with low social desirability. In the context of self-neglect poor hygiene and personal cleanliness problems may be overemphasised when professionals make judgements about self-neglect (see Chapter 5).

Banyard and Hayes (1994) in their brief overview of Attribution Theory research argue that causal attributions have been shown to be important and have a real impact on how we respond to people based on the meaning we attribute to their actions. Attribution theorists have identified a phenomenon they describe as the Fundamental Attribution Error (Ross 1977). This refers to the fact that people have a tendency to attribute behaviour to a disposition of the individual rather than to situational variables. This may explain the trend which places emphasis on individual personality disorders or underlying psychopathology causing self-neglect at the expense of contextual factors such as culture and social class.

1.4.7 **Personal Construct Theory**

The attitudes and beliefs of the self-neglecting individual have not been well documented. Personal Construct Theory has been suggested as a psychological theory which attempts to explain why people develop unique and sometimes idiosyncratic beliefs about themselves and illnesses (Kelly 1955). The proposition that people construct their own ideas about the world and their experience of that world is the organising principle of Personal Construct Theory (Kelly 1955).

Personal Construct Theory is based on the constructionist assumption that people make sense of the world through a set of ideas which Kelly refers to as personal constructs. Kelly captures the dialectic process of meaning-giving in the metaphor of `man-the-scientist` through which he communicates that people create a set of working hypotheses about their world. These hypotheses are then constantly tested against what actually occurs.

Rogers (1991) is critical of this theory in general and specifically in the relation to constructions of disease. Rogers suggests that Personal Construct Theory has little to say about how people collectively construct meanings of disease. In essence this theory does not deal with social processes. He further suggests the bipolarity of the theory does not adequately describe the complexity of human constructions of disease.

Rogers extends his critique to psychological theories in general. He asserts that such theories present the view that constructions of disease are the product of human cognitions which are then externalised. Rogers suggests that a dialectical approach, in contrast, would assume that constructions have an external as well as internal origin. The term dialectic can be understood to describe the mutually constituting process in which the external social world and the internal world of the individual interact with and influence each other. Dialectical theories accept that constructions are influenced by external factors such as social norms and cultural values and practices. He further adds that a dialectical approach would place

constructions of disease in an historical context and describes how this context leads to the reification of a particular construction. Likewise Mulhall (1996) believes that psychological theories do not adequately deal with the role of culture and constructions of disease.

Rogers provides an explanation of how constructions of self-neglect involve an interaction of both the personal constructions of individuals and their external world, which includes cultural values on cleanliness and self-care. He also reinforces the notion that self-neglect must be understood in an historical context, and in this way we can understand why a particular construction of self-neglect has been reified in the form of a medical diagnosis such as the Diogenes Syndrome. At the heart of this dialectical process are questions of what is normal and what is abnormal (Mulhall 1996).

1.4.8. **Notions Of Normality**

It has been already suggested that normality has been given a privileged place in nursing discourse on chronic illness (Welland 1998). The diagnostic process in general and self-neglect specifically is centred around the issue of normality (Armstrong 1994). Armstrong asserts that at the very heart of judgements on the presence or otherwise of a given disease is a judgement as to whether a phenomenon is normal or abnormal. Gerhardt (1989) describes the underlying dynamic at play in the diagnostic process as the undercurrent of presumptive normality. Implicit in the notion of presumptive normality is a view that similarity rather than diversity applies to disease behaviour and that the clear cut division between

normality-health and abnormality-disease is true. The issues of similarity and diversity in constructions of self-neglect are central to this thesis and will be explored in stages one, two and three of the main study. Gerhardt (1989) claims that the certainty of medical pathology textbooks does not reflect real life. He suggests that a gap exists between the textbook definition of a disease and how it actually presents to doctors and other health care professionals. He offers the counterclaim that normalcy is uncertainty.

Doctors make a diagnosis, not by reference to an operation definition but by reference to a professional construction (Mulhall 1996). Mulhall concludes that the range of theories and lay beliefs available to facilitate our understanding of how illness is constructed raises important questions about who will define illness. She states

> *In this somewhat confusing area there are three principle `actors` who may recognise sickness - self, lay others and professional others. `Recognition` in this sense means both a conscious construction of a category (sickness) which is matched against previous experience, and a legitimisation of that category in a social world* (p 45).

Mulhall believes that the answer to the question of what is to be defined as a disease, in this instance self-neglect, revolves around ideas of normalcy. Normalcy refers to ideas of what is to be regarded as normal behaviour and in the case of the suggested medical syndrome of self-neglect what is to be regarded as normal or abnormal levels of cleanliness and self-care. Thus self-neglect syndrome is defined by the

medical and nursing professional and is made when individuals do not conform to expected behavioural norms with respect to cleanliness and hygiene.

A number of other issues make the application of diagnoses even more problematic and include `when does a behaviour pattern become so abnormal that it warrants medical intervention?` and `when does behaviour move from being distasteful and unappealing to being pathological?`. These are ambiguous issues not dealt with to any extent in the self-neglect literature. The whole question of context and degrees of self-neglect is alluded to in the literature but in no way resolved.

1.4.9 **Summary**

The social constructionist perspective offers a radically different way of looking at self-neglect. It suggests that self-neglect is socially constructed and that understanding this social construction requires one to place an individual's construction in a social, cultural and historical context. Thus the medical syndromes of self-neglect may be normative value judgements of behaviours which are seen by medical professionals as abnormal, rather than objective and universal diagnostic categories. The problem for the Medical Model is that self-neglect may not be an objective, universal reality but may in fact be a human construction which must be located in an historical, cultural and social context.

CHAPTER 2: OVERVIEW OF THE STUDY

STUDY DESIGN AND METHODOLOGY

2. **STUDY DESIGN AND METHODS**

Methodological limitations in self-neglect research outlined in Chapter 1 included the predominance of single case studies, or more accurately case histories, the use of hospital-based populations, and an absence of the patient's perspective of self-neglect. This chapter outlines the design and methods employed during this study which overcame these limitations by using multiple-case studies, recruiting a community-based sample, and by describing a range of perspectives of self-neglect, including the patients' perspective. The specific aspects of the design and methods which are outlined include sampling, data collection, statistical techniques, and details of the variables examined in the study. The results of the pilot study are also be reported, highlighting issues of feasibility and practicality of the methods used in the main study.

2.1 **Study Aims**

The overall aims of the study were to obtain a greater level of conceptual clarity of self-neglect and to describe the ways in which self-neglect is constructed by so-called self-neglecters and professional carers. A number of specific questions and objectives were set to meet this aim (Figure 2.1).

Figure 2.1 Study Questions, Objectives and Hypothesis

STAGE 1

Questions

1. What are the most common medical and nursing diagnoses in patients identified by District Nurses as self-neglecting?

2. What is the functional status of patients identified by District Nurses as self-neglecting?

Hypothesis 1. Patients who have been identified as self-neglecting will have lower levels of self-care agency than patients in a comparison group

STAGE 2

Questions

1. Do patients and professionals carers share perceptions of what constitutes self-neglect?
2. Is self-neglect intentional or unintentional?
3. What is the relationship between psychiatric disorders and self-neglect?
4. How do professionals and patients treat self-neglect and what constitutes success in the treatment of self-neglect?

STAGE 3

Objectives

1. To compare judgements of self-neglect made by psychiatric nurses, general nurses, and student nurses.

2. To compare judgements of lifestyle choice made by psychiatric nurses, general nurses, and student nurses.

3. To identify the patient characteristics which influence judgements of self-neglect

4. To identify the patient characteristics which influence judgements of lifestyle choice.

2.2 **Study Design**

The study design comprised of three distinct but interlinked stages. Each stage employed different methods as a consequence of, and in response to, the research objectives set and questions addressed. The research design was a sequential design (Denzin and Lincoln 1994, Miller and Crabtree 1994). Sequential designs describe a study design in which a number of methods are used within the same overall study, and when findings of one stage informed the design of subsequent stages of the same study. Miller and Crabtee (1994) illustrate a sequential design in the case of a hypothetical investigation into back pain. This hypothetical study would begin with a survey of subjects in a non-specific general population, during which those with severe back pain were identified. Those patients subsequently formed the sample frame for the next stage of the study in which subjects were purposively sampled for in-depth interviews. Snadden and Brown (1991) used a sequential design in a study of asthma and stigma. These researchers began their study by measuring sufferers' attitudes towards their asthma. This enabled sufferers who were experiencing high levels of stigma to be identified. This sub-group were then recruited to a second study which used qualitative interview methods.

In the three stages the principles of sequential design were followed by employing three methods with each being informed by the previous method. The first stage was a survey of self-neglect in the community. This allowed a description of self-neglect to begin to emerge and, in

addition, it provided a sample frame of a low-visibility population. The second stage involved a sub-sample of subjects identified in stage one. The use of a multiple-case study method permitted a number of important questions which emerged from both the literature review and from the findings of stage one to be explored in more depth. In the third stage a number of research questions which emerged from stages one and two or from the literature were investigated using a factorial survey design (Figure 2.2).

Figure 2.2 Methods And Type Of Data Collected In Main Study

STAGE 1	STAGE 2	STAGE 3
Survey	Multiple-Case Study	Factorial Survey
Quantitative	Qualitative	Quantitative

The benefits of a sequential design were illustrated in the question of the relationship between self-neglect and psychiatric illness. There is a suggestion in the literature that 50% of self-neglecters have a psychiatric illness. In the first stage a survey of psychiatric diagnoses suggested that psychiatric illnesses did indeed frequently co-exist with self-neglect, although many self-neglecters did not have a mental illness. This finding casts doubts over a single cause-effect relationship (Chapter 3). In stage two the relationship between self-neglect and psychiatric illnesses was explored in more depth, including the perspectives of patients as well as professional carers (Chapter 4). This stage suggested that psychiatric illness and self-neglect may have a

very complex relationship which varies markedly between cases. It was also suggested that self-neglect may be a social judgement which is influenced by the presence or perceived presence of a psychiatric illness. In stage three this proposition was tested (Chapter 5).

2.3 **Selection of the Study Sample**

The lack of operational definitions of self-neglect and the absence of readily accessible sample frames for this population dictated that self-neglecters be recruited from practitioners who have `in-sider` knowledge. Consequently in stage one a sample of self-neglecters and a comparison group was selected from the caseloads of District Nurses. The rationale and limitations for this procedure are discussed in Chapter 3. The sample in the second stage comprised a sub-sample of subjects initially recruited for stage one. A case comprised of patients, relatives, and professional carers. Relatives and professional carers were recruited by snowballing sampling methods. The sample recruited for the third stage comprised an entire 1997 intake of nursing students in a DipHE programme, and a random sample of qualified psychiatric and general nurses. Pragmatic reasons prevented a sample of District Nurses being recruited to the third stage (Chapter 5).

2.4 **Selection of Study Variables**

The limited theoretical development of self-neglect and the lack of operational definitions of self-neglect research dictated that variables selected for the main study should be identified from a range of sources (Figure 2.3). The literature on self-neglect is primarily

descriptive and is located within medically-orientated journals. The literature supports the Dependency Theory proposition that pathology/illness (operationalised by nursing and medical diagnoses) and functional ability are important variables in self-neglect (Gruman et al 1997). In addition there is some confusion in this literature about the question of intentionality, in fact Gruman et al (1997) suggest that this problem has prevented any operational definitions of self-neglect being developed. Intentionality refers to whether self-neglect is a lifestyle which is chosen or is an unfortunate consequence of a disease process which is outwith the control of the individual. What little literature is to be found in nursing publications has used Orem's Theory of Self-Care and Self-Care Agency (1985) as a theoretical framework which nurses use to understand and provide a rationale for professional support for self-neglecting patients. The literature found outwith the medical sphere suggests an approach to self-neglect which stresses the ways in which this phenomenon is socially constructed. Self-neglect as a social construct implies that self-neglect may have different meanings to different social actors. The consequence of this approach is to suggest that these different meanings may lead different professional sub-groups to make different social judgements about self-neglect. It was therefore deemed necessary to investigate these judgements and the factors which influenced them.

Figure 2.3 Summary Of Factors Which Are Potentially Related To Self-Neglect

Psychological/Physical Variables	Social-Cultural Variables
Pathology/Illness Functional Ability Intentionality/Choice Self-Care Status and Self-Care Agency	Social Judgements Professional Support

2.5 **Data Collection**

There is a paucity of research studies investigating self-neglect. Consequently the stages were organised to move from a description of self-neglect, then to an in-depth exploration of various constructions of self-neglect, and finally through to a multivariate analysis of the factors which influence judgements of self-neglect. Therefore a range of data collection methods were employed.

(Figure 2.4).

Figure 2.4. Summary Of Study Populations, Measures Used And Types Of Data Obtained In The Three Stages

STAGE 1 Survey	STAGE 2 Case-Studies	STAGE 3 Factorial Survey
Sample		
63 subjects (41 self-neglect; 22 comparison)	Sub-set of 5 cases. (5 patients; 7 District Nurses; 2 CPNs; 3 GPs; 2 relatives)	190 subjects (59 general nurses; 67 psychiatric nurses; 64 nursing students)
Type of Data		
Quantitative data	Qualitative data	Quantitative data
Measures		
Self-Care Agency measured by ASA- B Scale Functional ability measured by IADL Index Pathology/Illness measured by nursing and medical diagnoses	Constructions of Self-neglect, Intentionality, Professional Support and Self- Care elicited by semi-structured interview, documentary evidence, and field notes.	Social Judgements measured by Rating Scales linked to vignettes

Note: Questionnaires and Rating Scales included in appendices

Stage One

This stage was designed to provide a description of the functional status, accommodation status, medical and nursing diagnoses, and self-care agency of patients who were self-neglecting. The description of self-neglect was complemented by recruiting a comparison group of non self-neglecters identified by District Nurses. This data were collected by survey methods in which two instruments measuring functional ability and self-care agency were administered.

Stage Two

In stage one it was suggested that self-neglecters share some commonalties but also many differences. In fact self-neglect is a very heterogeneous and complex concept which may be used to describe a wide range of behaviours. The complexity of self-neglect and the way in which this is perceived by self-neglecters as well as health-care professionals highlight the need to investigate self-neglect in more depth than is possible using survey methods. Therefore in response to this need it was decided that data were to be collected by means of in-depth interviews of a sub-sample of the stage one sample.

Stage Three

In stage two it was shown that different social actors had different perspectives of self-neglect. This suggested that self-neglect may be a product of social judgements influenced by a range of factors, including gender and functional ability. Stage three investigated the factors which influence general nurses, psychiatric nurses and student nurses' judgements of self-neglect. Data were collected by means of a factorial survey using vignettes developed for the study.

2.6 **Data Management**

Quantitative data from questionnaires and vignette ratings were entered into the SPSS (Windows) v 8.0 and Minitab 10xtra statistics programmes. Data were initially examined for errors and omissions. When such anomalies were uncovered relevant changes were made to the database. Qualitative data comprised of documentary evidence from casenotes, field notes, and verbatim transcripts of interviews. Interview data were audio-taped and transcribed in full. All data appertaining to a particular case were stored in a case file. Data were managed by the researcher manually by colour coding themes and specific data which related to those themes within each interview transcript, field note, or other documentary data. Themes refer in this instance to data relating to specific research questions. Data relating to each theme were then stored in hard copy form and in Microsoft Word 95 format.

2.7 **Pilot Studies**

Two pilot studies were conducted to identify and refine the methods to be used in the three stages which make up the main study (Mishel 1989, Bond 1991). The pilot studies also permitted the researcher to develop a greater insight into what is a poorly conceptualised phenomenon. The first pilot study was carried out prior to the main study and involved the methods to be used in stages one and two. The second pilot study was conducted after stage two and before stage three. This allowed the methods to be used in stage three to be piloted.

2.7.1 **Pilot Study Objectives**

1. To refine data collection and analysis methods
2. To develop and evaluate the data research procedures and data collection instrument
3. To modify the procedures and data collection instruments in the light of evaluation

2.7.2 **The Sample**

The sample for pilot stage one comprised a convenience sample of District Nurses (N=3), Health Care Assistants (N=1), and General Practitioners (GP) (N=3). The District Nurses and GPs were requested to complete ASA-B Scale (Appendix 1) and IADL Index (Appendix 2) (see Sections 3.3 for a fuller description of instruments) on 12 patients who had been identified by these professionals as self-neglecting. Data on five patients were returned giving a relatively low return rate of 42%.

GPs were the highest source of non-returns which led to the decision that in stage one of the main study data on self-neglecting patients would be obtained from District Nurses.

The sample for the second pilot study was a convenience sample of qualified nurses who were employed as teaching fellows (N=13) and first year nursing students (N=24) in a Department of Nursing and Midwifery. There are no hard and fast rules regarding the number of subjects to be included in a pilot study but as a rule of thumb 10% of numbers to be sampled in main stages may be a useful benchmark. Subjects were recruited by the researcher from those groups of staff and students who were readily accessible during the conduct of the pilot study.

2.7.3 **Findings**

Pilot Stage One

Data were collected by means of a semi-structured interview of District Nurses and General Practitioners. Interviews focused on subjects' understanding of self-neglect and patients they had cared for whom they regarded as self-neglectful. Interviews were audio-taped and fully transcribed. A content analysis (Morse 1994) of interview data identified the themes of self-care, non-compliance, failure to seek help, limited functional ability, disease, and nurse/medic-patient relationships. The picture painted of the self-neglecting person was a very undifferentiated one in which the label self-neglect appeared to be used in a variety of ways. This was evident in the relationship between disease and self-neglect, which some subjects thought was a causal

relationship but others thought was an "alternative lifestyle" and was not related to disease. Non-compliance was cited as being a salient feature of self-neglect and this led directly to one of the main goals of treatment which was to increase compliance to prescribed treatment. Failure to seek help was another notion which was thought to characterise self-neglect. A GP reported how self-neglecters would only consult the doctor in the later stages of illness. Another GP commented that he had encountered self-neglecters who would not even recognise that a problem existed. This idea of different perspectives of self-neglect or denial of the truth as perceived by the professional is an interesting issue for investigation in the main study. Nurses told how they went to great lengths to develop an effective interpersonal-relationship with the self-neglecting person. They would consciously modify their normal approach to patients as self-neglecters were usually suspicious and untrusting.

Self-care agency levels in patients identified by DNs were measured by the ASA-B Scale (see Section 3.3 for a description of ASA-B Scale). The ASA-B scores of patients in the pilot study ranged from 48-57 with a mean score of 53.2. This mean score is very low compared to other published studies. ASA-B scores of 82.45 (mean) were found in geriatric rehabilitation patients (Lorenson et al 1993). The functional ability of patients was measured by means of IADL Index (see Section 3.3 for description of the Index). A number of patients (N=3) were independent in all ADLs.

Pilot Stage Two

Stage 3 of the main study (of which this was the pilot) was a factorial survey of nurses' judgements of self-neglect and choice in lifestyle. The instrumentation employed in this pilot study consisted of vignettes depicting a short case history. Each case history was randomly constructed from six previously identified variables with each variable containing a number of levels (see Section 5.4 for more details of vignettes). Subjects were asked to complete two 7 point-rating scales in which subjects were required to judge the level of self-neglect and the extent to which the individual depicted in the vignette had chosen to lead this lifestyle (Appendix 3). Basic biographical data on occupational speciality of subjects were also collected. Each subject was administered 10 vignettes. Vignette packages were not randomly selected in the pilot study, although randomisation was used during the main study. There were 370 vignettes available for analysis but 7 were rejected as data were incomplete. Only data provided by university staff members were missing, all student vignettes were complete. Therefore a total of 363 vignettes were entered into analysis. Data were analysed using SPSS 8.0 programme. Data were initially examined for accuracy of data entry and missing data.

The ratings for self-neglect judgements showed a mean of 4.15 (sd 1.73). The distribution of responses was skewed and a tendency for scores to cluster around the mean is evident. Ratings were well

distributed across the scale and thus the scale provides for a degree of discrimination of judgements (Table 2.1).

Table 2.1 Vignette Ratings In Judgements Of Self-Neglect

		Frequency	Percent
Not Self-Neglect	**1**	21	5.8
	2	61	16.8
	3	46	12.7
	4	78	21.5
	5	67	18.5
	6	52	14.3
Severe Self-Neglect	**7**	38	10.5

Subjects' ratings of the degree of choice patients described in the vignettes had exercised in the lifestyle they were leading showed a mean of 3.56 (sd 1.84). The distribution of choice ratings was positively skewed (Table 2.2). Fewest subjects rated cases as having no choice in the lifestyle they were leading. In summary it was judged that in these few vignettes self-neglect was not a lifestyle patients wished to lead but for some reason it was forced on them by circumstances as yet unspecified. The distribution of ratings were generally well spread across the scale.

Table 2.2 Vignette Ratings In Judgements Of Choice

		Frequency	Percent
Has Chosen to Lead Lifestyle	**1**	59	16.3
	2	62	17.1
	3	66	18.2
	4	47	12.9
	5	53	14.6
	6	50	13.8
Has Chosen No Aspect of Lifestyle	**7**	19	5.2

2.7.4 **Evaluation by Subjects**

Pilot Stage One

The ASA-B Scale and the IADL Index were thought by subjects to be understandable and easy to complete. Both instruments provided the type of data necessary to answer the relevant research questions. Problems were encountered with the interview schedule. The wording of some questions was reported as being clumsy and difficult for a small number of participants to understand. Other questions did not seem relevant to some participants and finally participants seemed reluctant to provide the time needed to finish the interview. Return rates for questionnaires was poor and in stage one return rates were

increased by a sampling technique which involves initially using District Nurses to obtain questionnaire data.

In general the various aspects of the research design were feasible and appropriate in the context of the stated research questions. The pilot identified some problems with the interview schedule and the initial sampling plan. This finding informed the conduct of stage two of the main study.

Pilot Stage Two

Subjects were asked to comment on the usability and their general impression of the instrument. The large majority of subjects were able to complete the ratings with little difficulty but a number of problems were noted. Some subjects found the instructions on using the rating scale difficult to follow and as a consequence did not place a cross directly on a number within the scale but on the line between numbers. This presented difficulties when scoring responses and the instructions were amended to indicate to subjects that they should place a circle around a number which best represents their judgements. A number of minor spelling and gender-related language problems were also identified and were amended in final instrument. Some aspects of the vignettes were thought unrealistic; for example one subject thought that it was not credible to include a vignette of a woman who was a roadsweeper.

2.8 **Summary**

The methods to be employed in all stages proved to be practical and realistic. The data collected by these methods provided answers to the research questions. The key concepts informing stages one and two are disease/illness (medical and nursing diagnoses), self-care and self-care agency, functional ability, professional support and intentionality (choice). On the basis of the pilot study it seemed likely that these concepts are useful in providing a clearer description of self-neglect than currently exists in the literature.

The aims of the second pilot study were also met. The procedures and data collection instrument were generally acceptable to subjects. There were modifications made to the vignettes and rating scale response format in the light of evaluation by subjects. These modifications included revised instructions for completing the rating scales and in addition gender-related language was also amended.

CHAPTER 3: STAGE ONE

A SURVEY OF SELF-NEGLECT IN THE COMMUNITY

3. **A SURVEY OF SELF-NEGLECT**

The first stage of the main study involved a survey of District Nurses. The main aim of the survey was to explore self-neglect by investigating the concepts of self-care and self-care agency, functional ability and disease/illness (medical and nursing diagnoses). These concepts were previously described in the literature review (Chapter 1) and they also emerged during the pilot study stage as having a relevance to self-neglect (Chapter 2). The medical literature generally operates from the consensual position that self-neglect is causally-related to disease. Exactly which disease or combination of diseases lead to self-neglect is not clear, although psychiatric disorders are suggested as being the most likely (Wrigley and Cooney 1992). Self-neglect is generally conceptualised in terms of impaired ability to engage in activities of daily living such as personal hygiene (MacMillan and Shaw 1966). In the nursing literature Orem's Theory of Self-Care has been proposed as facilitating a greater understanding of self-neglect (O'Rawe 1982, Moore 1989). Consequently there is support for employing these concepts as a broad conceptual framework to provide structure and meaning to data collection and analysis in a study of self-neglect.

3.1 **Research Objectives and Hypothesis**

Objectives

1. What are the most common medical and nursing diagnoses in patients identified by District Nurses as self-neglecting?

2. What is the functional status of patients identified by District Nurses as self-neglecting?

Hypothesis

Patients who have been identified as self-neglecting will have lower levels of self-care agency than patients in a comparison group

3.2 **Research Design And Method**

Surveys have been a mainstay of research in health sciences (McQueen 1993). Surveys are a means of gathering data with the purposes of describing existing circumstances, identifying standards against which existing conditions can be compared, and determining the relationships that exist between specific events (Cohen and Manion 1989). In stage one the intention was to fulfil the first two purposes outlined by Cohen and Manion by describing patients with self-neglect and by using a comparison group as a standard against which patients with self-neglect can be compared. Survey methods provided an opportunity for data to be gathered in a natural setting, and the flexibility of a survey and its ability to answer a wide range of research

questions, including those specified for this stage, suggested it was an appropriate method to be used in this instance (Polit and Hungler 1991).

Abramson (1990) outlines the two basic forms of survey design as descriptive and analytical. He suggests that, in practice, the distinction is not always clear as many studies combine both forms of survey. Moser and Kalton (1971) imply that a survey design should be guided by the purposes of the study rather than adhering to methodological dogma. One common thread in the methodological literature is the pragmatic nature of survey design. Moser and Kalton (1971) describe how surveys must be designed in the light of technical and organisational factors. They highlight this point by suggesting that survey samples are determined by what is practical as often as by what is methodologically desirable. Pragmatic considerations include costs, time available and labour. Abramson (1990) supports this view and makes the observation that very few surveys are perfectly designed. This, he suggests, does not necessarily invalidate a study, and it is possibly more important that the researcher is aware of the limitations in a design and takes this into account when reaching any conclusions.

A number of limitations in survey designs have been articulated and include the possibility that data may be superficial and will not allow insights into the complexities and contradictions of the human experience (Polit and Hungler 1991). Other criticisms levelled at surveys relate not to the method *per se* but to the way it has been

used. It will be argued throughout this chapter that many of these criticisms and limitations in both the design and conduct of surveys do not apply to this study. The use of a sequential design and methods in the various stages are designed to highlight the complexities and contradictions which Polit and Hungler allude to. In fact one major strength of the various methods in the this study is that the complexity and contradictions of self-neglect research will be brought into sharp focus. The theoretical rationale for the concepts to be explored during the study has been clearly explicated in contrast to most studies investigating self-neglect which have no clear theoretical basis.

3.2.1 **Sample**

Sampling Difficult to Locate Groups

Selecting a sample of self-neglect patients is not an easy procedure. This is a result of there being no widely accepted operational definition of a self-neglect syndrome, and the fact that there are no well tested field techniques which will allow a community-based population to be identified (Tantam 1984, Abramson 1990). Tantam (1984) elaborates the former point when stating

> *The definition of a disease is difficult because a disease, particularly a psychiatric disease, often expresses itself differently in different individuals and there is rarely a conclusive piece of evidence, or pathognomic symptom, which will definitely establish the presence or absence of the disease. In fact there is often argument about where the boundaries of a disease should be drawn* (p 721).

Faugier and Sargeant (1997) believe that when researching difficult to locate populations "*innovative sampling techniques*" need to be used although they acknowledge that there is little advice to be found in the literature. Biernacki and Waldorf (1981) comment on this problem when stating that some populations may have a relatively high social visibility and whilst the researcher may have difficulty in gaining access to these populations their whereabouts is known. Other populations, for many reasons, including moral, legal or social, may have low visibility and consequently present problems in locating and contacting subjects.

Faugier and Sargeant (1997) and Berg (1988) all recommend that insider information from people who have knowledge of these low visibility populations is the best way to recruit samples. Nevertheless the problem of bias is one that must be acknowledged (Faugier and Sargeant 1997). Abramson (1990) also suggests that when no operational definition is made the diagnosis can be made by another, including the patient. He supports the use of second-hand diagnostic information when this is the only option open to researchers. He adds the rider that if this procedure is the only practical option it should be used, provided that consideration is given to the consequences it may have on the findings. In a nutshell findings should be interpreted with some degree of caution. The method of selecting patients for inclusion in stage one can be criticised for introducing selector bias into the process. Nevertheless with this limitation in mind there is support in

the literature for using methods similar to that used in stage one as the best practical method when there is no clear conceptualisation and operational measure of self-neglect available to the researcher (Rathbone-McCuan and Fabian 1992).

District Nurse Sample

District Nurses participating in the survey were drawn from two geographically distinct sub-populations, one group practising in a rural setting and the other in a relatively urban setting. A total of 28 District Nurses (16 rural, 12 urban) agreed to participate in the survey. This represented 85% of the total number of District Nurses (N = 19) practising in the rural area, and 63% of District Nurses (N = 18) practising in the urban area. The recruitment of District Nurses practising in a rural and a relatively urban setting fulfilled the purpose of achieving some sense of representing community nurses in the region as this is a relatively rural area with a few urban locations.

Self-Neglect and Comparison Groups

The patients, on whom survey data were to be collected, were likewise drawn from the same two geographical areas. In each geographical area a group of patients identified by District Nurses as being self-neglectful and a comparison group quasi-randomly drawn from the District Nurses' caseload were recruited. The study group comprised one or two patients who best represented what the District Nurse regarded as self-neglect. The quasi-randomisation of patients into a comparison group

was achieved when a list of all patients on each District Nurses' caseload was made from patients classified by District Nurses' as non self-neglecting. Quasi-randomisation is a sampling methods which approximates random sampling but every member of the sampling frame does not have an equal chance to be selected. The researcher used a number system whereby a small numbered card was drawn from an envelope and the patient whose name was listed against that number was selected to participate in the study. Comparison groups are different from the type of matched group found in randomised controlled trials. Comparison groups may not be matched with the study group in relation to some known variables. Tantam (1984) argues that using comparison groups may be a cheap and practical method which allows a hypothesis to be tested. If the hypothesis is rejected then there may be no need for further expensive studies. If, on the other hand, the hypothesis is supported then future studies can be designed to take into account the sampling limitations found in the earlier study.

Sample Characteristics

The sample were drawn from two District Nurse catchment areas, one of which was predominantly urban and the other was predominantly rural. Included in the sample were 33 patients from the rural area (25 self-neglect group, 8 comparison group), and 30 patients from the urban area (16 self-neglect group, 14 comparison group). The sample comprised of 63 patients, of which 41 (22 female, 19 male) were included in the self-neglect group and 22 (19 female, 3 male) were

included in the non neglecting comparison group. It can be seen that there were more males in the self-neglect group than were recruited for the comparison group. The number of males and females in the self-neglect group were also similar with a very small (N=2) difference in numbers of patients selected. This may be a product of sample bias in which District Nurses are predisposed to use gender as a factor which influences their judgements about self-neglect. The role that gender plays in influencing such judgements will be investigated in stage three (Chapter 5).

The age of the self-neglect group ranged from 40-96 years with a mean age of 70.76 years (sd 14.09) (Table 3.1). In the self-neglect group the age of females ranged from 44-96 years with a mean age of 71.73 years (sd. 14.19). The age of males ranged from 40-90 years with a mean age of 69.63 years (sd. 14.28). The ages of the comparison group ranged from 44-93 years with a mean age of 74.55 years (sd. 14.11) (Table 3.3). In the comparison group the ages of females ranged from 49-93 years with a mean age of 76.47 years (sd 13.07) and the ages of males ranged from 44-78 years with a mean age of 62.33 years (sd. 17.16).

Table 3.1 Characteristics Of The Sample

GROUP	TOTAL	AGE RANGE (Years)	MEAN AGE (Years)	FEMALE (N)	MALE (N)
Self-Neglect	41	40-96	70.76	22	19
Comparison	22	44-93	74.55	19	3

The mean age of the self-neglect group was less than the comparison group although this age difference was not significant (T = 1.02 df = 43, P = 0.31). Nevertheless a mean age difference of 3.7 years may have some clinical significance bearing in mind the exponential rise in illness with age. Therefore it is possible that the age difference may indicate that the prevalence of certain diseases may be greater in the older comparison group.

Data on the marital status of both groups were collected (Table 3.2). There were 3 married patients (7.32%), 19 single (46.34%), 17 widowed (41.46%), and 2 separated/divorced (4.88%) in the self-neglect group. There were 6 married patients (27.27%), 4 single (18.18%), and 12 widowed (54.55%) in the comparison group. These numbers were too small to allow for chi-square tests to be performed properly and thus cells were collapsed into two groups - married and unmarried (single/widow/separated/divorced). Differences between the groups was statistically significant (P = 0.04; Fishers Exact Test: One-Tailed).

It appears that there are very few people in both self-neglect and comparison groups who are married. This may be explained by the age of both groups and by the possibility that patients receiving care from District Nurses are more likely to be unmarried than people of a similar age who are not receiving care from District Nurses. This difference should be taken into account when considering any differences on other variables between the self-neglect and comparison groups.

Table 3.2 Marital Status Of Comparison And Study Groups

	SELF-NEGLECT	COMPARISON
	N= 41	N= 22
MARRIED	3 (7.32%)	6 (27.27%)
SINGLE	19 (46.34%)	4 (18.18%)
WIDOW	17 (41.46%)	12 (54.55%)
SEP/DIVORCED	2 (4.88%)	0

3.2.2 **Procedures**

Access to the District Nurses who participated in the survey was gained after an initial approach was made to the Community Service Manager responsible for each geographical area. Subsequently it was arranged that the researcher address all District Nurses at their

regular monthly staff meetings. At this meeting the survey procedures were briefly outlined and appointment times to meet the District Nurses were organised. Individual meetings were then confirmed either by letter or telephone.

At the individual meetings with District Nurses the purpose of the study was again further outlined and it was explained that the survey would focus on people with self-neglect. When asked to define what was meant by self-neglect the researcher informed the District Nurse that it was her definition that was desired but that self-neglect in general terms referred to patients who, for whatever reason, did not look after the themselves and/or their home. The District Nurse was then required to identify each patient on their caseload and specify age, sex and whether they thought this patient was or was not self-neglecting. When all patients has been described in this way the District Nurse was required to identify two patients, or one if only one patient had been identified as self-neglectful, who best represented what the District Nurse regarded as self-neglect. The comparison patient was randomly selected from the patients identified by the District Nurse as non self-neglecting.

3.3 **Measures**

Biographical Data

Biographical data were collected for each patient by means of a data collection sheet prepared for the current study. Data collected included

age, gender, housing, and past/present occupation. Past and present occupation was classified using the Standard Occupational Classification (OPCS 1990).

Nursing and Medical Diagnoses

Nursing problems were re-classified using the North American Nursing Diagnoses System (NANDA 1988). NANDA is a major initiative in USA which is designed to provide a standard diagnostic classification for nursing diagnoses and a universal language to label diagnostic categories. This was achieved by the researcher comparing each patient problem, as defined by the District Nurse, with the NANDA diagnostic classification. Problems were linked with the diagnostic category which best matched the description provided. Medical problems were classified using a similar procedure. The classification system used with medical diagnoses was the International Classification of Diseases format (ICD 1992).

Self-Care

The ability to engage in self-care activities was measured with the ASA-B Scale (Isenberg 1987). This scale is based on the assumption that the ability of an individual to engage in self-care actions is dependent on self-care agency. Self-care agency comprises of two interdependent elements, power components and self-care operations, which together determine whether an individual will engage in necessary and appropriate self-care actions (Aish & Isenberg 1996). Items on the ASA-

B Scale were designed to measure 10 power components and 5 self-care operations (Evers 1987). Gast et al (1989) imply that the construct validity of this scale needs to be tested. Construct validity can be tested by conducting a Factor Analysis of the scale. A Factor Analysis was undertaken during this stage of the study.

The Self-Care Agency Scale can be completed by the patient (ASA-A) or by another (ASA-B). The scale consists of 24 items each of which are scored on a five-point Likert scale. Of the total number of items 15 of the items are positive statements and 9 items are negative statements, with weighting being reversed for negative items. All items in the scale are scored and scores summed to give an overall scale score with a theoretical range of 24-120, with the higher score representing a higher level of self-care agency (Lorenson et al 1993).

The test-retest reliability of the scale has been given as 0.87 (Kristal et al 1990), and 0.91 with myocardial infarction patients (Aish & Isenberg 1996). Internal consistency has been given as 0.62 (Kristal et al 1990); 0.74 and 071 (Aish & Isenberg 1996); 0.77 and 0.86 with cardiac patients (Isenberg 1987); 0.72 with elderly patients (Evers 1987); 0.72 (ASA-A), 0.82 (ASA-B) with elderly patients in rehabilitation and living independently at home (Lorenson et al 1993). Discriminant validity was demonstrated by Lorenson et al (1993) who reported that the ASA Scale can discriminate between elderly patients receiving institutional rehabilitation care and elderly patients living at home.

Functional Ability

The need to develop a means to detect hidden health problems in the elderly population has been recognised since the early 1960s (Williamson et al 1964). It has been suggested that the most appropriate way to measure such problems is in terms of functional assessment (Rubenstein et al 1984). Functional ability is normally conceptualised as the ability to undertake a number of specific activities of daily living (ADL). ADL have a central place in the everyday practice of many health care workers. Harris (1992) argues that functional assessment was one of the most important developments in the NHS. Whilst there may be a general consensus that ADL assessment is important in health and social care it may be true to say that ADL measures do not stem from a clear and explicit theoretical base (Barer & Nauri 1989).

The Index of Independence in Activities of Daily Living (IADL) was originally developed as a measure of the effectiveness of medical and nursing treatments (Katz et al 1970). The Index was based on the assumption that functional ability is lost during a period of illness in a manner which is both progressive and predictable. Gilleard and Christie (1990) suggest that this scale measures a single construct which in turn reflects the underlying assumption that changes in the scale represent changes in pathology/disease which in turn is manifested in changes in functional ability.

The scale is a Guttman-scaled, rank-ordered ordinal scale measuring six activities (bathing, dressing, toiletting, transfer, continence and feeding). The instrument is scored by an observer recording the most dependent level of performance in a patient. There are three levels of performance for each activity. Each activity is scored in turn and aggregated and converted into an overall grade, ranging from A-G. This final part of the procedure is not Guttman-scaled (Wilkin et al 1992). Wilkin et al (1992) believe that although the scale is popular there is little evidence demonstrating its validity and reliability.

3.4 Validity and Reliability

The sampling method employed raises questions about the external validity of the study. Therefore generalisations to the wider population should be undertaken with some caution. Nevertheless the sample did provide a satisfactory test of a research hypothesis as generalisation in this instance is to the theory and not to a given population. The construct validity of the ASA-B scale has not been tested with this client group. Construct validity was tested through a Factor Analysis of the scale.

The reliability of the ASA-B scale and the IADL scale were tested for internal consistency. Internal consistency attempts to measure whether all items in a scale do in fact measure the same concept (Polit and Hungler 1991). Internal consistency was tested by Cronbach's

Alpha (Chronbach 1951). An alpha score of 0.80 is thought to be a satisfactory measure of reliability (Polit and Hungler 1991). The reliability of ASA-Scale was found to be 0.89, and the IADL scale was 0.80. Thus both the ASA-B and the ADL scales were found to be reliable for the study population. The reliability of the reclassification of District Nurse identified patient problems to NANDA nursing diagnoses was not tested.

3.5 **Data Analysis**

Data were analysed using the Minitab 10x statistical analysis programme. Both descriptive and inferential statistical analyses were conducted, with differences between groups being analysed using t-tests for continuous level data or Chi-Square tests for nominal and ordinal level data. The t-test was carried out on data that were slightly non-normally distributed. This is appropriate as this test is robust in such circumstances (Polit 1996).

Data were initially screened for errors. These errors were all input errors caused by keying errors produced by the researcher and all were amended. There were large numbers of missing data on the variables Occupational Status, Accommodation, Nursing Diagnosis and Medical Diagnoses. The numbers of missing data limited the type of analysis which can be carried out using these variables. Missing data was found not to be a problem for other study variables.

3.6 **Findings**

3.6.1 **Accommodation Status**

Accommodation status was categorised as either private ownership-owner occupied or as council ownership-sheltered housing. This broad categorisation was a compromise based on the small numbers identified in sub-categories such as living in a caravan. It may have been the case that using sub-categories such as living in a caravan or sheltered housing may have revealed more subtle differences between groups.

The category of owner-occupied was a mixed category which includes both those who own their own flat/house and one individual who lived in a caravan. The category council/sheltered includes all those individuals who live in accommodation which they do not own themselves, this includes sheltered housing and other local authority provision. A number of responses (N=15) did not indicate whether accommodation was owned or rented and these responses were omitted from analysis. In the self-neglect group more people lived in council/sheltered housing (N=17) than lived in owner-occupied housing (N=15). The reverse was the case in the comparison group with most living in owner occupied (N=9) than lived in council/sheltered (N=7), although this difference was not significant ($x^2 = 0.375$, d.f. = 1, $P > 0.05$).

3.6.2 **Occupational Status**

Data on the occupational status, past and present, were collected. Data were categorised using the Standard Occupation Classifications (OPCS 1990). An additional classification of housewife was added to this for the purposes of the study as this category was reported by District Nurses. Occupational classification is a difficult label to apply and the interpretation of this information is fraught with difficulties in groups that are predominantly retired and female. The occupational classification also contains most non-responses, possibly as a consequence of District Nurses not having recorded this information in case-notes (Table 3.3).

Table 3.3 Occupational Status Of Self-Neglect And Comparison Groups

	SELF-NEGLECT			COMPARISON		
	N=36			N=16		
	ALL	F	M	ALL	F	M
Managers	3	0	3	0	0	0
Professions	1	0	1	3	3	0
Associate professions	2	1	1	0	0	0
Craft & related	6	5	1	0	0	0
Personal & protective	3	0	3	1	1	0
Sales occupation	6	4	2	2	2	0
Plant/ machine	1	1	0	1	1	0
Other	8	2	6	4	2	2
Housewife	6	6	0	5	5	0

The small numbers in each classification make any meaningful analysis difficult. Nevertheless the data provides support for the Clark et al (1975) claim that self-neglect is to be found in all occupational groups. The self-neglect group had all males in the manager-administrator classifications and the comparison group had nobody in that classification.

3.6.3 **Medical Diagnoses**

District Nurses were asked to list medical problems experienced by patients. The diagnoses had already been made by medical practitioners and nurses were simply reporting these from case-notes. Patients in both self-neglect and comparison groups had a wide range

of medical diagnoses (Table 3.4). The most common diagnosis in both groups was disorder of the coronary circulation (self-neglect group N=7; comparison group N=5), with peripheral vascular disease being the joint most common in the self-neglect group (N=7) and the third most common medical diagnosis in the comparison group (N=3). The other most common disease in the comparison group, along with disorder of coronary circulation, was arthritis (N=5). Arthritis did not feature as prominently in the self-neglect group. Other differences in the disease profiles of groups were the larger number of patients with diabetes mellitus (N=6), cerebro-vascular disorder (N=6) and obesity (N=3) found in the self-neglect group. This is not consistent with Adams and Johnson's (1998) finding that food disorders are central to nurses understanding of self-neglect. The general perception of nurses that food disorders are central to self-neglect may be inflated when compared to the actual number of self-neglecting patients with food disorders cared for by nurses.

It was noticeable that those medical diagnoses which could be described as psychiatric/psychological disorders (organic mental, psychoactive substance abuse, schizophrenia and mood disorder) were more commonly reported in the self-neglect group (N=10) than in the comparison group (N=1). Individual psychiatric disorders were not though amongst the most commonly reported disorders. It is possible that some diagnoses are unreported, as the numbers of patients reported as having a mood disorder is less than one would have expected to see in the light of epidemiological data on the prevalence

and incidence of mood disorder in the age ranges of patients in the current study (Murphy 1986).

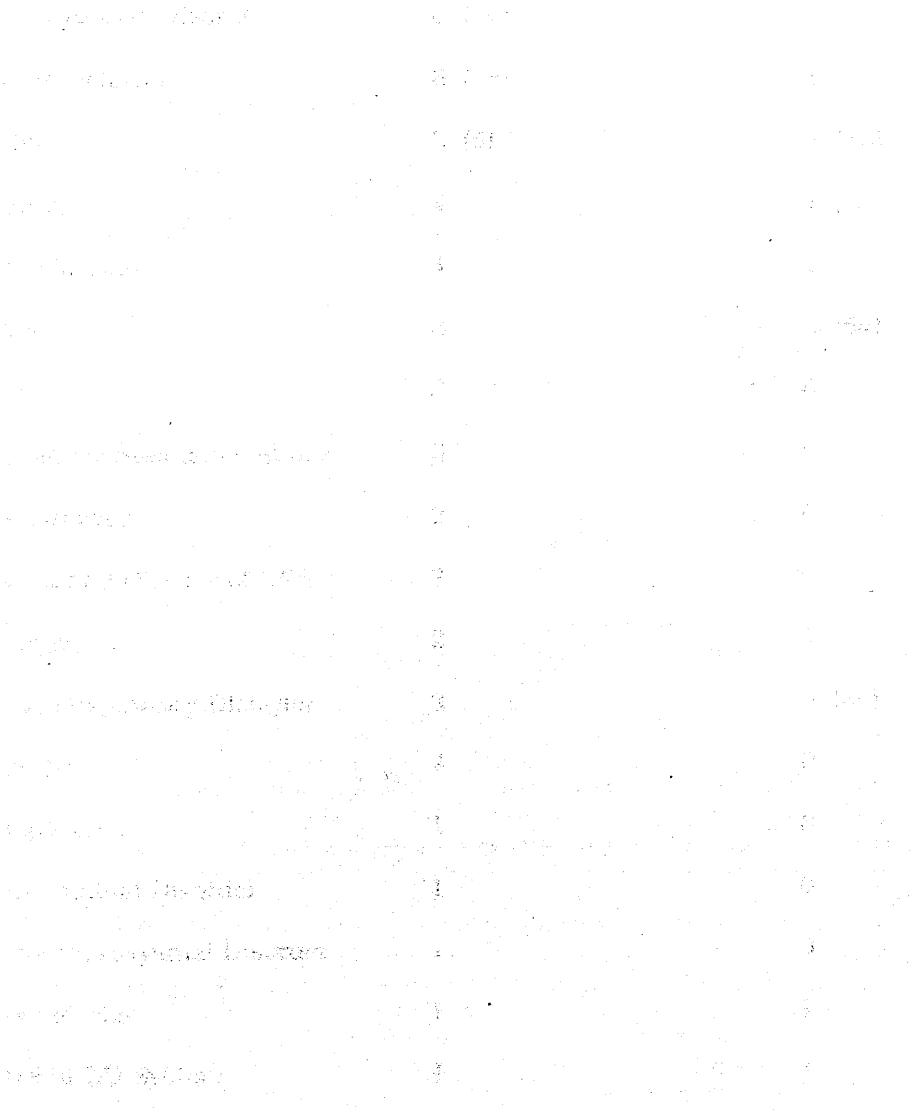


Table 3.4 Medical Diagnoses Of Self-Neglect And Comparison Groups As Reported By District Nurses

	SELF-NEGLECT	COMPARISON
	N	N
Disorder of Coronary Circulation	7 (1=)	5 (1=)
Peripheral Vascular Disease	7 (1=)	3 (3=)
Cerebrovascular Disorder	6 (3=)	1
Diabetes Mellitus	6 (3=)	1
Arthritis	5 (5)	5 (1=)
Tumours	4	1
Organic Mental	4	1
Anaemia	3	2 (5=)
Obesity	3	0
Psychoactive Substance Abuse	3	0
Mood Disorder	2	0
Demylinating Disease of CNS	2	0
Glaucoma	2	1
Chronic Respiratory Disorder	2	3 (3=)
Paraplegia	2	0
Schizophrenia	1	0
Extrapyramidal Disorder	1	0
Episodic/Paroxysmal Disorder	1	0
Disease of Ear	1	1
Disease of GU System	1	1
Amputation of Lower Limb	1	2 (5=)
Disease of GI System	0	1
Subarachnoid Haemorrhage	0	1

rank in brackets ()

3.6.4 **Nursing Diagnoses**

District Nurses were asked to list the nursing problems for each patient. These problems were then re-classified by the researcher using the North American Nursing Diagnoses Association typology (NANDA 1988). A wide range of nursing diagnoses were found in both self-neglect and comparison groups. The two most common nursing diagnoses found in each group were bathing/hygiene deficit (self-neglect group N=17; comparison group N=7) and impaired tissue integrity (self-neglect group N=13; comparison group N=5) (Table 3.5). The third and fourth most common diagnoses in the self-neglect group, ineffective management of therapeutic regime (N=10) and non-compliance (N=8) were not found in the comparison group. The diagnosis of altered protection (at-risk) was the third (=) most commonly reported diagnosis in the comparison group but was not among the five most commonly reported diagnoses in the self-neglect group (N=6). No patients in the comparison group were reported as having either of these nursing diagnoses. A relatively small number of patients in the self-neglect group had the diagnosis of instrumental self-care deficit (N=3). Coenen et al (1996) found a similar pattern of diagnoses in a group of patients receiving nursing care in a community nursing centre in USA.

Diagnoses related to prescribed medication regimes, such as non-compliance and ineffective management of therapy, were among the five most common nursing diagnoses in the neglect group. Nursing

diagnoses which explicitly included the concept of deficit in the diagnostic label (knowledge deficit, instrumental-self-care deficit, toileting care deficit, dressing/grooming deficit, bathing/hygiene deficit) were more commonly reported in the self-neglect group (N=33) than in the comparison group (N=10).

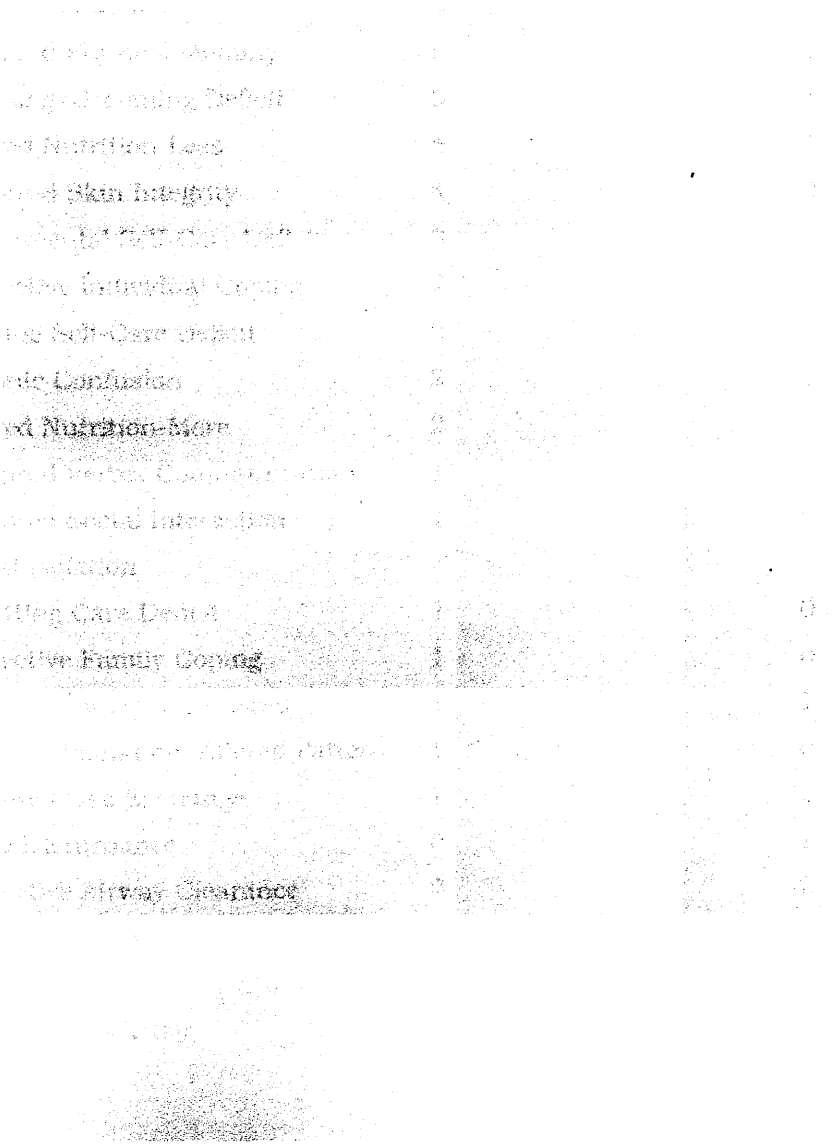


Table 3.5 Nursing Problems In Self-Neglect And Comparison Groups As Reported By District Nurses Classified Using NANDA Typology

	SELF-NEGLECT		COMPARISON	
	N		N	
Bathing/Hygiene Deficit	17	(1)	7	(1)
Impaired Tissue Integrity	13	(2)	5	(2)
Ineffective Management/ Regime	10	(3)	0	
Non-compliance	8	(4=)	0	
Urinary Elimination;Altered Pattern	8	(4=)	4	(3=)
Altered Protection (at risk)	6		4	(3=)
Knowledge Deficit	5		0	
Impaired Physical Mobility	5		3	(5)
Dressing/Grooming Deficit	5		1	
Altered Nutrition-Less	5		1	
Impaired Skin Integrity	4		0	
Instrumental Self-Care Deficit	3		1	
Ineffective Individual Coping	2		0	
Feeding Self-Care Deficit	2		1	
Chronic Confusion	2		0	
Altered Nutrition-More	2		0	
Impaired Verbal Communication	1		0	
Impaired Social Interaction	1		0	
Social Isolation	1		0	
Toiletting Care Deficit	1		0	
Ineffective Family Coping	1		0	
Sensory/Perception Altered	1		1	
Faecal Elimination; Altered Pattern	1		0	
Impaired Gas Exchange	1		0	
Mood Disturbance	0		1	
Ineffective Airway Clearance	0		2	
Risk of Loneliness	0		1	

rank in brackets()

3.6.5 **Functional Ability**

Functional ability was measured by the Independence in Activities of Daily Living Index (Katz et al 1970). It was found that 17 (41.66%) of the self-neglect group and 12 (54.55%) of the comparison group were independent in all activities of daily living which are measured in the IADL index (Table 3.6). Dependency in one area of functioning was found in 11 (26.83%) of the self-neglect group and 5 (22.73%) of the comparison group. Dependency in two areas of functioning was found in 10 (24.39%) patients in the self-neglect group and 4 (18.18%) patients in the comparison group. A relatively small number patients (N=3) were dependent in three or more areas of functioning in the self-neglect group and in the comparison group (N=1).

Table 3.6 Index Of Independence In Activities Of Daily Living In Self-Neglect And Comparison Groups

	SELF-NEGLECT	COMPARISON	TOTAL
Independent	17 (41.46%)	12 (54.55%)	29
Dependent in one area	11 (26.83%)	5 (22.73%)	16
Dependent in two areas*	10 (24.39%)	4 (18.18%)	14
Dependent in three areas	1 (2.44%)	1 (4.55%)	2
Dependent in four areas	1 (2.44%)	0 (0%)	1
Dependent in five areas	0 (0%)	0 (0%)	0
Dependent in six areas	1 (2.44%)	0 (0%)	1
	N=41	N=22	N=63

* Categories C and G in IADL index classification aggregated

When the data on IADL classifications were collapsed into two categories, independent and dependent, it was found that in the self-neglect group 17 (41.46%) patients were independent in all areas of functioning and 24 (58. 54%) patients had between one and six areas of functioning in which they were dependent to some degree. In the comparison group 12 (54.55%) patients were independent in all areas of functioning and 10 (45.45%) patients had between one and six areas of functioning in which they had some degree of dependence. There was a greater proportion of the comparison group who were independent but this was not statistically significant (x^2 = 0.986, d.f. = 1, $P > 0.05$).

The specific activities of daily living in which patients were dependent to some degree are outlined in Table 3.7. It was found that bathing was the most common activity in which patients were dependent in both self-neglect (N=16) and comparison groups (N=9). This is consistent with the finding that bathing/hygiene deficit was the most common nursing diagnosis in each group and lends some support to the validity of analytic procedures. The ranking of activities in each group was very similar and the most noticeable differences between the self-neglect group and comparison group is to be seen in the number of patients who had some degree of dependency in continence, toileting and feeding. In the self-neglect group 14 (48.78%) patients had problems related to continence/toiletting, in contrast 3 (18.19%) patients in the comparison group had problems in this area of functioning. Feeding problems were the least common activity in which patients were

assessed having some degree of dependence (self-neglect group N=4; comparison group N=0).

Table 3.7 Functional Ability Requiring Some Degree Of Assistance In Self-Neglect And Comparison Groups

	SELF-NEGLECT	COMPARISON	TOTAL
	N	N	N
Bathing	16 (1)	9 (1)	25 (1)
Dressing	9 (3)	4 (2)	13 (3)
Toiletting	6 (4)	1 (5)	7 (4)
Transfer	4 (5=)	2 (4)	6 (5)
Continence	14 (2)	3 (3)	17 (2)
Feeding	4 (5=)	0 (6)	4 (6)

*rank in brackets ()

3.6.6 **Self-Care Status**

Self-care was conceptualised and operationalised using Orem's Theory of Self Care (Orem 1985). In this theory self-care agency is a central concept and this was operationalised using the ASA-B Scale. A lower ASA-B score represents a reduction in an individual's self-care agency levels and therefore a reduction in the capacity to engage in self-care activities.

Factor Analysis of ASA-B Scale

The ASA-B scale conceptualises self-care agency as the power of an individual to engage in those operations necessary for self-care (Gast et al 1989). Items on the scale were developed to represent 10 power components (e.g. reasoning; controlled use of energy) and 5 self-care operations (Evers 1987). It is not clear from Evers' description of the conceptual structure of the scale if the power components and self-care operations are conceptually distinct and if they are in what way. Gast et al (1989) take a similar view when arguing that this scale has no explicit dimensions and they suggest that a Factor Analysis may be needed to identify underlying dimensions in the instrument.

Factor Analysis is a technique for reducing a larger number of variables into a smaller number of coherent underlying factors (Tabachnick and Fidell 1989). It is also used to test the validity of a measurement scale (Kessler 1998). There are a number of different types of Factor Analysis and the one selected for this study was Principal Components Analysis (PCA). The goal of PCA is to extract maximum variance from a data set. It is the technique of choice when the goal is to produce an empirical summary of a data set (Tabachnick and Fidell 1989). Correlation Coefficients produced by PCA are not interpretable till they are rotated. Rotation in this study was Varimax Rotation with Kaiser Normalisation. Varimax is rotation technique which has the advantages of producing maximum variance within and across variables and simplicity of reporting results. Criteria for factor

extraction were a) Examination of a scree plot to determine the junction at which a line drawn through various points on the plot demonstrates a readily observable change in direction and thereby producing a different slope (Cattell 1978); b) Eigenvalues over 1.00. Eigenvalues represent variance and a score over 1 is more important than a score less than 1. In studies with small numbers eigenvalues may over or under estimate the number of factors (Tabachnick and Fidell 1989); c) Minimum of 5% reported variance per factor; d) A minimum of five variables loading at least 0.50 on each factor. Tabachnick and Fidell (1989) suggest that the usual convention of 5 subjects for each item may not be necessary when a few factors which show good correlations are identified.

The first PCA produced 6 factors with eigenvalues over 1.0. These six factors accounted for 70.98% of the variance. Four of the factors identified in this solution loaded with less than 2 variables and examination of the scree plot slope, which demonstrated clear changes in the slope between factors 3 and 4, suggested that a 3 factor solution was more appropriate. A second PCA was computed with the 3 factor solution. The factors in the second and final solution had eigenvalues of 8.378 (F1), 2.744 (F2), and 2.134 (F3) respectively. These factors accounted for 55.24% of the total variance (Table 3.8).

Table 3.8 Principal Component Solution

	Intial			*Rotated*		
Factor	Eigen-value	Variance %	Cumu-late %	Eigen-value	Variance %	Cumu-late %
1	8.378	34.91	34.91	5.751	23.96	23.96
2	2.744	11.43	46.34	4.067	16.95	40.91
3	2.134	8.89	55.24	3.439	14.33	55.24

In the final solution no item had crossloadings above 0.50 (Table 3.8.1). This suggests that there is little statistical overlap between factors. Factor 1 (Control and adjustment) was the dominant factor and explained 34.91% of the total variance. A total of 8 items loaded on this factor. The items which loaded on Factor 1 purported to measure 7 of Orem's power components. Items loaded on this factor included `as circumstances changed, makes needed adjustments to stay healthy` and `when mobility is decreased, makes needed adjustments`. The loaded items required the individual to maintain a state of homeostasis by controlling and making adjustments to the internal and external environment.

Factor 2 (Awareness and concern for self) accounted for 11.43% of the variance and 7 items loaded on this factor. The items which loaded on this factor purported to measure 5 power components. The items which loaded on this factors included `seldom has time for self` and `often lacks energy to care for self in the way he/she would like`. The items

which loaded on this factor required the individual to be aware of and concerned for self. There was a large degree of overlap of power components with other factors.

Factor 3 (Repertoire of skills to bring about change) accounted for 8.89% of the variance and 6 items loaded on this factor. Items which loaded on this factor measured 5 power components. Again there was a large degree of conceptual blurring as there were power components represented in this factor which were also represented in other factors. This suggests that there is no clear and obvious relationship between power components and factors and thus the underlying structure of the ASA-B scale may require to be modified. The items which loaded on this factor included `when taking new medication, obtains information about the side effects` and `routinely takes measures to insure the safety of self and family`. This factor is action-oriented and involves the individual acting on their world.

There appeared to be no clear fit between the factors and the power components measured by the ASA-B scale. Soderhamn (1998) in his structural analysis of self-care abilities experienced by elderly Swedish men also identified three themes, one of which was similar to repertoire of skills to bring about change (Factor 3). He also suggests that an important aspect of self-care is a perception of self which is a similar construct to Factor 2.

In summary three factors were identified in this analysis. Factor 1 contained items which concern an individual's ability to engage in

actions which intended to adjustment to change. Factor 2 contained items measuring awareness and concern for self. Factor 3 loaded on items which equate to Orem's (1991) power of repertoire of skills to bring about change (Table 3.8.1). Nevertheless the three factor solution is not consistent with the theoretical model underpinning the ASA-B Scale (Evers 1987). This PCA needs to be replicated in the future with a larger sample to explore factor stability.

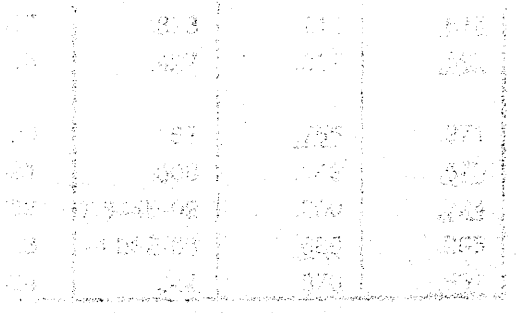


Table 3.8.1 Rotated Component Matrix

	Component		
	1	2	3
C1	.769	.249	.278
C2	.380	.660	.114
C3	.624	.150	.326
C4	.787	8.581E-02	-2.36E-02
C5	.772	.243	.279
C6	.183	.726	-.251
C7	.796	.305	.143
C8	.820	.136	.109
C9	.637	.291	.186
C10	.556	-.256	.386
C13	-.222	.617	.223
C14	.304	.629	.160
C15	.436	.611	.135
C16	.219	.180	.689
C17	.373	.214	.616
C18	.427	.217	.593
C20	.167	.755	.271
C21	.309	.143	.675
C22	7.844E-02	.260	.724
C23	-4.06E-03	.689	.205
C24	.244	.370	-.537

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization

The correlations between factors were 0.49 between Factors 1 & 2; 0.46 between Factors 1 & 3; and -0.12 between Factors 2 & 3 (Table 3.8.2). This suggests that there is some degree of overlap between Factors but as no correlation is higher than .80 none is redundant (Cattell 1978). The internal consistency (Chronbach's Alpha) of Factors were Factor 1 .91, Factor 2 0.84, Factor 0.71 and thus all Factors have a satisfactory reliability coefficient.

Table 3.8.2 Component Transformation Matrix

Component	1	2	3
1	.745	.487	.456
2	-.492	.863	-.117
3	-.450	-.136	.882

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization

ASA-B Scores

It was found that the ASA-B scores of the self-neglect group ranged from 43-96 with a mean score of 66.46 (sd. 10.55) and ASA-B scores of the comparison group ranged from 67-107 with a mean score of 89.09 (sd. 10.15) (Table 3.8.3).

Table 3.8.3 ASA-B Scores For Self-Neglect And Comparison Groups

	Self-Neglect	**Comparison**
Mean	66.46	89.09
Median	66	91
SD	10.55	10.15
Range	43-96	67-107

The differences in ASA-B scores in self-neglect and comparison groups was measured using a two-sample t-test. Equality of variances was not assumed and therefore t-test was computed with this assumption in

mind. It was found that the difference between comparison and study groups was significant (T = 8.32, df = 44, P = 0.0001). For the purposes of comparison with other studies Table 3.8.4 contrasts the Lorenson et al (1993) ASA-B scores for elderly patients living at home with the self-neglect group and it can be seen that these are higher than those found in the latter population. This opens up the possibility that cultural differences between USA, Continental Europe and Scotland may undermine the validity of the scale. It is suggested that the validity of the ASA-B scale for use in Scotland needs further testing.

Table 3.8.4 Comparison Of ASA-B Scores In Lorenson et al (1993) And Self-Neglect Patients In This Study

	Self-Neglect	**Home Patients** (Lorenson et al 1993)
Mean	66.46	93.35
SD	10.55	9.46
Min	43	80
Max	96	114

Age is another variable which is thought to influence self-care agency levels in individuals (Orem 1991). The relationship between age and ASA-B was analysed using Pearson's product moment correlation. It was found that there was a very weak negative correlation between age and ASA-B scores for all patients ($r = -0.031$, $P > 0.05$).

3.6.7 **Self-Care Agency and Self-Neglect**

Orem's Theory of Self-Care (1992) proposes that self-care agency is a necessary prerequisite for effective self-care. It was hypothesised that subjects in the self-neglect group would have lower levels of self-care agency than patients in the comparison group. This hypothesis was supported and therefore it is suggested that self-neglect and self-care agency are related. Self-neglecters have lower levels of self-care agency. This relationship between self-care agency and a failure to engage in adequate levels of self-care, which in turn leads to self-neglect being diagnosed, is support for Orem's Theory of Self-Care. Alternatively a social constructionist view might suggest that this finding simply reflects the underlying constructions of District Nurses about self-neglect. The constructions of nurses will be investigated in stages two and three.

3.7. **Discussion**

The marital profile of the study group was similar to other studies of serious self-neglect which also found that most self-neglecting patients were single or divorced (MacMillan and Shaw 1966, Wrigley and Cooney 1992). Clark et al (1975) found that 28 out of 30 patients with severe self-neglect lived alone. Orem's (1991) notion of dependent care giving suggests that in situations where an individual does not have the capacity to care for themselves another may take on the role as a way of compensating for this self-care deficit. When there is no significant other available to occupy this role self-care needs are not

met and self-neglect may develop. Broadhead et al (1989) argue that since the 1970s there has been general consensus that social support has a direct positive influence on health and acts as a buffer to the effects of stress.

Patients in both groups lived in a range of accommodation which included sheltered housing, local authority housing, caravan, and owner-occupied housing. The numbers of people in the self-neglect group living in owner-occupied (N=15) and local authority housing (N=17) was relatively evenly distributed. MacMillan and Shaw (1966) and Clark et al (1975) concluded that housing type may not be as important a factor in severe self-neglect as had been imagined, a view which has been supported by the findings in this stage of the main study. Accommodation is seen by Orem (1991) as a Basic Conditioning Factor (BCF) but the role played by variables which can be considered as environment BCF is not clear in Orem's theories (Fawcett 1984, Gast 1996). Gast does suggest that the construct of Basic Conditioning Factors may provide a conceptual link between environment, health and self-care.

It was found that patients in both groups experienced a wide range of medical disorders, as reported by District Nurses. The most common disorders in the self-neglect group were disorder of coronary circulation, peripheral vascular disease, arthritis, and diabetes mellitus. In the comparison group the most common disorders were disorder of coronary circulation, peripheral vascular disease, chronic

respiratory disorder, arthritis, amputation of lower limb, and anaemia. The pattern of pathology reported in the self-neglect group is similar to that found by Gannon and O'Boyle (1992).

It was found that when aggregated psychiatric disorders were more commonly found in the self-neglect group. This is consistent with the literature which suggests that psychiatric disorders are commonly found in cases of self-neglect. Nevertheless it remains the case that only a minority of the self-neglect group had a psychiatric diagnosis in contrast to the claim that 50% of patients with extreme self-neglect have a psychiatric disorder (Post 1985). This finding can be explained by the possible underreporting of psychiatric disorders by District Nurses and the fact that the self-neglect group did not comprise of only extreme cases of self neglect. The relationship between medical diagnoses and self-neglect is unclear as we do not know if a particular medical diagnoses, or pattern of medical diagnoses, cause self-neglect?' or alternatively if self-neglect results in an increased likelihood of a medical diagnoses developing? These issues raise questions about the validity of both the single-cause hypothesis and the catch-all concept of `end-point` of a range of diseases hypothesis. The perceived relationship between medical diagnoses and self-neglect was investigated further using methods which allowed for in-depth exploration during stage two.

There were a large number of nursing diagnoses found in both self-neglect and comparison groups. Both groups shared the same two

most common nursing diagnoses (bathing/hygiene deficit, impaired tissue integrity). The presence of impaired tissue integrity is not surprising as this is a well recognised problem for District Nurses (Hall 1997). Another major difference between the self-neglect and comparison groups was the number of subjects with ineffective management of therapeutic regime and non-compliance nursing diagnoses found in the self-neglect group. Reed and Leonard (1989) in their analysis of self-neglect suggest that non-compliance is an important component of self-neglect. They claim that self-neglect and non-compliance are similar concepts as both allude to the lack of participation by patients in a prescribed or necessary health care regime, although they acknowledge that there may be differences between both notions. It may be the case that non-compliance and ineffective management are important characteristics of self-neglect. Whilst this may be true it remains the case that there are many people with self-neglect who did not have either of these nursing diagnoses. People may not, for example, comply with a prescribed medical regime for a variety of reasons other than intentionality, which they argue is at the heart of self-neglect. Therefore whilst the presence of a non-compliance diagnosis increases the probability that the diagnostic label of self-neglect is applied in a particular case the label self-neglect is also applied in the abscence of this diagnosis. The role of non-compliance in professionals' constructions of self-neglect were also be explored in stages two and three of the main study.

The notion of deficit (self-care) is central to Orem's Theory of Self-Care Deficit. Nursing diagnoses in which the term `deficit' was included in the diagnostic label were three times more commonly reported in the self-neglect group. Thus self-neglect in some sense may refer to a deficit in carrying out actions designed to care for one's self. It must be recognised though that the relationship between any nursing theory and nursing diagnoses has not been extensively explored in the literature (Jenny 1991). Jenny suggests that nurses find it difficult to make accurate diagnoses, possibly due to inadequate conceptualisation of theories and diagnoses.

The findings indicate that a sizeable proportion of the self-neglect group and the comparison group were independent in all areas of functioning. This suggests that dependency and neglect, whilst in some ways linked, are essentially different concepts. People can be regarded as self-neglecting but may be fully independent in ADL functioning. Lorenson et al (1993) make a similar point when arguing that being competent in ADL function does not necessarily mean that an individual will be able to cope with everyday activities. The reverse is also true in that people who are self-neglecting may also be fully dependent in ADL functioning. There was no significant difference between the self-neglect group and the comparison group in the proportions of each group who were independent or who had some degree of dependency. This is further support for the belief that functional ability and self-neglect may be different concepts (Smits and Kee 1992). Gruman et al (1997) found a very similar pattern of

functional ability in elderly with self-neglect who were referred to Adult Protective Services in North Dakota. Using the Katz scale they found that 56.6% of those referred were not dependent in any area of functioning and fewer had higher levels of dependency than abused elderly referred to the same service. It is difficult to understand the rationale for their claim that this finding lends support to the Dependency Theory of Self-Neglect. The Dependency Theory may explain why a proportion of people self-neglect but it does not explain why people with similar levels of dependency do not self-neglect. In addition it fails to explain why the majority of people in the Gruman et al study were independent but still were self-neglecting.

The relationship between functional ability and self-neglect is further complicated by the finding that there were differences in the type of functional ability impaired in each group. There were proportionately more people with continence and feeding problems in the self-neglect group than in the comparison group. Continence was the second most common area of dependency in the self-neglect group and third most common in the comparison group. Continence was also the ADL in which the largest difference between groups was found. Jitapunkul et al (1994) argue that urinary and faecal incontinence should be regarded as distinct from other ADL due to the underlying diversity and complexity of causes of incontinence. Incontinence as an ADL has been omitted from other ADL scales summed scores in order that the hierarchical qualities of these scales is improved (Spector et al 1987, Kempen and Suurmeyer 1990).

Both groups were similar in that both shared the same most common ADL in which there was some degree of dependency (bathing). Bathing may represent the most complex function and thus is likely to be the first ability to be affected. Similarly feeding is the most overlearned and most basic ability and is likely to be the last to be lost and thus the finding that this ADL was least impaired in both groups was expected. This may also suggest that there is a sub-group within the self-neglect group whose functional ability profile is different from the group as a whole. This group may be much more dependent and this high level of dependency may be closely related to self-neglect in this group. The possibility that there are sub-groups of self-neglect, one of which comprises of patients with severe mental illness (dementia) and who are highly dependent in ADL functioning, informed the selection of cases in the multiple-case study design in stage two (See the case of Mrs H).

It was found that there were significantly lower levels of self-care agency in patients with self-neglect. Thus if an individual has less self-care agency their ability to care for themselves is reduced. In Orem's Theory of Self-Care self-care agency is the construct which explains the ability to engage in the appropriate actions designed to maintain self-care. It is the failure to engage in the appropriate level of self-care which leads to an individual becoming self-neglectful. Therefore it was hypothesised that patients with self-neglect would have lower levels of self-care agency than patients who were not self-neglectful. This

hypothesis was supported and thus in any formal construction of self-neglect, self-care and self-care agency may play a central role. The construct validity of the ASA-B scale was tested by means of Factor Analysis. The underlying theoretical structure of this scale was challenged when it was found that the scale had three underlying factors. This may provide the basis for further work which may simplify the complex structure of self-care agency proposed by Orem (1991).

3.8 **Summary**

The main concepts explored in this stage were functional ability, disease/illness (medical diagnoses, nursing diagnoses), self-care and self-care agency. It is suggested that there is enough evidence to, at the very least, warrant further exploration of these concepts. The relationship between functional ability and self-neglect is more complex than may at first be imagined. It did not appear to be the case that high levels of dependency *per se* led to the development of self-neglect. Likewise the relationship between self-neglect and medical diagnoses does not seem as clear-cut as has been previously suggested as most disease classifications were found in both groups. There is a suggestion though that psychiatric illness may play some, as yet unspecified, role in the development of self-neglect. The evidence did lend support to the belief that self-care is an important concept in understanding self-neglect. Individuals who had low levels of operable self-care agency may be more likely to self-neglect. The picture of self-neglect which emerged is of a complex and heterogeneous

phenomenon. The complexity and variations in self-neglect were explored in the next stage of the main study.

3.9 **Methodological Critique Of The Survey Design In Self-Neglect Research**

The first aspect of a critique of the survey is essentially one of methodology, specifically the philosophical assumption that people can be objectively placed in categories which reflect some underlying general reality. The self-neglect literature generally operates from the assumption that there exists a class of people who are self-neglecting and that this group are more similar that they are dissimilar. Self-neglecters are proposed to be a relatively homogeneous group. Rogers (1991) argues that the apparent similarities between patients assigned to a particular class is an artefact of the methodology used. He suggest that commonality is a product of

> *homogenising methods of data analysis, not true commonality of understanding (i.e. the research methods used did not uncover the similarity - they created it) (p 65)*

The problem is that in the survey similarities and universals have been demonstrated at the expense of the dissimilarities within the self-neglect group. What appear to be a homogeneous group may in fact be very dissimilar in many ways.

Thorne et al (1997) suggest another limitation in the positivist orientation of the survey is that generalisations are made which render the individual invisible. This is the so-called ecological fallacy. Thorne et al suggest that post-modernism offers a challenge to positivist thinking

> *Nurse scholars have also discovered that post-modern thinking provides a challenge to traditional assumptions about "truth" within all of the sciences, and provides a broad foundation for inquiry that respects the dialectic between the general and particular, between commonality and individuality, between truth and perception, between theory and practice (p 171).*

The survey method, in common with most positivist methods, is concerned with measurement rather than explication of the meanings held by participants. This is especially problematic in self-neglect research as there is the possibility that professionals and patients may have different meanings of what constitutes self-neglect (Johnson and Adams 1996). The dominance of the Medical Model as a theoretical framework has compounded this problem as the Medical Model is a way of understanding the experiences of those who have diseases from the perspective of the profesional carer. The diseased person is abstracted from their context. In a similar vein Mulhall (1996) comments

> *These epistemological concerns are perpetuated through quantitative methods used to seek explanations. By their very construction these*

methods preclude any meaningful analysis of social processes, separating as they do experience from phenomena (p 152)

The acceptance that the constructions of patients are valid representations of their truth provides an epistemological challenge to medical research (Williams and Popay 1994). The invisibility of the self-neglecting person's construction and the failure to place that construction in a social context is a consequence of research methodologies

Thus in scientific medical discourse the social setting of disease events and the moral component of the medical regimen is obscured or negated by the interest of an orientation to human discomfort which is positivist and unidimensional (Turner 1991, p 17)

A claim that definitions of self-neglect are a product of circular reasoning can be made in the light of the fact that District Nurses were used to define and select the sample of self-neglecting patients. This is problematic both in terms of methodology and methods. The sampling methods have been discussed in an earlier section. This section will deal with the methodological circularity that some suggest can be seen in the scientific approach in general and in the study of self-neglect specifically.

Weatherall (1996) claims that the entire project of "scientific medicine" is based on circular logic. Armstrong (1994) suggests that the circularity of medicine is further entrenched by means of the research

methods which are rooted in this project. He points out that medical positivist research starts from the assumption that symptoms are either present or not and questionnaires and other data collection methods are designed to elucidate these. Thus the patient experience is moulded by the methods used. A recent light-hearted quote in the British Medical Journal sums up the circularity of science and medicine

> *Gravitation: The tendency of all bodies to approach one another with a strength proportional to the quantity of matter they contain - the quantity of matter they contain being ascertained by their tendency to approach one another. This is an illustration of how science, having made A the proof of B, makes B the proof of A* (Ambrose Bierce 1906, quoted in BMJ, p 1056).

Hart (1985) defines circularity in this context as the manufacturing of a conclusion to provide a solution to a problem of its own making. Scientific medicine and its positivist assumptions takes the view that knowledge and knowledge development can only be legitimately discovered by the scientific method (Melies 1985). The methodological assumption is that truth is rooted in the correspondence view of truth in which

> *Validation is based on congruence between propositions and reality; that reality being one reality, an existing reality, and not reality as it may appear to different viewers* (Melies 1985, p 69-70)

This is an explicit rejection of the claims that there are multiple realities and multiple truths. Suppe (1977) argues that this is clearly circular logic in that science begins by proposing a conceptual perspective which in turn determines which questions are worth investigating and what sorts of answers are acceptable.

The problem of circularity in the attachment of a diagnostic label related to self-neglect becomes even more apparent when one considers self-neglect from a constructionist perspective. Constructionist perspectives force one to consider the underpinning philosophical position of the Medical Model (Mulhall 1996). One assumption that has been identified in a preceding section is the claim that there is a single reality, one truth. Constructionism on the other hand asserts that there are multiple realities and multiple truths (Toulmin 1990). Gerhardt (1989) suggests that constructionism does indeed highlight the circularity inherent in the Medical Model

> *The relativist [constructionist] standpoint makes the definition of illness tautological: illness is what medicine defines as such, and medicine defines as illness what benefits its function as a social-control agency. The medical profession, understood as a self propelled power-conscious body, is seen to use diagnostic and therapeutic decisions solely on the basis of unchecked clinical expertise* (p 85).

In essence it can be suggested that self-neglect may have different meanings for different people and what constitutes self-neglect may be subject to disagreement. The diagnosis of self-neglect has itself

become problematic. In the next stage the methodological limitations of survey methods will be overcome by using methods which are rooted in a social constructionist perspective. In this perspective the multiple realities of different social actors are explicitly recognised and legitimised. This perspective explicitly legitimises the constructions held by all social actors whether they are professional or lay constructions. Thus the apparent uniformity of positivism and its picture of self-neglect as an homogenous phenomenon may dissolve into a heterogeneous and complex pattern of similarities and contradictions.

CHAPTER 4: STAGE TWO

MULTIPLE-CASE STUDIES OF SELF-NEGLECT

4. INTRODUCTION

This stage of the main study builds on data collected in both the pilot study and the first stage of the main study. Patients recruited for the second stage were selected from those who had participated in stage one. In stage one a need to understand the complexity and heterogeneity of self-neglect was identified (Section 3.7). This facilitated a greater understanding of self-neglect in the context in which it is experienced. The pilot study also suggested that there may be different constructions of self-neglect held by nurses, medical practitioners and patients. In the first stage it was found that the relationship between disease and self-neglect was unclear, although more self-neglecters had a mental illness than non-neglecters, this was not an obvious causal-relationship (Section 3.6.3). The relationship between mental illness may be perceived to be a causal one or may be part of a process of attribution in which professionals' judgements of self-neglect are influenced by the presence of a mental illness. The causal question is addressed in stage two (Section 4.7) and the attribution question is addressed in stage three (Section 5.6.4). Finally although there was a significant difference in self-care agency levels of self-neglecters and non self-neglecters (Section 3.6.6) the use of statistical tests which compare arithmetic means obscures individuals. This is important because there were individuals who were self-neglecting who had higher self-care agency levels than non self-neglecters. A qualitative approach which uses a language other than mathematics to convey the meaning of self-neglect complemented insights gained in the earlier first stage. In essence the very concept of self-neglect, or the way in which this concept is used by different social actors, still proved to be

somewhat elusive. A multiple-case study design was chosen to facilitate an exploration of self-neglecters and their carers in their natural setting. This contextualisation allows relationships to be uncovered within a specific historical and biographical context. There is a lack of a biographical context in extant self-neglect research (Johnson and Adams 1996).

4.1 **Research Questions**

1. Do patients, and professionals carers share perceptions of what constitutes self-neglect?

2. Is self-neglect intentional or unintentional?

3. What is the relationship between psychiatric disorders and self-neglect?

4. How do professionals and patients treat self-neglect and what constitutes success in the treatment of self-neglect?

4.2 **Design and Method**

Case studies have been a traditional method employed in nursing and medical education. They offered qualitative insights into disease in the language and genre which replicated the methods practitioners use to understand patients' problems in their everyday practice (Keen and Packwood 1996). Eisenhardt (1989) argues that much of what is known in medicine, especially psychoanalysis, is through case studies. A large proportion of the self-neglect literature takes the form of case studies or case reports (O'Rawe 1982, Moore 1989). It can be suggested that these case studies are very limited in scope and, arguably, do not conform to the rigour that is expected of a research study. It would be

fair to add that these case studies did not claim to be research studies but, rather, took the form of the educative case study which has a time honoured and effective place in nursing and medical education (Yin 1994).

Gilgun (1994) argues that case studies have been rejected by sections of the scientific community, not as a consequence of the limitations in the method as they would have us believe, but as a result of how uninformed researchers have used the method. Yin (1994) describes the case study as taking place under natural conditions and it investigates a single or multiple case(s). Yin believes that the case study provides an in-depth analysis of a subject. In a similar vein, Eisenhardt (1989) also suggests that the case study involves the intensive investigation of a single unit. Cohen and Manion (1989) advocate the use of case studies which they see as being rooted in the constructionist research paradigm.

The focus of a case study is to determine the dynamics of why the subject of case study thinks, behaves, or develops in a particular manner (Polit and Hungler 1991). The purposes of case study research, according to Polit and Hungler, are to provide information that can result in hypotheses for future testing and also for use in conjunction with large scale research, in which they serve as illustrations. Yin (1994) implies that this is a very limited conception of a case study, which he argues has a much wider application than that suggested by Polit and Hungler. Eisenhardt (1989) believes that the purposes of case studies include gaining insights into little known problems, providing

background data for broader studies, developing explanations of social-psychological and social-structural processes, and offering rich descriptions to illustrate generalised statistical findings. McCorcle (1984) believes that many of the hidden difficulties found when implementing treatment, including situational barriers and characteristics of individuals, can be uncovered when case study methods are employed.

The case study was not seen in this stage of the main study as developing a new theory of self-neglect, if that were the purpose a grounded theory method would have been employed. The case study was employed to answer four discrete research questions which emerged from the pilot and first stage of the main study.

The philosophical assumptions underpinning any research design should be made explicit and the design understood in the context of these assumptions. Burrell and Morgan (1979) describe the assumptions which need to be addressed as ontological, epistemological, human nature and methodological (Figure 4.1).

Figure 4.1 The Assumptions Underpinning A Research Design

The constructionist approach to social science		**The positivist approach to social science**
Idealism	*-Ontology-*	Realism
Constructionism	*-Epistemology-*	Positivism
Voluntarism	*-Human Nature-*	Determinism
Idiographic	*-Methodology-*	Nomothetic

Adapted from Burrell and Morgan (1979)

In stage two the assumptions at each level from the ontological to the methodological are those corresponding to the constructionist approach. In this approach social reality is constructed by each individual. These constructions can be understood through the language and concepts of each individual. The constructionist orientation asserts that the notion of a single truth, a single version of events or a single way to understand and explain phenomena is to be rejected (Crabtree and Miller 1992). Crabtree and Miller describe constructionist inquiry as asserting that understanding is context-bound. The knowledge constructed in such an inquiry is to be understood within the context of each individual case and therefore idiographic methodology is the logical choice of methodology in this stage of the study.

It has been proposed that the logical conclusion of the philosophical assumptions underpinning the case study method result in the adoption of an idiographic approach to data. Silverstein (1988) argues the contemporary debate about individual differences and general processes is an echo of the classical philosophical tension between the particular and the universal. The nomothetic view proposes that one must transcend the uniqueness of the individual case by developing generalised scientific theories. The idiographic view asserts that the uniqueness of each particular must be studied and understood in its own context. Silverstein supports the claim that researchers can move from a study of the particular to the general when she claims that we may conclude that the value of the biographical case study is to gain an understanding of both the uniqueness and the general laws regarding a human phenomenon.

Gilgun (1994) argues that case studies are by their very nature idiographic. This is reflected in his claim that in a case study a single unit with its multiple variables is investigated, and generalising is analytic rather than statistical and probabilistic. Gilgun contrasts probabilistic generalisation inherent in the nomothetic approach with analytic generalisation. Probabilistic generalisation has many fundamental strengths but also has limitations. This form of generalising informs us about populations but tells us little about individuals within that population. Rubin and Babbie (1989) refer to the ecological fallacy in which the assumption is made that general findings fit individual situations. Likewise, Barley (1988) recognises that one feature of generalisations is that they always tell a little lie in

the service of a greater truth. This problem was alluded to in an earlier section in relation to the self-care agency scores of groups in stage one (Section 3.6.6). The claim that self-care agency scores between self-neglecters and non neglecters are significantly different hides the fact that there is some overlap inasmuch as some self-neglecters have higher self-care agency levels than non neglecters and vice versa.

Eisenhardt (1989) argues that exploring particulars is epistemologically consistent with the way in which professional practice unfolds. The intimate relationship between the idiopathic approach to case study data is highlighted by Gilgun (1994) who states that

> *idiographic findings fit well with practice. Embedded in context and characterised by multiple variables, practice situations themselves are idiographic. Caseloads are not probabilistic samples but rather sets of cases. In addition, practitioners enter new case situations, they bring their knowledge of past cases and of related research and theory: they attempt not to impose their prior knowledge on new cases, but to assess how this knowledge fits (p 372).*

Sandelowski (1996) argues that in fact case studies do permit generalisations of an idiographic nature. She claims that to deny this is to deny the case-bound casuistry of clinical practice. She also claims that a large amount of knowledge in many practice professions is not scientific but derives from idiographical generalisations from one case to another. Guba and Lincoln (1982) reject the generalisability of case studies but believe that they provide knowledge which develops an

idiographic body of knowledge which is best encapsulated in a series of working hypotheses which describe the individual case. Although generalisations are problematic since phenomena are neither time- nor context-free there may be some transferability of these hypotheses from situation to situation, depending on the degree of temporal and contextual similarity (Guba and Lincoln 1982).

The idiographic and nomothetic issue is also evident in the problem of whether cases should be studied as single cases or whether groups of cases should be the focus of study. This highlights the tensions between across-case analysis and analysis of a single case. Stake (1983) and Sandelowski (1996) contrast the single-case orientated approach and the across-case variable orientated approach. The former looks at single case as a whole and attempts to understand its essences. The latter looks at a number of cases and attempts to identify the key themes and variables which provide meaning and structure across all cases. This departure from the single case emphasis of qualitative inquiry reduces data to the lowest common denominator and fails to take account of the diversity amongst cases (Sandelowski 1996). She states that

> *regardless of the kind of analytic techniques employed, qualitative analysts are obliged, first and foremost, to make sense of individual cases. Looking at and through each case in a qualitative project is the basis from which researchers may make idiographic generalisations and move to cross-case comparisons to construct aggregations,*

syntheses, or interpretations of data from and faithful to individual cases (p 525).

The notion of generalisability is central to this debate (Schofield 1993). Stake (1978) shares some of the concerns regarding the generalisability of case study research, but agrees with Schofield that the concept of generalisability requires to be broadened. Broadening generalisability to include naturalistic generalisation, a notion similar to idiographic generalisation, means that findings of one study can be applied to the understanding of another similar situation. Cronbach (1982) describes the same process but uses the term working hypotheses. Guba and Lincoln (1982) offer the criteria of fittingness as an alternative to generalisation. By this they mean that findings can be transferred from one situation to another depending on the degree of fit between each situation.

Eisenhardt (1989) provides a framework for case study research which incorporates within-case analysis and across-case analysis (Appendix 4). The procedures outlined were used to structure stage two, although data analysis was developed to a greater extent than is evident in Eisenhardt's methodology.

Gilgun (1994) outlines some general considerations which should be taken into account when conducting case studies. These guidelines show some overlap with the work of Eisenhardt (1989). Gilgun deals in more depth with the need to develop a broad conceptual framework based on existing literature and the experience of the researcher, although she recognises that this is provisional and will be subject to change as data analysis develops.

4.3 **The Sample**

The principle unit of study was the single case. A case was defined as a patient who had been identified by the District Nurse as being self-neglecting, any professional carers involved in treatment, and any close relatives. Eisenhardt (1989) suggests that between 4-10 cases is ideal. Less than 4 provides a limited and restricted variation and more than 10 will result in too much data to handle. Patton (1990) does not specify numbers of cases in his discussion of sampling but instead insists that the validity and meaningfulness of qualitative sampling has more to do with the information richness of samples than the sample size. Sandelowski (1995a) takes a different view when she argues that sample size is a factor which must be taken into account in qualitative research. She argues that, depending on the particular methodology employed, sample sizes can be too small to make idiographic generalisations, and in other instances, too large to deal with the amount of data collected in any meaningful way. In this stage of the main study five cases were recruited. This provided the number of

cases which were manageable by a single researcher but still allowed sufficient diversity and depth of analysis.

Yin (1994) and Eisenhardt (1989) both regard the underpinning logic of sampling in case studies as being replicative rather than conforming to the sampling logic of quantitative designs. Therefore in this stage of the main study the sampling logic is replication, that is, the logic of treating a series of cases as a series of experiments with each case serving to confirm or disconfirm the hypotheses (Yin 1994). Eisenhardt (1989) draws parallels with experimental designs when claiming that each case is analogous to an experiment and multiple cases analogous to multiple experiments. Cases which confirm emerging relationships between data increase the validity of emerging concepts. Cases which refute relationships provide an opportunity to refine and extend concepts.

In this stage sampling was further organised around Morse's (1991) distinction between the primary sample and the secondary sample. In the primary sample the researcher has control over the sample, whilst in the secondary sample the researcher has less control over this part of the sample as this emerges in the course of data collection.

The Primary Sample

In keeping with the replicative logic of case study sampling it was decided that the primary sample were selected by means of a sequential sampling procedure (Yin 1994). Cases were chosen from the sample of self-neglecting patients who had previously been identified

as self-neglecting during stage one. The initial case was chosen to facilitate a general entry into the field and to explore aspects of the case in the context of the research questions. The first case confirmed that there may be a relationship between psychiatric diagnoses and self-neglect. There was also a suggestion that high levels of dependent-care giving (Orem 1991) may allow self-neglecting patients to live in the community longer than they would otherwise have. This case also indicated that self-neglect may be unintentional inasmuch as the patient was not in a position to exercise any choice in her self-neglecting behaviour. Therefore the next two cases in the sequence were selected to explore these issues with a view to confirm or disconfirm findings from the first case. The second and third cases did permit exploration of these issues and in addition it was found that different participants had different perceptions of self-neglect and thus the fourth case was selected to explore this issue, as well as other issues. The fourth case, or for that matter any of the previous cases, was not a `textbook` case of serious self-neglect as it is portrayed in the literature. Therefore the fifth case was selected to provide an extreme case of self-neglect. This allowed a range of issues to be explored including the notion that self-neglect may represent a continuum of behaviours

The Secondary Sample

The secondary sample comprised of relatives and professional carers who were recruited by means of snowball sampling (Morse 1991). This element of the sample was recruited by the DN or the patient in each case. Cohen and Manion (1989) suggest that snowball sampling is

often the sampling method of choice in case study research. In two cases the patient's GP declined to participate in the study (Figure 4.3).

Figure 4.2 The Secondary Sample

CASE	SECONDARY SAMPLE
Case 1	Son, District Nurse, District Nurse
Case 2	Mother, District Nurse, District Nurse, CPN
Case 3	District Nurse, CPN, GP
Case 4	District Nurse, GP
Case 5	District Nurse, GP

Evaluating the Sampling Method

Morse (1991) proposes that qualitative samples can be evaluated using the criteria of appropriateness and adequacy. A sample is deemed appropriate if the sampling method facilitates an understanding of the research problem. A sample is adequate when there is sufficient high quality data which is relevant, complete and makes sense in the context of the research question. It can be argued that the sample, both primary and secondary, was appropriate in that it did facilitate an understanding of the research questions. On the other hand the reverse is true of adequacy where the limited number of cases did not permit completeness (saturation) to be achieved. This was a

consequence of the limited time-scale available to the researcher and the large amount of data which were generated from five cases.

4.4 **Data Collection**

In case study research a variety of data collection methods including interviews, field notes and documentary evidence are used (Eisenhardt 1989, Cohen and Manion 1989). Consequently in this stage of the main study data were collected by semi-structured interviews, field notes, and other documentary evidence. The interview schedule was organised around pre-defined topics which were explored in depth (Appendix 5). These pre-defined topics had been developed directly from the findings of the pilot study, stage one, the existing literature of self-neglect and from Orem's Self-Care Deficit Theory. Support for the use of such *a priori* topics is to be found in the literature (Eisenhardt 1989, May 1991, Polit and Hungler 1991, Crabtree and Miller 1992). Nevertheless it is still recognised that such *a priori* notions are tentative and provisional and are subject to revision and rejection (May 1991, Polit and Hungler 1991). Yin (1994) argues that constructing preliminary hypotheses before data collection is one of the major differences between case studies and other methods such as grounded theory and ethnography. In case studies, theory development during the design phase is essential (Yin 1994). This allows for a great deal of flexibility on the one hand and a degree of consistency necessary for across-case comparison on the other (May 1991). Interviews were audio-taped and transcribed fully. The use of audio-taping is thought to increase the validity and reliability of qualitative research by providing an audit trail of data collection and data analysis (May

1991). Data were also collected in the form of field notes which comprised of hand written and word processed data on observations, conversations, records of case notes, and impressions of the researcher.

The order of questions to be asked and the exact wording of questions varied from interview to interview depending on the researchers judgement of the context. The questions themselves also changed as the research study progresses (Morse 1991). As the data collection/analysis progressed themes and ideas needed to be redefined and expanded and thus new areas of relevance appeared which were taken into account in subsequent data collection

The interview as a method has strengths inasmuch as it allows for exploration of issues in greater depth than some other methods. Interviews allow probing and permit issues to be clarified with respondents. They have been criticised as having the potential to be subjective, biased, expensive and having limited reliability (Cohen and Manion 1989). Potential sources of bias include the attitudes and opinions of the researcher, the tendency for researchers to seek answers which support preconceived notions, misinterpretation of interview data and misunderstanding of what is being asked (Cohen and Manion 1989).

4.4.1 **Data Management**

The data collection, management and the analysis processes in this form of research are not clear-cut discrete processes but instead each overlap. The data management process involved recording, retrieving and coding data (Field and Morse 1985, Huby et al 1995).

Field notes data, verbatim transcripts of interviews and other documentary evidence on each case were stored in a separate file for each case. Data analysis was facilitated by the construction of a code-book which outlined the research questions to be answered and the various themes and ideas which were to be incorporated into each question.

4.4.2 **Data Analysis**

Sandelowski (1995b) describes data analysis as a means of knowledge production which involves the separation of elements of data according to some *a priori* or data-driven system. The essence of data analysis is thus the creation of new knowledge that is different from raw data, but is faithful to the data in its pristine form. Analysis can take place at various levels of abstraction but all levels seek to generate a set of meaningfully linked categories which capture the informant's constructions (Huby et al 1995). Eisenhardt (1989) describes data analysis as the least documented element of case study research. She refers to the gap between data and conclusions in published studies as a "huge chasm" (p 539). Yin (1994) also makes the point that this phase of case study methodology is the least developed and no clear

consensus has emerged regarding any gold standard method of data analysis.

Yin (1994) proposes that case study analysis must take place within a general analytic strategy. This general strategy allows investigators to choose among different analytic tactics. The strategies used in this stage of the main study were: 1. Developing a case description; 2. Testing working hypotheses. In the first instance a case description of each individual case was prepared. After the case description was completed data were analysed across-case to provide answers to the research questions, and the working hypotheses which were developed in relation to each question (Figure 4.4).

Figure 4.3 Analytic Strategy Used During Stage Two

Strategy	**Level**	**Tactic**
*Case Description	Single case	plausibility;seeking themes and relationships.
*Testing Working Hypotheses	Across-Case	Making contrasts and comparisons, noting patterns, making conceptual coherence.

Case Descriptions

This phase of analysis involved analysis of each individual case in its own right. Analysis was, in the first instance, organised around a number of research questions (Crabtree and Miller 1992, Sandelowski 1995b). Preliminary analysis began by getting to understand each interview. Thus the researcher read each interview transcript as often as was necessary to understand the essential meaning and identify the key themes/ideas in the interview (Sandelowski 1995b). These constructs were open to both rejection and modification as well as verification (Eisenhardt 1989). Huberman and Miles (1994) outline a number of tactics which can be effectively used during data analysis. These tactics include identifying themes, seeking plausibility, clustering concepts, identifying the relationship between variables, and seeking relationships between variables. Having gained a good degree of understanding of the case the task was now to write up the case. This stage of data reporting is normally descriptive in nature (Pettigrew 1985).

Across-Case Analysis

Having gained a understanding of each case and having written-up the case the next task was to move to across-case analysis. The analytical tactics used included noting patterns, clustering concepts, making contrasts and comparisons, seeking relationships between variables, and making conceptual coherence (Huberman and Miles 1994).

This stage of analysis was organised around the research questions. Yin (1994) supports this approach to data analysis in case studies as he believes this provides direction for data analysis and grounds data in implicit theoretical propositions, thereby increasing the validity of the study. During preliminary analysis tentative working hypotheses for each case were developed. These working hypotheses were related to the research questions. For example one such working hypothesis was `Self-neglect is perceived to be directly related to the presence of a mental illness'. This hypothesis was then tested during analysis of subsequent cases.

4.5 **Validity and Reliability**

There are number of ways in which qualitative research can demonstrate validity and reliability. These include the creation of an account of methods and data which can stand independently, thus setting up the potential for other researchers to analyse the same data and reach similar conclusions; the production of a plausible and coherent explanation of the phenomena being studied (May and Pope 1996); and triangulation and thick descriptions (Patton 1990).

Thick descriptions of data and analysis have been provided in this stage through the depth and coverage of primary data and subsequent analysis which are provided for the reader. This is relatively easy to provide in a thesis but less so within the constraints of a research report published in a journal. Schofield (1993) links the notion of fittingness to the provision of thick descriptions. He argues that there is a general consensus that findings can be transferred from one case

to another depending on the degree of fit between these situations. To enable judgements to be made about the degree of fit possible researchers must provide thick descriptions.

An audit trail is available for other researchers in the form of all transcripts, field notes and stages of the analysis. No respondent check was carried out during this stage of the study due to the very sensitive nature of some of the interviews which on second reading might have been of some concern to participants. The GP who said that a patient might be better dead may have wished that this remark not be included in the final report. This problem may be specific to phenomona in which the researcher probes very sensitive issues. In such cases remarks are made about a specific case which respondents would not normally make outside the confidences of the actual interview situation. When these remarks are seen in the hard light of day in a draft research report respondents might reconsider their position.

4.6 **FINDINGS**

Analysis of the case studies is dealt with in two interrelated parts, the first of which is a description and analysis of individual cases and the second part is the across-case analysis. The case descriptions are primarily descriptive and explanatory. The perspectives of individual participants in each case will be described followed by an analysis of this case.

4.6.1 **Mrs H**

Biographical details

Age - 96

Sex - Female

Marital Status - Widow

Occupation - Retired Domestic Servant

Medical Diagnoses - Disease of the ear; Organic mental disorder (dementia)

Nursing Diagnoses - Chronic confusion: Bathing/hygiene deficit; Dressing grooming deficit; Impaired verbal communication

Index of Independence in Activities of Daily Living Scale - Category C (Dependent in bathing, continence)

ASA-B Score - 70

Background Information

Mrs H lives in a remote rural area in the Scottish Highlands. Her house was located mid-way up a highland glen and is four or five miles from

the local village. There is one narrow access road and the glen is bounded by hills. There is no public transport and the local shop is some miles away. Mrs H lives in a post-war prefab type house, which is red tiled and is detached. The son and daughter-in-law live 100 metres away. Their house was a log cabin built by the son himself. The second son lives a mile or so down the glen and one grand-daughter lives in the local village itself.

The remoteness of the area is illustrated when the previous week the DN had not been able to visit Mrs H as the glen was snowbound. The area is not serviced by meals-on-wheels as there is no local volunteer driver to deliver food to the house. In this area meals are delivered to the local post office in the village and are picked up there for onward delivery. Mrs H in any case declines the offer of meals-on-wheels.

Mrs H had lived in the area since 1949 when she moved there with her husband. She had been in domestic service since leaving school and continued in service till she was 75 years old. She was described as an independent lady who was well known in the area. During the data collection period Mrs H had fallen in the home and had been found by her son lying on the floor and a decision had been taken to seek to admit her to a local cottage hospital (25 miles away). Mrs H had been visited at home by the researcher in the company of the DN. She was very deaf and in conjunction with her memory impairment it was not possible to conduct a research interview. The house was very tidy, due to the support of relatives and was very warm. Mrs H was not in a

position to give informed consent to participate in the research study and permission was sought from her son.

The District Nurses' Perspectives

There were two DNs who had shared responsibility for Mrs H's care. The DNs appeared to be very much part of the community, and both lived in the general area, one in fact had lived in the local village for 25 years. These DNs were triple duty nurses who would provide care for the local population from pre-natal care to care of the elderly. The DN's relationship with the locals was very easy and friendly.

District Nurse 1

This DN described Mrs H as

she's deaf so its difficult to communicate with her. She's always pleasant enough ...she likes to go to church on a Sunday, she likes to do that and one of the family helps. I've not seen her down in the village, but I think that's just her way of life. She's been most of her life living up the glen and she's very independent, that's just her way of life she always has, and she always wants to have. She doesn't want to rely on others.

The DN reported that Mrs H was self-neglecting and this was directly related to her memory loss. Her memory loss had become increasingly worse over the last year. This had resulted in her not being able to care for herself properly as she was not able to maintain an adequate diet. She was also becoming a safety risk.

My colleague and I thought about she was in danger cause she's burnt her leg on the fire just the other day. She took, she's not got a full fire-net. She's got an electric fire. Well she's burnt her leg, and we thought that she wasn't eating appropriately at times and she wouldn't even accept, when we went up to give her a bath and she wouldn't accept her incontinence. I think she was just living on bread and jam and the family and we discussed it with her son and he thinks the same. You know, he says he knows she not eating and then when he goes and finds no food in the house. You know before we got this sort of rota set up. I just feel that, I wish that we could have got a more organised help, but because of the environment it's not possible.

The fact that she lived in such a remote area was also a concern to the DN as with the onset of winter there was the distinct possibility that Mrs H would be snowed in and would be at risk of developing hypothermia. The DN described her relationship with Mrs H as very good. The focus of DN care was the family

I think it is just the whole family because we can't get any sort of external help and because where she lives.

It was noticeable that the DN included both herself and the family in a collective *we* at various times during the interview. This was especially noticeable when asked about family decisions regarding treatment. This close nurse-family relationship, which was both professional and also personal, was observed during the interactions when house calls

were made. The son was interviewed in the presence of the DN and both seemed to contribute to a shared view of the problem and how best it could be treated. The DN was concerned at the lack of services that were available to Mrs H. This was due to the remoteness of the area and also the lack of co-operation between services.

The DN said that co-operation between services was not very good, in part, as a consequence of the GP being located in one town and the social worker being located in a larger town around 30 miles from the GP practice. This presented difficulties for communication. She was not very complementary about the input of some social work staff. The DN suggested that social workers did not really understand the needs of patients, they seemed more concerned with budgets and finance.

The DN appeared to be operating two contradictory notions of what could be described as success in terms of treatment for Mrs H. On the one hand success would be

Well she wants to live there and as long as she's fit to live there, its more support services for her in her own home because that what she's going to be happy with. She's not going to be happy in a home. She will deteriorate very quickly in a home, she needs to be at home. I don't think she'd thrive in a home for example, this would be the end for her. She needs more support and ideally we would like meals-on-wheels

On the other hand she also stated that it was necessary for Mrs H to be admitted to hospital now because of the strain that was being placed on the family and Mrs H's increasingly limited ability to care for herself.

The DN painted a picture of an elderly lady living in a remote location who has a supportive network of relatives close at hand. This family has become increasingly strained by the demands placed on it

..... her son and daughter-in law live across the road and they are in just about everyday to see their mother.....I think it is very difficult for them as one of the daughters-in-law works full time and she says that she cooks before going to work and she cooks enough for all the family and puts her meals in a flask. She's got grandsons as well which is quite good.

The co-operation between the family and the DN is evident in the comment that

Yes, if we phone, if we're up that way we call in, we're in about once a week, if not more. If we're up that way we will call in, but the son is in, the son and daughter-in-law. I think on balance she gets three visits every day and at least she's in a hot room. She's better since she got the regular visits.

On the surface the family relationships seemed sound but there had been an undercurrent of suspicion and disharmony between Mrs H and her daughter-in-law for some years

There was some incident maybe over five years ago, but this daughter-in-law, there is just a little bit atmosphere when she is in about. But my colleague thinks that there was nothing to this allegation and we think she has just misplaced money. And her son has said that he found money in places all over the house and we think that there has been a lot of rambling with her about the money and sorts of, she'll think she's got money and she's forgotten where she has put it.

The DN also thought that the strain on the family was beginning to take its toll and the existing tensions were now coming into the open. The family wanted Mrs H to be admitted to hospital for respite care. The DN agreed with this but was worried that the other DN would be unhappy because she would want Mrs H to be nursed at home.

<u>District Nurse 2</u>

This DN described self-neglect, in the general sense, as a failure to wash, keeping an untidy house, not eating properly and perhaps being a "little depressed". She further suggested that self-neglecting individuals were seeking attention

Well sometimes its old age, but a lot of the time it can be just attention seeking. No I mean not all of them, but I mean wanting more visits than you can give them.....I think they're just lonely. Its loneliness.

and

Well I think it was good in that it was near her sons but otherwise I think it was terrible because she was so much on her own and this was the one big thing that she used to say she was so lonely. I mean they were going out to work in the morning and she would be all alone all day except for whoever would drop off her lunch, you know, and then the nurse once a week. The rest of the time she was more or less on her own.

According to the DN Mrs H was an "amazing woman" who had been independent and resourceful. Mrs H was on the caseload for about two years. This was initially a supervision visit to check she was okay and also assist with bathing. This was at the instigation of the family who informed the DN that Mrs H was not bathing properly. She had noticed a sharp deterioration in Mrs H's health over the last year. This was noticeable in her inability to cook for herself and the risk she presented of sustaining an accident in the home. She believed that Mrs H was self-neglectful and this was increasingly the case as her memory was deteriorating. This memory loss was perceived directly linked to her inability to care for herself.

Although she began visiting Mrs H for weekly bathing/supervision purposes she did "not honestly know why" a DN should have visited for these purposes. Many of the problems experienced by Mrs H were exacerbated by the geography of the area. The DN cited the lack of public transport and the lack of care facilities available for Mrs H in the locality. The nearest day centre was nearly 20 miles away. In the ideal

world the DN would have liked to have been able to offer a range of services to Mrs H

Well I think it would have been nice if she had been able to have gone to a day centre you know on a maybe weekly basis, or if she had gone, you know. I think it would have been nice if she had got out maybe once a week at least and you know and that sort of thing. It was just that she was so reluctant you know, we did mention a day centre. I mentioned that a few years ago to her but she wasn't keen on that at all. I feel she was too much on her own you know.

Essentially the DN was not able to identify what treatments could realistically be offered to Mrs H and the only criterion of success she could identify was to place Mrs H in a nursing home in which family could easily visit her. The DN had observed that the various family members enjoyed a supportive relationship with one another. This allied to the fact that most immediate family members lived in the locality was an important factor in Mrs H remaining at home

Och, well they have been pretty good really. I mean they have, they have been seeing her in the evening quite a bit and before they go to bed at night and as I say they were arranging for someone to bring in a meal, a hot meal during the day because we felt it was unsafe for her to be using the cooker. In the past year it has been totally unfair because you know one day I was in and she was sound asleep in the chair and she had the fire on and you know I just felt it's almost ... you know.

The DN had noticed that the family's willingness to take Mrs H back home if she was discharged from hospital had recently changed

...But since granny went in I've had that feeling, you know because they are very keen that she is kept in.....I think the family were voicing concerns and weren't keen to have her back home. I think as far as I know they were going to discharge her on the Saturday after she was admitted but the family were not keen about that...You know I think they're not keen to get her home.

The Son's Perspective

The son was a man in his 50s who had taken early retirement as a gamekeeper due to ill health. He lived in a house he had built himself. This house was less than 100 metres from his mother's house. He told how his mother had worked till she was 75 and had been cycling up and down to the village until she was in her 80s. When asked to describe his mother he stated that

Describe my mother? Well she's always been very fit and healthy. Never mixed a lot with people because we were never in the places you know we were always in places that we were well away from people like, you know, and um, we didn't really have any transport until ..... In 1960 the car came on the go and that you know. So I suppose that doesnae help her nowadays. She refused to go to the village you know, she's just maybe not too used to mixing with people like you know and it's worse since she got deaf like.

He told how they had a difficult task trying to get her to stop using the cycle and had to resort to refusing to repair a puncture to achieve this end. His mother's memory was deteriorating as she had begun to mistake him for her husband and was unable to retain memories from one moment to the next. He thought that the memory loss itself was not a problem but the fact that this prevented her for caring for herself was the problem. She wouldn't manage to care for herself if the family did not live close by

Well not like at the moment you know, she certainly couldn't put her clothes on this morning if (daughter Y) hadn't come up and she wouldn't have got to bed last night if we hadn't gone over. She would never manage like you know but I mean she's been very independent until things like this happen like you know. She had this sort of crisis that she burnt her leg by the fire or something and in the summer we sort of tried to get meals-on-wheels didn't we and then so then it was the family that set up a rota that they went in three or four times a day and the meals, because she was forgetting to eat wasn't she? She was eating jelly pieces and X (son) said she was going through loaves and jars of marmalade, but she wasn't eating anything else and you would think she was forgetting it was lunchtime so that she gets that regularly, well she gets four visits a day and one at lunch.

He thought that his mother would be embarrassed about her incontinence and that she would try and cover this up as much as could

Yes that's why I think she insists on doing her underwear and that herself like you know, but...as I say Y (grand-daughter) bullies her into giving it like, she hasn't much choice you know. But I mean, a lot of the time she does wash her underpants and underwear like.

He indicated that he was worried about his mother's inability to maintain a safe environment. She had recent episodes of falling and she had also fallen asleep in front of the open fire and nearly got burnt again. The son did not have any clear idea about how his mother could be treated. He indicated that she was now at the stage when only hospitalisation would suffice. When asked how he and the family would feel about hospitalisation he commented that

Oh, how would they feel? Well probably everybody would understand that it's for her own benefit like you know. Um, I mean we'd feel very guilty but if she was lying behind a door or something ..... Helpcall and she wouldn't use it like you know. You know we're over there at eight o'clock at night and she's going to bed. She just needs to get up through the night and fall like she did the other night and nobody knows nothing about it like you know. I mean the Helpcall is fine but whether she would ever be able to use it you know. I don't know if she realises to press the button because I'm over there quite often when... (Helpcall Base) *phone up, you know that the button's gone off and it's quite often like and eh, it's just when she's taken the button off to go to bed and things like that and she touches it and away it goes*

The son believed that his mother could not have lived at home if it were not for the extensive support provided by the family. He was also conscious of her previous independent nature

Of course, aye, yes. Quite a bit like you know. But it's very difficult, she's very independent and you don't want or I don't want to force her into anything like you know..... Hoping she'll manage on her own like you know but I know she's not managing you know, she's just lucky enough that we're close enough to hand you know. We can see her three or four times a day like you know.....Well somebody goes in at least four times a day. Somebody will be in the morning and at lunch-time and they'll be in at supper-time and then go over later on to see that she's all right like you know.

and

Oh yes aye, yes I mean I go over every morning and if she's not up I can't do anything about it like because you know sometimes she's up at seven o'clock in the morning like you know and eh, that's okay but I mean a lot of mornings I go off and she's not up and even (daughter B) goes off now. We have to go into (daughter A) ..... And they come up like but you've always got in the mind that there's always something wrong like you know.....and my daughter-in-law's in the village. They're all very good like you know so they go and see her and that like. My daughter does her washing if she can. I mean she's up in..... she does a lot of her own washing like you know.

It was suggested that the support from family members may not be equally shared and for some reason the prime carer for Mrs H was the grand-daughter who lived in the local village

Sometimes she maybe when X (grand-daughter) comes up and does it, pushes her but she wants to do it herself and she'll be doing it maybe the next day when it's not needed and things like that you know. As I say she's been that independent all her life like you know. The lassies, I mean, I feel sorry for them too because she'll follow them about the house like. You know, and they're a bit uneasy you know. But as I say they do it, they don't take no for an answer which is a big help.

He contrasted the grand-daughter's role with that of his wife's

Well the lassie's very good. I wouldn't say my wife, she's never been that close to my wife like you know but my daughter's very good with her like you know. X (wife) admits herself that she's not good with old people like you know. She would say that herself like you know. She just wasn't cut out to be a nurse or something like that you know but the lassie she can handle her all right you know.

4.6.1.1 **Within-Case Analysis**

There was agreement between all participants that Mrs H was self-neglectful and that this was directly attributable to her memory loss. Clark et al (1975) found that dementia was commonly associated with self-neglect. The clear-cut perceived relationship between major mental illness and self-neglect in this case is support for Ungvari and Hantz's (1991a) notion of secondary self-neglect. Orem (1995) also outlines a link between mental illness and limitations in an individual's capacity for self-care. It is suggested that mental illness, in this case dementia, adversely affects the foundational capability elements of SCA. Foundational capabilities include perception, memory and orientation (Gast et al 1989). This memory loss had increased Mrs H's risk of having some form of household accident or suffering from hypothermia. She was also self-neglectful inasmuch as she was no longer able to cook for herself and would eat nothing but bread and jam if she were left to her own devices. In essence she was no longer able to independently care for herself. There was also agreement that this self-neglectful behaviour was not intentional. One DN thought that in other cases self-neglectful patients may intentionally behave in this manner but this did not apply in the case of Mrs H. This raises interesting questions about the extent to which self-neglecters choose or are able to choose their lifestyle. Mrs H's case is not consistent with the active-choice hypothesis in which individuals choose to self-neglect. In fact it supports the passive-choice hypothesis in which individuals do not choose to self-neglect. The issue of choice is a

constant theme in the case studies and will be investigated in stage three.

The DNs reported that the rural setting created problems in treating Mrs H as there were not the services available for her that they would have liked to have seen. Again there was a consensus that there was no real solution apart from having Mrs H admitted to hospital. One DN thought, wrongly as it turned out, that the son would be reluctant to have his mother admitted to hospital for long-term care.

The DNs reported that there was not a lot of co-operation between health care and social care services. They were especially critical of the social work department who it was suggested, in the case of Mrs H, were more interested in the cost of services as opposed to the need for them. The son commented that the wider social support networks available to people living in what were once close knit communities no longer existed.

Mrs H received a lot of practical support from her relatives, most of whom lived close at hand. This support involved many visits each day. One DN hinted at difficulties in family relationships and both mentioned the increased stress the family were experiencing as a result of caring for Mrs H. The son was more open about family stresses and suggested that his daughter was the main carer whilst his wife played a less active role in care-giving. Nevertheless it was agreed that Mrs H could not have lived in her own home so long if it were not for the support of her family. This is again consistent with Orem's (1991)

notion of dependent-care giving, in which another can offer care in order to compensate for an individual's self-care deficits.

4.6.2 **Miss E**

Biographical Details

Age - 44 years

Marital Status - Single

Gender - Female

Occupation - Unemployed Manual Worker

Medical Diagnoses - Schizophrenia

Nursing Diagnoses - Ineffective management of therapeutic regime; Instrumental self-care deficit; Altered nutrition - less than required; Ineffective family coping.

Index of Independence in Activities of Daily Living Scale - Category A (Independent)

ASA-B Scale Score - 52

Background Information

Ms E lives with her disabled uncle in a council-owned bungalow in a small county market town. The uncle was reported to have learning difficulties and had recently suffered a stroke as a consequence of which he now had some degree of paralysis. She had recently been allocated this house by the local authority and had previously lived with her mother and brother. The family had been travellers but had given up this form of lifestyle many years ago.

The mother's house, from which Ms E had recently moved, was also a council-owned bungalow located in a small estate. The garden was relatively unkempt and it was noticeable that the front door letter box was sealed-up with heavy masking tape. The interview with Ms E and her mother took place in the kitchen of her mother's house. The kitchen was very warm and was heated by a 2-bar electric fire. The kitchen was long and narrow and was rather unkempt. The kitchen was the room in which the mother and daughter had to live and sleep in. The bed was propped against the wall and would be put in place at night-time. There was also a 2-seater wicker chair which doubled as a seat and a bed for Ms E.

The District Nurses' Perspective

There are two DNs who care for Ms E: the case holder and a relief DN. One DN was interviewed formally whilst the other supplied case notes, written information and was interviewed over the telephone. The case holding DN did not appear happy with the fact that she had to visit Ms E regularly to administer a long-acting major tranquilliser injection. She thought that this problem was not within her area of competence as she did not undertake any psychiatric study during her training. This is reflected in the case-notes which identify Ms E's sole problem as `mental illness' and the documented nursing care was to `visit and administer an injection'. She had taken responsibility for Ms E when a male Community Psychiatric Nurse asked her to administer this injection as he was not able to give an injection to a woman. The DN believed that this meant that she had become the case holder by default. The DNs both care for Ms E's mother as well as Ms E. It was

apparent that the mother's entries into the nursing notes were more extensive that those of Ms E.

The DNs both believe that although Ms E has been diagnosed as schizophrenic and that their input was to administer a regular tranquilliser injection the real problem revolved around the family circumstances. The DNs reported that Ms E's schizophrenia is stable, although both commented that they don't know a lot about mental illness. The brother exhibits, according to the one DN, a range of bizarre behaviours and the older uncle, who is cared for by Ms E, has learning difficulties and had recently suffered a stroke. The family are very protective towards the brother and the case notes indicate that they get angry when any suggestion that he is cared for in hospital is put forward.

The relief DN commented that

He's a half-brother who is a schizophrenic who has enormous behavioural problems....he won't go for treatment and therefore any treatment that's put into the house is only what they will allow. The old lady has to flush the toilet 36 times in the morning and 36 times again every night. If he decided he wants a bath she has to scrub the carpet between the bedroom and the bathroom..... sometimes he'll do that 6 times a day.

The brother refuses to wear clothes more than once and he will only eat crisps, coke and other convenience snack foods that come in a sealed package. The DNs have never met nor spoken to him as he occupies the entire house except for the kitchen and will not let anybody except Ms E and the mother into that area and even then they must follow a complex set of extreme ritualistic behaviours. These rituals forced Ms E and the mother to live in the kitchen. They cannot run the water during the day and have to use a bucket as a toilet, which is then emptied in the garden during the night.

The DN felt that although Ms E does not eat well and her weight had dropped to six and a half stones she coped remarkably well. So much so that they suggest that

She's the linchpin of three other problems. If anything happens to her we're going to have four problems on our hands.

and

She puts up with an awful lot of stuff and doesn't seem to get stressed out whereas other people I would say wouldn't be able to put up with half of what she has to put up with.....she's not eating properly, she's probably neglecting herself.

The DNs both feel that part of the problem is the reluctance on the part of the family to accept help and specifically Ms E's lack of interest in

asking for or accepting any advice from the DNs on problems such as her poor diet. The feeling that there were limits on the amount of help that would be accepted was a frequently expressed view

The frustrating part of her is that we can do very little to help her with her three people she cares for. We can do as much as they'll allow us to do.

One DN summed up the problem as

I would say first of all it's not just the person its the family, the care in the house. But if you're looking at her as an individual she has suffered enormous weight loss. She suffers from stress, she doesn't sleep well at night and she is the main carer for at least three other people not all living in that house. Those things all together make up a picture that she isn't doing as well as she could be.

Ms E was part of a large family of ex-travelling people who are well known in the region. The DN described the family as part of an enormous network of ex-travellers who have settled in the area

Yes, a huge family, huge families and they're all, there lots of inter-relations there. They're ..Romany, whole lot of Romany ones and they

look completely different. They look Italian and they're all. They're sorts of all shoots of them all over the place with sort of foreign names.

The family were regarded as having both positive and negative effects on Ms E's situation. The DN felt that the family were stigmatised by their past as travelling people and the fact that the extended family had three cars provided by the social services was a source of friction in the village. The DN stated that

Yes, I feel sorry for them. I think they're in a catch 22 because of their own feeling and the family, this family, they're notorious....and they're all very supportive. You rarely find that you have to put home care or use facilities like day care or meals-on-wheels or anything for this type of family. They all support each other greatly.

This view would seem to be supported by the level of support which Ms E provides for her mother, brother and uncle in-spite of her own circumstances. On the negative side the DN felt that the family's reluctance to allow social services or psychiatric services to admit the brother to hospital meant that the root of the problem could not be tackled. In addition the DN felt that there were other aspects of the extended family life that left a lot to be desired

The other thing I don't like about this household is that you can go in, we go in quite early in the morning when we're doing the Depixol and you

can find children from part of the family, not part of the nuclear family, but another branch of the family, sleeping the night in the kitchen with the 90 year old granny and Ms E. I just sometimes think that's not on really. I mean this is 10 o'clock in the morning when they should be at school.

Leininger (1987) found that amongst Gypsy families a cultural value system operated which meant that children were cared for by many different members of the extended family. Child-care was the responsibility of the entire family. The DN also thought that the reluctance of the family to allow social workers to become more fully involved was also to the detriment of her condition. The relationship between the DN and Ms E and her family was one which was consciously developed

.....We've got a good relationship with her.....We both know her quite well and she's receptive to both of us and I feel its quite good for her to have somebody who knows her, somebody that she feels she can probably trust.

The DN appeared to acknowledge that there is always some degree of tension in the relationship when she states that

You get the feeling that she suppresed, but there are days when she tells me everything and other days when she doesn't want me to know

anything. You know if I probe into how things are some days she'll just say they're fine and I can tell she's not interested in me knowing any more than that. Other days I get the whole story.....

The DN indicated that although the nurse-patient relationship was important she felt that it might be difficult to justify these visits to auditors as she could not prove that they were bringing about any measurable change in Ms E's situation. According to the DN there were definite limits set on the relationship by Ms E

..but with them I feel they'll let me go to a certain point and then I won't get any further than that.....When she's receptive to me and is willing to tell me stuff I can get as much out of her as I can, but if I make any further suggestions towards things like GP involvement or (Hospital) , nope, not interested. It's almost as if she trusts me but she's not going to have anyone else coming in.

The DNs were both pessimistic about what could be done for Ms E. Their ability to help was hampered by the limits to which the family were prepared to let health and social agencies become involved, the reluctance of other professionals to get fully involved and the fact that the brother, according to the DN, was almost holding Ms E to emotional blackmail. The extent of this sense of therapeutic nihilism can be seen in the statement that

Yes, its a maintenance that were doing just a maintenance. We're not going to, one part of me wants to pull out altogether and to just say well lets just hand this right on to the psychiatry and let them deal with it. But to be honest I doubt if that would work.

The care plan for Ms E consisted of one goal. One DN suggested that they have no objectives or aims for Ms E. Both DNs seemed puzzled by this case and implied that responsibility should be given to mental health specialists. The wish to involve psychiatrists and CPNs is illustrated in the comment

I was trying to get more involvement from psychiatric nursing to go in to do her Depixol not just as a task of doing her injections but a medium for looking at the rest of the problems in the family, because we feel at a loss really as to how to deal with a lot of the problems.

The only successful interventions that were obvious to the DNs were the provision of a house and a car by Social Work for Ms E. The house allowed Ms E to cook food and have a bath when she chose to and not when her brother permitted. The DN defined success as far as the DN input was concerned would be to provide a "better quality life" and an "independent quality of life". Both DNs felt that this level of success was unlikely to be achieved.

The Patient's Perspective

The patient was interviewed in the presence of her mother. The mother seemed to have an effect on the conduct of the interview, although she seldom made any contribution except when the subject of the son/brother was mentioned. Her interjection usually consisted of minimising the problem and closing the topic as a source of conversation. Ms E could not clearly indicate what her problem was and what caused it. She suggested that when she was not active thoughts would be "swimming in my head". When asked about the state of her health she gave contradictory views. On the one hand she thought her health was not good and on other occasions indicated that her health was fine.

She did complain that the prescribed tranquillisers were making her very tired to the extent she could sleep at any time and anywhere. Both Ms E and her mother suggested that she was very compliant with the medication regime and knew exactly what medication to take and when it was to be taken. Ms E also displayed a slightly ambivalent attitude towards having to look after her brother, uncle and to a lesser extent her mother. She seemed torn between the duty to care for family members and the need to lessen the burden she was experiencing. This ambivalence is obvious in two comments regarding how she coped with the care-giving demands placed on her

Sometimes I don't mind much. You have to get it right the first time you know.

and

I don't like it but there's nothing I can do about it you know because its the only way....You know it takes him hours sometimes before he gets out to get some food.

The problems of the brother were the major topic of conversation, although the mother seemed to monitor and control what was said about him. Nevertheless it was clear that the brother's ritualistic behaviours placed many demands on Ms E that she believed were adversely influencing her health and her ability to look after herself. It was his behaviours which forced her to occupy the kitchen with her mother. She seemed resigned to the fact that this had happened but was glad she could now get some respite at her own home. Ms E conceded that she had "let herself go a little" but did not define her situation in terms of her being self-neglecting. In fact she seemed to suggest that the problem was a combination of the brother's mental illness and the need to care for her uncle.

Ms E's sense of caring for others was also evident in her expressed concern for the family who had just moved next door. She was worried that the family had a young baby and they might be disturbed by her brother's shouting and screaming. She wondered how she would cope with this situation. She seemed to assume responsibility for this potential problem. Ms E was unhappy with the local GP who she

thought did not take their plight seriously. She stated that the GP did not believe her when she told him of her brother's behaviour

I have seen him going for seven days in his bed without eating and drinking. The doctor said `Oh he can't go that long'.

and

All the doctor said to me when I told him about the worst problems...'amuse him...amuse him'

Ms E felt let down by the Social Work Department who had not followed her up when she was discharged from hospital two years ago. There was a general sense of pessimism regarding her future treatment

Well as far as I can see it ...I just don't think they bother...well there's nothing they can do really...there's absolutely nothing the doctor can do. In the end we're just left it to ourselves.....to try and cope.

Ms E also detected a similar sense of pessimism from other professionals who care for her when she states that

They don't bother. They just don't bother because they know there's nothing they can do.

The two successes in treatment that Ms E reported were material provisions. She thought that the car provided by social work and the

house she recently gained tenancy for were very positive developments in her life. They offered the opportunity to get away from the kitchen she had occupied for the last few years. She was also able to take a bath when she needed to and go to the toilet without having to take account of the brother's rituals. Success in terms of treatment was the desire to "be back to normal". Normal was defined as being able to go to the toilet and also for the brother to get his own food when necessary.

Ms E told of the extensive social networks that comprised her extended family. This network was intergenerational in nature and she told how teenage family members would frequently visit her and her mother. The family would provide support in the form of money in order that she could keep her car on the road. They also provided support in terms of company.

The Community Psychiatric Nurse's Perspective

The CPN reported how this patient had been admitted to psychiatric hospital in the past with a manic depressive psychosis. The CPN suggested that other health care workers thought that Ms E may be depressed at the moment but she did not think that this diagnosis was accurate. The CPN could see no symptoms which would lead to this diagnosis. She suggested that in fact Ms E was coping very well given the circumstances she found herself in. She thought Ms E was resourceful and when she needed treatment or resources would initiate contact herself.

The CPN indicated that Ms E's physical problem was her weight loss and suggested that any problems she is experiencing are directly linked to the brother's behaviours. The CPN conceptualised this problem at the family level and indicated that there were a range of dynamics which revolved around the brother. Self-neglect was not about physical problems but was a psychological phenomenon from which the more obvious physical problems emerged. This psychological perspective of self-neglect seemed to indicate that self-neglect was the failure to care for oneself due to having to devote psychological resources to care for other family members.

In-spite of the family level focus the CPN reported that any goal of treatment must involve the brother being removed to hospital and to minimise any guilt felt by the family which would stem from this solution. She felt frustrated at the family's unwillingness to grasp this fact and was frustrated at providing support in a situation which does not change. The CPN suggested that the DNs do not provide anything different from what she provided and believed that they should be the key workers as a result of the relationship they had built up with family. The CPN reported her role was to provide psychological support in the form of listening to the family and she also felt that the Social Work Department had handled this problem very poorly and that they were not "pulling their weight".

The CPN reported that the provision of a house had been a major success but that the family's reluctance to have outsiders interfere with family matters prevented the real roots of the problem being tackled. The CPN also suggested that the extended family had "wiped their hands" of Ms E. She thinks that the relationship between the mother, Ms E and the brother is a caring one in which they are prepared to sacrifice their own comforts for the sake of others.

4.6.2.1 **Within-Case Analysis**

The DNs described Ms E's self-neglect as a failure to eat properly and consequent weight loss, smoking and the general state of untidiness about the house. The DNs thought that many of Ms E's problems related to self-neglect were directly attributable to the circumstances she found herself in. Specifically self-neglect in this instance was reported to have been caused by the brother's extreme obsessive-compulsive behaviour. The problem was rooted in the family situation although the GP, according to the family, did not believe the problems created by the brother were all that bad. There appeared to be an overtone of value judgement about this family. They were an ex-travelling family and this possibly coloured opinions about their lifestyle and values. Johnson and Adams (1996) suggest that perceptions of self-neglect may be influenced by the social class of the professional and/or the person being categorised as self-neglectful. Orem (1991) also suggests that self-care behaviours and the relationship between patient and nurse are influenced by social status.

One DN diagnosed the problem of ineffective family coping whilst the CPN reported that the family and Ms E in particular were coping very well in the circumstances. Ms E was scored as having low levels of self-care agency and did not seem to put her own care as a high priority relative to that of her family. The paradox is that her capacity to care for others, in what were very trying circumstances, appeared very high. Nevertheless although she acknowledged that she had not looked after herself as well as she could have Ms E did not see herself as self-neglectful. The relationship between self-care ability and the care-giving burden is described by Schott-Baer (1989). Schott-Baer argues that family traditions may have negative impact on female family members. The implication is that females may have a particular role in relation to care-giving which has a detrimental influence on them. The conflict between family duties and personal need is illustrated in the comment that family members must on occasion make choices between the value they put on meeting the care demands of family members and the value they place on their own self-care (Schott-Baer 1989)

Schott-Baer (1989) conceptualised care-giving for others as a Basic Conditioning Factor. Orem (1991) also proposed that self-care ability may be adversely affected by caring for another. Orem (1995) outlines a number of factors which limit an individual's capacity to engage in self care. In the case of Ms E these may include

Family members' or others' deliberate interferences with the performance of the courses of action necessary for individuals to know and meet their therapeutic self-care demands (p239)

and

Patterns of personal or family living that restrict engagement in self-care operations (p239)

There may be an issue related to the set of values held by an ex-travelling family in which primary emphasis is placed on the integrity of the family and a mistrust of others. Kornblum and Lichter (1972) identified three themes in their study of USA Gypsy family culture. These themes included the need to maintain the family integrity at all costs. Leininger (1987) in her study of European Gypsies identified a number of cultural values which again included maintaining strong kinship ties and a mistrust of outsiders. Sutherland (1975) found that gypsy families were aware of prejudice against them and this resulted putting up barriers against the outside world. Whilst the family in this particular case were not gypsies but were ex-travelling people they still demonstrated values which were similar to those found in studies of gypsies.

The mother seemed to be the key decision maker and Ms E may be torn between her duty to the family and the need to care for herself. Ms E seemed very passive and accepted the role of carer to the family although her actions since getting her own house would indicate that she can exercise some degree of control over her life. It may be difficult for Ms E to distinguish between her needs and the family needs.

It was difficult for the DNs and the CPN to perceive any clear-cut relationship between the diagnosis of schizophrenia and self-neglect. This is not consistent with Ungvari and Hantz's (1991a) position that in the case of secondary self-neglect there is an obvious relationship between major mental illness and self-neglect. Seligman's Theory of Learned Helplessness (1975) offers another possible explanation for Ms E's self-neglect. Seligman proposes that Learned Helplessness may limit an individual's ability to care for themselves. Learned Helplessness may explain why individuals do not use self-care abilities even when they outwardly appear to have sufficient self-care resources. Individuals who come to see no relationship between their actions and any consequences may learn not to use any innate capacity to care for self. The proposed relationship between self-care agency, learned helplessness and self-neglect is one which may be worthy of further study.

The treatment which Ms E was offered comprised of tranquillisers and occasional visits from the CPN and the DNs. The DNs feel that the family reject help, whilst the family feel that the social and health

services do not offer help when it is needed. Anderson and Tighe (1973) found that nursing and medical care post-discharge for travelling families was not satisfactory. In addition the services are fragmented inasmuch as different family members may be cared for by different people. There is a sense in which the family were not treated as a unit. This is reflected in the CPN's goal to have the brother admitted to hospital in-spite of the family having rejected such an option. There is some confusion and tensions about which type of community nurse should accept responsibility for caring for Ms E.

Treatment and prognosis were characterised by a lack of direction and a feeling of hopelessness. This sense of therapeutic nihilism was held by all involved and Ms E had also detected that professional carers felt this way. The CPN takes a very psychological approach to the problem and how it should be responded to, the social work services a material approach and the DNs feel that they have little or no role to play in this situation. One DN described success in broad terms such as improved quality of life and independence. Ms E had a much more limited and practical definition of success which was the ability to visit the toilet when she felt the need.

The family and the DNs reported that there were extensive social support networks available to this family. The CPN adopted a different view to the DNs when she suggested that the family had washed their hands of Ms E. There was a feeling that the family relationships and values had both positive and negative affects. On the positive side the

family cared for one another and provided material assistance. On the debit side the burden of caring was seen to be the single biggest factor in Ms E's self-neglect. In fact one could claim that the self-neglect in this case was characterised by caring for others to the detriment of caring for oneself. The family orientated values of this family may be rooted in their travelling background. The family were reluctant to accept what they may see as interference in their affairs and take services on their terms. Broadhead et al (1989) argue that although social support may be a protective buffer the qualitative elements of support should be distinguished from the quantitative aspects. Therefore although Ms E had a large number of family members living in close vicinity this does necessary mean that she is receiving adequate social support. It is the qualitative aspects of social support, such as emotional support, that Broadhead et al (1989) believe are the most important.

4.6.3 **Mrs S**

Biographical Details

Age - 67 years

Occupation - Retired Housewife

Medical Diagnoses - Schizophrenia; Arthritis; Anxiety Neurosis; Diverticulitis; Chronic Obstructive Airways Disease; Peripheral Vascular Disease

Index of Independence in Activities of Daily Living - Category A (Independent)

ASA-B Scale - 65

Background Information

Mrs S lived in a mid-terraced council-owned house in a relatively deprived area. The lady had lived all her life in this area and was part of a well known family. The family are somewhat notorious and sections of the family were travelling people who were housed in the town over 20 years ago. The house appeared untidy, as did Mr S herself. There were clothes drying on wall heaters and there was loud music coming from both upstairs and downstairs rooms. The dining room was the exception as this was full of memorabilia and was very tidy and neat.

The District Nurse's Perspective

The DN indicated that Mrs S's self-neglect was linked to a lifestyle which involved periods of excessive drinking during which times she experienced a number of other problems. These problems included domestic violence, household fires and other potential safety risks

She drinks. Sometimes gets drunk and has accidents, like maybe scalding herself with a cigarette. Things and like, well, she'll lie in the chair all night and get a bit negligent. This doesn't happen all the time but it happens fairly frequently. She smokes heavily and in a way she's obsessed with her health, because she complains of constipation, bowel problems, urinary problems and she produces specimens for both of us

to test and there's nothing. There's nothing there, she just seems to think that she's unwell when she's not. The house is very unkempt, she's unkempt.

The DN reported that self-neglect in this case was characterised by periods of self-neglect and periods in which she looked after herself a little better. Other aspects of her self-neglect which the DN suggests were constant included the untidy nature of her house

Its really full of furniture....sorts of old bits of furniture, clothing sometimes you can't get up the stairs for the pile of clothing at the foot of the stairs. Well it's not tidy it's untidy. Possibly dirty and untidy...it's the sort of situation for you to see to think she does neglect herself.

The DN did suggest that Mrs S's personal hygiene was not that bad and that she did take regular baths. In addition Mrs S also managed her faecal incontinence very well and received minimal input from health services, in fact only receiving pads. The DN described Mrs S as looking "hard" and wizen, features which she felt reflected her particular lifestyle. The DN clearly suggested that Mrs S was happy with her lifestyle, including the self-neglecting elements. In fact Mrs S appeared to find her lifestyle desirable.

The diagnosis of schizophrenia was mentioned by the DN but she reported that Mrs S did not show any symptoms or signs that were

associated with this major mental illness. The "biggest problem" was Mrs S's preoccupation with her health problems which she believed were becoming worse. Mrs S would phone the GP or the nurses and describe a catalogue of complaints which the DN thought did not exist. The issue of her wish to continue to be prescribed Dihydrocodeine when she did not need it was a constant theme

She was on it and Dr X felt that she didn't need I....I don't know why she was on it. But she didn't take kindly to being taken off it. She felt she needed that. She felt better on it so she's back on it again, but she was off it for a long time.

The DN regarded her relationship with Mrs S as a very good one which did not require a conscious approach but had developed naturally. She also reported that Mrs S managed her medication "okay" and could not abuse this because she only received enough to last a short period of time. The major demand placed on the health services was the demands she placed on the GP

She's well known to the doctors...she's often dissatisfied with the results she gets. She is on Dihydrocodiene and now she was taken off that.....she nearly drove us up the wall until she was put back on Dihydrocodiene. ...I mean she has lifted the phone to the Health Board to complain about the service she gets from the doctors.

The DN did not believe that the role of District Nurses with this lady was very extensive and consisted of a monthly visit and "physical nursing" such as wound dressings. The DN believed that she did not really help Mrs S with incontinence but that the real value was just listening to Mrs S. She felt that she was simply listening to the lady in order that this

keeps her off your back for a while and away from the GPs for a while. The attention she gets seems to keep her happy for a while.....we don't help her bladder, we don't help her bowels and it must just be a bit of attention. She seems quite happy for us to go and sit and listen to her and say 'Oh yes, you'll be all right. We'll call again soon'.

Success in terms of treatment would be to

Leave her as she is. Because that's the only way she'll be happy and being happy is more important than being safe. You know I think it's more important to be happy and be at risk than to be perfectly safe and not happy.

The DN painted a picture of this lady as belonging to a family with a difficult history. The relationship with her late husband vacillated from being friends to violent quarrels which frequently involved the police. The son also has an alcohol problem and much of the extended family

have alcohol and other social problems. The family constantly "fall in and out.. and then they'll make up".

The DN thinks that the family support network is such that Mrs S provides more support for the family than they provide for her

Well I think sometimes she gives them money..... She won money at the bingo and she just seemed to have a bit money about her so she used to give them money. She took one or two of them on holiday in a caravan.

The DN reported that Mrs S has friends who she meets in the local pub, a pub which is regarded as the least desirable in the town. She knows many people of all age groups and they all tend to buy her drinks.

The Community Psychiatric Nurse's Perspective

Mrs S was referred by her GP to the CPN on the basis of her on-going anxiety. The CPN said that her role was to administer a tranquilliser injection to Mrs S. The CPN also stated she did not know a great deal of about this lady's psychiatric history and had not consulted her past case notes. She stated

I am not sure what the problem is. I mean I was just asked to go in and administer this depot and I suppose to monitor the effects that it was having on her.

The CPN did not think that the diagnosis of burnt-out schizophrenia could be applied to this lady as she appeared not to have any symptoms that would be expected if this were the case. When asked what the problems were she replied

I didn't see anything wrong with her to be honest. You know I really didn't see anything wrong with her. She maybe doesn't live the way I live, but I mean I go into hundreds of houses and we all live differently. I mean she's an elderly lady who likes her smoke and got up when she liked. I mean I felt that it was all a bit chaotic maybe in the sense that she was getting up in the middle of the day and up all night sort of thing. But then that's how things worked out for her...She seems no different from an awful lot of people.

The CPN stated that Mrs S's lifestyle may not fit the norm but that did not constitute a health or social problem. In fact the CPN saw this lifestyle as a legitimate choice and was no different from many other people. The CPN also disagreed with the GP and DN when suggesting that Mrs S's house may have been cluttered but was not dirty.

The CPN saw her role as administering and monitoring the tranquilliser injection. She regarded Mrs S's claim that she did not want a tranquilliser injection to be reasonable and one which agreed with. She thought Mrs S wanted to be "in control". The decision to prescribe the injection puzzled the CPN

The reason for Dr X maybe trying her on some Clopixol to see if it would settle her. Because if she is constantly going back and forward to the GP's surgery it's like she's seeking reassurance all the time that she's all right. Maybe he thought it would settle her. It has not worked in the sense that she just feels it was making her drowsy. She didn't like that but I just wondered what was meant to be wrong with you. No doubt she's had problems in the past but she presented to me as being all right. If that make sense.

According to the CPN Mrs S got "quite a bit of support" from her son and daughter. This, in her experience, was unusual as most of her other patients did not receive the amount of support that Mrs S received.

The General Practitioner's Perspective

The GP didn't seem to think that Mrs S was neglectful to any great extent. If she was self-neglecting, he suggested, it was only in a "minor way". He described her domestic situation as

The house is filthy, as you probably know. There are cigarette burns over the bed sheets. The bed is manky. I don't know whether you noticed that usually the radio, the telly upstairs, they're all on. They're all on for noise, you know it is. I mean that's a psychiatric thing. I mean that's not normal.

The GP also used the phrase "*its not normal*" to describe how he felt about the fact that Mrs S had on occasion spent the night in the police cells after a particularly troubled incident. The GP did not think that the daughter was supportive to Mrs S even after he had explained the situation to the daughter. When asked about the extent to which Mrs S was self-neglecting he replied

I think that she's someone who has had a fairly hard life. I mean her husband had died from..cancer of the lung...I think they used to fight. Her notes are full of minor assaults and things....she's got a daughter who is a drug addict...but certainly the whole social set up is a nightmare. She had another, I think it was a nephew came in about a year ago, he kicked the door in and went up the stairs and got into bed with her. Now it never got any further than that but that's the sort of set up...It would seem that the family are not the nicest of people.

The GP described her problems in terms of medical history and in terms of how her problems impacted on his practice. The medical history of Mrs S was given as

A really long medical history particularly the psychiatric. In 1956 she was receiving psychiatric treatment in hospital for a neurosis about cancer. She had a number of different diagnoses over the following years such as anxiety neurosis, psychopathic personality, alcohol abuse. She had taken an overdose.....20 years later she was diagnosed as having paranoid schizophrenia.

The GP also listed the range of other physical problems that this lady had experienced over the last few years. These problems included severe peripheral vascular disease, chronic obstructive airways disease, angina and arthritis of the spine. When asked to say what her main problem was the GP replied that although she had all these other physical problems, anxiety about her illnesses was the main problem. The GP felt that it was often difficult to understand the exact nature of Mrs S's difficulties

...very, very difficult and it's very much with this lady it's a sort of cry wolf situation where whenever we hear her on the phone we think `what is it now?'. There will be nothing wrong with her nine times out of ten. At least nine times out of ten there is nothing in particular. She complains about backache. She gets all the backache drugs. She's dissatisfied,

she's dissatisfied with her bowels, she's lost the power of her legs, she's dissatisfied with everything and it just goes round in circles really.

The problem of compliance was evident in the GP's claim that Mrs S's smoking was a real problem in the light of her vascular diseases. He had never been able to persuade her to stop and had given up trying. When asked if she was in fact non-compliant he stated

Yes. She had hormone replacement therapy. I mean she's just too dizzy really if you like. She was given hormone replacement and took it on and off and I just stopped it, really because she wasn't taking drugs appropriately and the same thing with her, she had Dihydrocodiene, an addictive, abusable drug, and I stopped it because she was taking six at once and that sort of thing and really in the last years she's been moaning at me for four or five years to get this drug again. Eventually I gave in and she's back on it but she's not happier. She says that herself.

The GP indicated that there was a constant battle with this lady between what she wanted in terms of treatment and what he judged was needed. He described this as a real compromise. The GP was exasperated in the extreme with Mrs S's constant demands for treatment and referral to specialists

She's seen everybody. She's seen the rehabilitation department, the physiotherapist. She's seen everybody she could possibly see and its unusual for somebody with purely physical disease to keep going on about things that long. I think people come to accept some degree of disability or some degree of pain.... I think most people learn to accept that and cope with it but this lady doesn't.

When asked about the prognosis for Mrs S the GP commented that things would not change and that in one years time he would find himself dealing with same problems. He felt depressed about this and indicated that the fact that Mrs S was seen on 38 occasions last year was evidence of why he should feel like that. He would define success in treating this lady in terms of her being able to look after problems herself and to only consult him for major problems. He indicated that success would be a reduction in the number of attendances at the practice per year. If these could be reduced he could argue that she would be looking after herself better. He recognised that these criteria were "quite selfish".

<u>The Patient's Perspective</u>

When asked to describe herself Mrs S suggested that listening to music was very important to her

Quite easy going. I like music and am quite happy in the home and if I'm on my own. But I love music and that's the only company I have. I do like the music and that. I do read the papers.

Mrs S told how she had a history of being admitted to the local psychiatric hospital. The first admission to psychiatric hospital came soon after her brother died of cancer of the spine. She believes that her problems are directly related to her physical illnesses

Terrible. I haven't been very good since months. Its all put down to arthritis. I don't know. I seem to have it in my hands, neck the spine. I got that injection about three months ago, and then I had the flu, and I had a chesty, glandy infection or something.

and

I mean sometimes I'm in an awful lot of pain and as I say this tiredness I've been having lately, its been worrying me. It only stands to reason I'm bound to worry if there's something different everyday.

She thought that the GP's claim that she was suffering from mental health problems was wrong

I mean I know myself that there's nothing like depression or anything its wrong with me. If there's anything wrong wi me my health that's causing it, not worry and nerves.

Household tasks such as cooking, bathing and washing were not a problem for her and she managed these fine within the limitations of her illnesses. She saw herself as a very resourceful person who in-spite of her many health and other problems was coping well. She stated that "*I'm seasoned to that. I just take it as it comes*"

She seemed to have knowledge of the range of services available to her and accessed those she needed. She attended senior citizens groups in the local community centre and elderly support groups run by voluntary agencies. She had a home-help at one time and had recently just had an application for income support turned down by DSS. The DN visited her to deliver pads but the mainstay of treatment in her eyes seemed to be the GP. She acknowledged she visited the GP very regularly but did not see that as a problem although she hinted that the GP might be becoming fed up with her. She disagreed with the GP's diagnosis of anxiety and did not think that the treatment he prescribed was needed. She explicitly told the GP, DN and CPN that she did not want the tranquilliser injection and hinted that this prescription may be in response to her demands on the GP's time. When asked about the treatment she was receiving from the GP she could not really understand why she had been prescribed the tranquilliser injection

He said it was because of my illnesses. That...it was for the, more or less for to ease tensions and that...I don't know what he meant by it. I said to him `well my nerves is not bothering me' but I think it was sending to them and that they thought I was worrying over my sickness.....I mean you need to check with the nurse or Dr X what they're saying about me but as far as I'm concerned I got it because I was sending for them. They thought that would be worrying over my sickness.

Mrs S came from a travelling background. She would travel around Scotland in her younger days selling items. She really liked this lifestyle and still occasionally travelled with one of her daughters who still followed this lifestyle. Mrs S described a wide and varied support network. It was clear she knew many people in the area and had a large number of relatives living close by. She saw at least one family member each week and described the family situation as being

We were very close. We were always close but I don't think they, I feel the closeness has gone now that my husband's away. You know I don't think they can stick the thought of coming here and at one time my daughter wouldn't come. She brought the car to the back gate...and she wouldn't go through the kitchen because of her father's memory.

Her brother, sister and husband had all died of cancer and this seemed to be an issue that was frequently mentioned during the interview. The daughter also had a hysterectomy as a result of cancer and had some time later committed suicide. The social network seemed to be intergenerational and included the couple who run the local pub that she frequented. She would visit the pub and sometimes just sit and read the paper and would chat to some of her many friends who also frequented the pub. If she required any groceries she would phone the pub and they would get a customer to come up to the house and run any errand

There's a chappie stays down the road and he goes to the pub and he does odd messages for them. So they used to send him if I needed the shop or anything and if he wasn't there and I was needing the chemist or anything they would send some of the boys up.

Mrs S suggested that she was coping well and described how she managed the faecal incontinence she was experiencing. She also suggested that she was able to comply with her prescribed medication regime. When asked if she found it difficult to take all the tablets she was prescribed she stated that "*no, I'm well seasoned to them now, I've been you know, well seasoned to them*". She viewed herself as someone who had managed reasonably well with her problems and was "*quite satisfied myself the length I've came*". There was a sense of resignation when she stated that there was nothing more could be done for her.

She believed that the GP also shared this view "*he seems to say that he knows I'm an old woman but they've done all they can for me*".

4.6.3.1 **Within-Case Analysis**

There were differences in participants' perspectives with respect to self-neglect. The DN did think that this was a case of self-neglect. This was characterised by periodic episodes linked to alcohol intake. MacMillan and Shaw (1966) found that in a third of cases of serious self-neglect there was suspected or confirmed heavy alcohol intake. The DN implied that Mrs S's social background was linked to her lifestyle and consequently to her self-neglect. The features of self-neglect for the DN related to alcohol abuse, risk of accidents when under the influence of alcohol, an untidy house and personal appearance.

In contrast the CPN reported that, whilst there may be an element of self-neglect, the housing and lifestyle of this lady was acceptable and was little different from many people she has had to care for and her house was not in fact dirty but simply a little cluttered. Mrs S might have a chaotic lifestyle but this was not really a problem as such. The CPN did not really know what the problem was. The GP thought that Mrs S was self-neglectful but that was not her major problem, which he indicated was her anxiety. This anxiety was manifested in her constant demands on the GP practice for consultations and to be prescribed medication of her preference. Gallop et al (1993) found that medical and nursing staff had different perceptions of difficult to treat

patients and that these were linked to the specific characteristics which differed between medical and nursing staff. The most significant characteristics which influenced medical staffs' perception was related to the use and responses of patients to medication. Therefore the GP's perceptions of the problem may arise from her constant demands to be prescribed medication that the GP did not feel was needed.

Again there was a sense in which the GP may have found it difficult to empathise with Mrs S due to a social class barrier. The difference in perceptions is highlighted when the GP states that her constant playing of music, often from more than one source, was not normal and was a sign of mental illness. Mrs S on the other hand told how her one great source of enjoyment was music, she loved music playing at all times. Mrs S herself did not think she was self-neglectful in the least. Her lifestyle was one she was happy with and her problem was her many physical health problems. This divergence of perceptions presents a problem for Orem (1995). On the one hand Orem admonishes nurses, and presumably other health care professionals, to take cognisance of the patient's perspective but on the other hand

> *The reality that is the world of the nurse must be accepted as a world mediated by meaning. In nursing however, meaning must be attached to persons, things, events, conditions, and circumstances in terms of how they affect the actions nurses perform in designing and producing nursing care* (p4).

The logical extension of this contention is that the GP who defined Mrs S' problem in the light of how it affected him was correct in-spite of the fact that this ran counter to her perception of the problem and her views on the appropriateness of requiring her to accept a major tranquilliser injection.

The DN and CPN reported that Mrs S's behaviour was intentional in the sense that she had chosen a particular way of living her life. The GP implied that her mental illness may have reduced the capacity make choices and that people from a particular family background were predisposed to leading a particular lifestyle. There was no clear relationship between mental illness and self-neglect and in fact there was no professional consensus that she was suffering a specific mental illness. The perceived lack of a clearcut relationship between mental illness and self-neglect is further disconfirming evidence of Ungvari and Hantz's (1991a) notion of secondary self-neglect.

There were also different perceptions on the extent to which Mrs S complied with her treatment and the extent to which she was able to cope with her problems. The GP reported that not only was Mrs S non-compliant in respect to her medication but that she was too irresponsible to manage her drugs and was even abusing some. Mrs S thought she was capable of managing her medication regime. The CPN suggested that her decision to request stopping her tranquilliser

injection was perfectly reasonable and was not usually the case with the type of client she cared for.

There seemed to be no clear treatment plan for this lady. Practitioners seemed to respond to problems as they arise. The main issue at the time of data collection was the recent prescription of a tranquillising injection. The patient did not wish to continue with this treatment and there was a sense in which the injection was a response to her contacts with the GP practice. Much of the social and support services that the lady had access to were initiated by herself and not by professional carers. The DN's role seemed consist of supervisory-pastoral visits which were disguised by claiming the reason for visiting was to deliver incontinence pads. There was an all pervading sense of pessimism regarding treatment and prognosis with the belief expressed by all participants that Mrs S's situation will not change. Success for the DN was to leave her as she was and the GP defined success in terms of reducing the demands placed on him.

Mrs S had a wide range of social networks to draw on. Although she had a large family network in the area the main focus of her network was the local pub and its clientele. The pub was a place where she would drink, visit to socialise and meet friends and also a source of practical assistance. It can be argued that although the family network may look impressive in quantitative terms it offered little in the way of functional support. Functional support was provided by the informal network which had the local pub as its focus.

Mrs S's family background was very troubled and her lifestyle was very different from the professionals who provide care for her. It may be the case that the lifestyle or social class divergence between Mrs S and her GP and DN colour opinions as to her problem. This view is consistent with Orem's (1991) proposition that social status influences a nurse's interaction with a patient. Trexler (1996) describes how difficult patients who exhibit characteristics outwith the expected norms are likely to be judged as deviant. Kelly and May (1982), in their review of the literature on good and bad patients, contend that there is evidence suggesting that patients are treated differently according to their social class, appearance and behaviour.

4.6.4 **Miss D**

Biographical Details

Age - 59 years

Marital Status - Single

Accommodation - Council-owned flat

Occupation - Legal secretary

Medical Diagnosis - Varicose Ulcer, Diabetes Mellitus

Nursing Diagnosis - Impaired tissue integrity, Knowledge deficit

Index of Independence in Activities of Daily Living Scale - Category B (Required assistance with bathing)

ASA-B Scale - 57

Background Information

This lady resides in a small village in a very rural setting. She lives on her own in a one-bedroom first-storey council owned flat. Her house was exceptionally tidy and welcoming. It was obvious that Ms D took a great pride in her house and put a lot of work into keeping it tidy. She was born and brought up in the general area and had moved to that particular village 30 years previously. During this time she had worked for the same small legal firm and she obviously valued this work. She

was active in the life of the community but did not socialise outwith a small group of friends.

The District Nurse's Perspective

According to the DN Mrs D was a very likeable lady who was well known in the village. She was described as a woman who was very obese, diabetic, her toenails were like "talons" and she had a varicose ulcer. The DN also reported how Ms D had neglected her teeth to the extent that they were falling out and those which were left required to be extracted in hospital.

Ms D first came to the attention of the DN, in a professional sense, after the shop assistant in the local chemist told the DN about Ms D buying lots of bandages. Some time later the DN was required to visit Ms D to treat her varicose ulcer which by this stage had become potentially serious. The DN described how she had observed that "*I mean her legs were stinking and weeping but the house was always immaculate*". When the DN first visited Ms D she found that she was treating the varicose ulcer herself and had been for many months. She was reluctant to have the GP contacted and involved. The DN was under the impression that she would rather have the DN speak to the GP that speak to him herself. The DN took the decision to treat the ulcers and at the same time begin to develop a trusting relationship

When we first met her she wasn't keen to have the doctor to come in and see her legs at all. The ulcers covered, I mean both legs and were really

quite deep and we couldn't immediately get the doctor in to see her legs. We had to try and dress them ourselves for a few weeks until we built up her trust with us and then she eventually allowed one of the GPs to come and see her. Again he would normally have admitted somebody to hospital straight away but her feelings were so strong against going to hospital.

The DN still had concerns that although Ms D was now more amenable to seeking medical services there was still the problem that she did not seem to take up any preventative self-care actions. In Ms D's case this meant that

I'm just a bit disappointed about breast screening. ..you know I was a bit concerned about in one way I know I'm saying that I feel she would get in touch with the medical you know if she has any problems now but it might be on her assessment of how serious. You know she thought she maybe had a terminal illness. I don't know if she would get in touch with us....

The DN was sure that Ms D was complying with her treatment regimes, including the dietary aspects. She reported that Ms D was sticking "rigidly" to her diet apart from the occasional Saturday night treat. The DN also reported that Ms D was very pleased with herself for having lost around five stones in weight. When asked what she meant by self-neglect she replied that this referred to "*somebody that knows there's available treatment but just doesn't take it up for whatever reason*". There were a number of possible reasons for this such as fear of the

unknown, lack of finance, being scared of investigations and the feeling that what you don't know will not hurt you.

The DN defined success as

Well now she would go and see the doctor if she had any problems and I said to her the other day I wish we had photograph of her....and now she's got like she's got her teeth in and she's lost a little weight.....and she looks a lot happier in herself.

This lady is well known in the village as she is involved in a variety of local council matters. She has a close network of two or three friends who have been

...been very supportive about her diet and they were quite concerned about her you know prior to us starting dressing her legs. But they knew they couldn't really go behind her back and see anybody. She wouldn't trust them again if they'd gone to the doctor or anybody.

The DN reported that Ms D did not socialise outwith this small group of friends and had no other interests outside her community work. She was though a very friendly and likeable person.

<u>The General Practitioner's Perspective</u>

The GP had not seen this lady on many occasions in the past and he stated she was a non-attender. She had not had a consultation

between 1959 and 1983, and between late 1983 and 1993. Ms D was described by the GP as

A frightened elderly spinster who wants to get on with her life and not having people faffing around her. A woman who is totally scared to go into hospital or institution for fear of what may happen to her and someone who is quite happy to live her own life and get on with her job.....

The GP seemed reluctant to categorise this lady in any way but conceded that it would be fair to say that to the extent that she did not look after aspects of her health she was self-neglecting. He suggested that self-neglect in this case was the fact that the lady was aware of her teeth and ulcer problems but chose not to seek help. He was not sure that this desire to look after oneself was a bad thing and most cases are "by definition" not known to GPs and in fact it was usually a desirable attribute

I mean its probably quite true that she neglects her health. As I said to begin with lots of people have health problems they tend to try and deal with themselves for lots of different reasons. I suppose she was neglectful of her health, or, its quite normal for people to be optimistic and hope its going to go away. That's part of human nature and I'm not going to rush in and intervene before I'm asked..... There are lots of people out there who are quite happily neglecting themselves and hope that all is going to go away. I've enough to do with all the people that come in and see me without all the others.

He believed that self-neglect in this sense may be a common problem but was not of primary concern to him. He offered the suggestion that she might be someone who was "*wilfully neglecting herself*". He claimed that her non-attendance and lack of health-related self-care may be as a result of some phobia about medical professionals.

The GP was very insistent in the view that general practice was about compromise and that the balance of responsibility should favour the patient. It is the patient's responsibility to seek medical intervention when they think it necessary

I mean lots of folks keep their business to themselves and quite rightly to. I think there are various reasons which make them seek their dentist or doctor's advice.....It's her choice and it's totally up to her. Maybe the GP, he may have grounds for intervening surreptitiously...but I strongly resist that...I believe in patient's rights. In this instance to treat or maltreat, mistreat or neglect themselves. But maybe there are limits to be drawn.

The GP did think that perhaps Ms D was an extreme case and by implication had gone over the limits of what could be accepted as normal. In fact he related how Ms D's teeth had been surgically extracted by "devious means". He did not elaborate on what exactly was meant by this. The need to compromise is highlighted in the statement that

And there is lots of compromise in practice. The more you are in practice the more you realise the more one compromises and realises that ideals are not always achieved. Of course her particular case the consideration is that if we harp on too much about her obesity she will reject us and disengage and go away with her diabetes and get problems with it. So I think from ensuring that we have communication with her some sort of give and take is necessary.

The priority for the GP was to keep communication channels open and to develop a good relationship in order that he could "*know the score*". This was given primacy over sorting out the problems. Ms D was now "*doing really well and complying and her blood test would tend to substantiate that*". She also attended for her regular appointments at the diabetic clinic and was complying to the extent that the GP saw Ms D as a changed woman.

The GP had spent all his practising life in this small village and was sure that there were factors linked to support networks which were unique to such a setting. He told how these networks operated and how such an informal network had first brought Ms D to the attention of health professionals

I maybe said that we did know about her for a while from various folks in the village. A small village and for example anybody that goes into the chemists three times a week and buys lots of bandages for a varicose ulcer, and the chemist says to them you should see a doctor and they

say 'Oh no', but that sort of word gets round. These sorts of things are known about but that it's always the patient's prerogative when to decide to seek medical advice.

Success was not a clear cut notion and was a balance of minuses and plusses. In this case the plusses were her improvements in wound healing, having her teeth extracted and having her diabetes diagnosed and monitored. On the minus side she will never eat according to dietary advice but on balance there were more plusses than minuses.

The Patient's Perspective

This lady told how she had not had contact with her GP for 20/25 years. Any health problem she had during this time she treated herself. Ms D told how she presented to the District Nurse on this occasion as a result of her varicose ulcer. She had been treating this wound herself from July to the following February. She had been experiencing a great deal of pain, sleeplessness and incapacity as a consequence of the wound worsening. At one stage she believed that the terrible smell indicated that her leg was now gangrenous

Well as I say they started last July. A year last July and I didn't go to the doctor about them. I was attending them myself with sterile dressings because I am afraid I didn't like doctors. ...I just had to get the doctor in at the last minute because my leg was right up there. It was all septic.....

The problem with her leg ulcers had become very severe before treatment was initiated

Well in fact the girls at the office were telling me 'you should go to the doctor, Get the doctor because' ...I could hardly walk down the road with the pain in my leg and when I came up the stair I thought I can't stand this anymore. So the next morning when I got up and the first thing I did was phone the surgery and just asked if I could have the District Nurse to come down and dress a leg ulcer.

When asked why she did not seek treatment sooner she suggested that she had a phobia about doctors. This notion of phobia seems to have stemmed from a consultant who told her she had the 3-D phobia (doctors, dentists, dieticians). The idea of a phobia was a recurrent theme during the interview. She suggested that her mother also had a similar problem.

One factor which seemed to figure strongly in her thoughts about treatment was the effect this would have on her job. She was anxious that her employers would not be very happy with an employee who required to take a lot of sicktime

I mean I hardly stayed off work with a cold or anything. You know I think even when Dr Y says to me we'll sign you off for six weeks I said "six weeks!".

One other recurrent problem is her diet. She told how she had been overweight since primary school and had been subject to sarcastic comments from other children. Her mother blamed her grandmother for this problem. She also told how when she was admitted to hospital 25 years ago they had put her on a very severe reducing diet which resulted in her discharging herself against medical advice. She thinks her weight bothers other people more than herself. She is quite happy with her weight and diet. It appeared that Ms D was averse to actively seek treatment on her own initiative but when she found herself in a programme of treatment she complied willingly.

She also has recently had problems with her teeth. She had been for treatment and check-ups in the past but had

Never bothered after that and my teeth started falling out and I didn't bother about it...I had not problems with them, they just seemed to fall out and they broke and I left it as it was.....

She was very happy with the fact that she had had all her teeth removed. A similar problem was recently encountered when she found herself having to drink lots of liquid. She told how she would go into the supermarket and she would purchase cans of juice which she would drink before reaching the check-out. This and other symptoms were experienced for six or seven months and were only diagnosed when she was being treated for her leg ulcers. Prior to a diagnosis being confirmed she thought that she had diabetes but still did not seek medical help. She offered no reason for not seeking help. She

rejected the offer of a home help as she had plenty of spare time and enjoyed her household duties. There would be nothing for her to do if someone came in and did these chores.

Ms D had lived in the village for many years and had become a well known figure. The village had a changed in recent years and did not appear to be the cohesive place in once was

Its kind of changed now. I don't know so many and I think the ones that you do know you tend to keep close to.

This small group of two or three friends was an important source of support for Ms D

they asked if I wanted to and I said no but my friends rallied round and they did my washing and ironing and they cooked an odd meal for me.....My colleague at work she phoned up in the morning to ask if I wanted anything. She came down with my papers and any milk or bread or anything that I wanted. Messages she came down with. My friend in (the next village) they used to cook meals for me, take them down and took away my washing for me so I was, I really can't complain.

4.6.4.1 **Within-Case Analysis**

The professionals defined self-neglect in terms of not seeking health care when problems occurred. The patient chose to care or not care for herself when the GP and DN thought that this was not appropriate and

she should have sought treatment from professional groups. The patient explained such behaviours as stemming from the fact that she had a phobia. This label was offered by a consultant physician. Subsequently the problem was constructed by the GP and Ms D in terms of phobias about health carers. Haralambos and Holborn (1991) describe how the labelling process can lead to a self-fulfilling prophecy when a person's self-concept is largely derived from the responses of others. This leads them to tend to see themselves in terms of the label. The consequence is the development of a self-fulfilling prophecy in which the deviant identification becomes the controlling one. The influence of psychiatric diagnoses on professional judgements of self-neglect will be investigated in stage three (Chapter 5).

Self-neglect was manifested by her refusal to seek help for serious ulcers, rotten teeth and diabetes. The GP and DN thought that she intentionally did not seek out help. This pattern characterises her self-neglect as far as the DN was concerned. The GP was not totally convinced that this was a problem. Although he conceded that Ms D was an extreme case he rejected the idea that self-neglect was the refusal to seek treatment when necessary. Gift et al (1997) describe cases of high levels of oral self-neglect in which they suggest that oral health should be conceptualised as part of general health. Other aspects of self-care such as hygiene, cooking and keeping the house tidy were carried out fastidiously by this lady. This distinction between neglect of health-related matters and neglect of household/personal hygiene is consistent with Orem's (1995) notion of health-deviation self-care requisites and universal self-care requisites. Orem (1991)

outlines six categories of health self-care deviation, two of which seem to have relevance to this case

> *Seeking and securing appropriate medical assistance in the event of exposure to specific physical or biological agents or environmental conditions associated with human pathological events and states....* (p201)

and

> *Being aware of and attending to the effects and results of pathological conditions and states, including effects on development...*(p 201)

Although it can be suggested that Mrs D did meet a third category of health-deviation self-care deficit which is to

> *Effectively carry out medically prescribed diagnostic, therapeutic, and rehabilitative measures directed to preventing specific types of pathology* (p 201).

Orem does not explain in her theory why some categories should be met and some not met by the same individual. This is an important limitation in the case of Ms D as she did not seek medical help willingly but when she had sought help she complied with treatment regimes faithfully. Additionally it is not clear in Orem's theories why someone would fail to meet one type of self-care requisites (Health) and not another (Universal). It may be suggested that the explanation lies in

the lack of adequacy or operability of SCA but this implies that SCA is hierarchically organised and differentially used. In essence when levels of SCA are inadequate certain self-care requisites are not met in order that others can be met. In this case SCA levels were adequate for universal self-care requisites and at least one health-deviation self-care requisite but were not adequate for other health-deviation self-care requisites. The very notion of a hierarchy may itself be a social construction which places greater value on some abilities/needs than others.

She had a small group of friends who provided much in the way of support. Nevertheless she was not a very gregarious lady and had little social contact outside this small group. The village culture was illustrated by the fact that the chemist was the person who first notified health care workers of her ulcer problem. This type of informal network may be feature of rural District Nurses' practice.

In terms of treatment the DN described how she consciously developed a relationship in which trust was explicitly developed. The need to develop a relationship, which is not necessarily an end in itself, but which allows other therapeutic factors to come into play is outlined by Orem (1991). The GP put the responsibility for seeking treatment on the patient. He did not feel that he had enough time to actively seek out patients who may be self-neglecting. The GP put a premium on passive surveillance and knowing that self-neglect was occurring in an individual rather than actively seeking out individuals who are self-neglecting. This position was a practical position in the sense that he

had a heavy workload to manage. This lady fully complied with treatment once initiated and managed her diabetes very well and attended follow up clinics. Her non-compliance appeared to revolve around taking preventative measures, one example of which was the refusal to attend local breast screening initiatives.

Success for the GP was a balance of minuses and plusses, which in this case favoured the plusses. He reported that giving her advice about her weight was on the minus side and should be avoided. The DN on the other hand thought that her weight loss was a measure of success. She also included the willingness to visit the GP for consultation without prompting as another measure of success.

4.6.5 **Mr W**

Biographical details

Age - 82

Marital Status - Divorced

Gender - Male

Occupation - Retired Local Government Legal Officer

Medical Diagnoses - Urinary Incontinence

Nursing Diagnoses - Altered Pattern of Urinary Elimination

Index of Independence in Activities of Daily Living Scale - Category B (Dependent in Continence)

ASA-B Score - 62

Background Information

This older man lived on his own in an owner-occupied house in a residential area of a relatively large town. He had lived in this town for 35 years, having moved from another area in the North of Scotland. He had moved to take up a post in the legal department of the Town Clerk's Office. He had lived on his own for some years since separating from his third wife. Mr W had been born and brought up in the North East of Scotland and had served in the navy during the second world war, in which he eventually commanded his own ship. After the war he returned to his legal work in local government. He had completed a law degree before the outbreak of war.

The house was a relatively older property which was obviously showing signs of being the worse for wear. In fact it first appeared to the researcher that nobody occupied this particular house. It gave all the appearances of a house which had began to structurally decay. On entering the house one was struck by the fact that there were no lights and that curtains were mostly drawn, in-spite of the fact that this was in the middle of the day. There were all manner of bric-a-brac on the floor of the entrance hall and the living room was extremely cluttered with dust covering everything, including a deep layer of dust on the mirror and walls. The floor was littered with old newspapers and a bag of scrap paper was sitting close by the 2-bar electric fire. He reported that he had the Observer and the Press and Journal newspapers delivered everyday. There was a television in the middle of the room which was switched on and Mr W was watching horse racing.

There was a bottle of urine on the floor and it seems he used this as he was finding it increasingly difficult to reach the toilet. Mr W sat in a chair, which also doubled as his bed as he spent his whole day in this room. He used an incontinence pad as a pillow. The wallpaper was brown and the impression was one of extreme squalor.

The Patient's Perspective

Mr W told how he was very aware that the house was very untidy and stated he did not hoover. He also stated that he had no interest in making any changes to his lifestyle as he was happy with the house the way it was. He told how he did not receive any visitors and also told how he was happy with that situation. He conceptualised his situation, not as self-neglect, but as having a painful foot which had limited his mobility. He was no longer able to go to the shop which was a short distance away and could not climb the stairs. He was not able to have a bath and at night slept in the chair. He expressed some anger at the possibility that "*officials*" would see at this as an excuse to meddle in his affairs

That's right, they think that this business of me sleeping in the chair is not right. I want to be the way I am. Just to be left alone.

He also accepted that his hygiene was not as good as some people would have wished for themselves

I don't have a bath or anything like that. I can't manage into the bath.

Mr W described himself as always having been something of a loner and preferring his own company. He did not want any visits from social or health-care workers as they were officials who would come in and tell him how he should lead his life. He included doctors and nurses in this category.

He felt that meals-on-wheels was an exception as this was a good arrangement. He was happy to accept this form of service and when the meals-on wheels person called during the interview Mr W had some brief but light conversation with her. He thought that he could be described as having been a healthy person for most of his life although in the last year or so he had began to experience more physical health problems. When asked about receiving a range of health and social services he replied that "*No, I don't want them*". It was the same response with taking medication, although it was interesting to note that he would take antibiotics. He refused to take any other medications as this was a "*slippery slope*" which he would resist as "*Oh I'm telling you I didn't want to get into the habit*".

He did not wish to say much about his family, apart from his daughter who lived some distance away. She seemed to be the only person who kept in contact. He was particularly scathing about his last wife and hinted that they had separated in acrimonious circumstances. He has a son from the marriage but he did not have any contact as the son chose to live with his mother rather than him. Mr W did not regret this

lack of contact and had no desire to see his son again. The only social contact that he has had over the last year, and even this had recently stopped, was with the people who owned the local corner shop. He knew them personally and would visit for a chat. The shopkeeper and his wife would also deliver food and other goods to his house when he was unable to carry these.

The General Practitioner's Perspective

The GP had known Mr W since the 1970s when they were golfing friends. The GP gave the impression that there was a small group of local middle class professional men who socialised together. He described Mr W as a very intelligent man who had a first class brain. The GP reported that Mr W was affluent and lived in a big substantial house and he was always well dressed and amiable within this small group. The GP admitted that Mr W had an awkward manner with other people, which members of the group knew how to handle. He stated that "*his bark was worse than his bite*".

Over the last 10 years or so Mr W had began to deteriorate to the extent that the GP had lost social contact with him. The GP reported that in retrospect Mr W had began to show signs of household deterioration at this time but he still remained immaculately turned out. He and the other men in the group tried to persuade Mr W to get his "*act together* "and do something about this, although these admonishments had no effect. Self-neglect, which at first manifested as neglect of the house, then began to extend to other parts of his life. He

then began to have less contact with this small group and the only time the GP now saw him was in a professional capacity.

The GP described his problem as "*refusing to accept professional help*". The phrase "*resistant to treatment*" seemed very important in the GP's perspective of the problem and was in fact used by the GP to classify Mr W's problem. He could not explain why this was happening but he did acknowledge that when his physical health was affected Mr W took advice and followed his treatment regime to the letter. He suggested that perhaps Mr W's failed marriages, especially the last marriage, might be the cause of the problem. He also suggested that no psychiatric illness was present but perhaps deep seated psychological factors related to his previous non-conforming personality may have some explanatory value. He thought that Mr W's self-neglect was intentional in that it was a choice he actively made. This is consistent with the active-choice hypothesis of self-neglect.

The GP believed that Mr W's problems could be prioritised as mobility followed by his refusal to want professional help. He thought that self-neglect to this extent was very unusual and was characterised by isolation and squalor. He was aware of the hygiene and household circumstances of this man and commented on how dirty Mr W's house was. The GP did appear genuinely puzzled with this case and was affected both in a professional and personal sense. It may have been the case that his views on the outcome of the case may have been linked to seeing a friend reach such an impasse.

The GP could offer no suggestions as to treatment for his self-neglect and even implied that this was not treatable when he indicated that the only hope was for Mr W to die a dignified death. He thought that it may be desirable for Mr W to die peacefully. He did think that his previous relationship had helped when dealing with Mr W and suggested that the DN had a good relationship with him.

At the time of the GP interview a crisis occurred in that Mr W's situation deteriorated after he had fallen. The GP now thought that his main problems related to his physical health. Mr W's daughter had been in contact with the GP and had expressed concern about Mr W and asked what could be done.

The District Nurse's Perspective

The DN offered the following general definition of self-neglect

I suppose just anyone who neglects either their health, just their general health, or the place where they are living to such an extent that it would affect their health, if their place they were living was so unhygienic or whatever. Anyone who doesn't take any interest at all in their personal appearance.

The DN reported that there were levels of self-neglect, with milder self-neglect consisting of not looking after one's health through actions such as smoking and a poor diet. The more serious forms of self-neglect were

Just somebody like this (Mr W), who doesn't care about their personal appearance or the place where they are living at all, who just lets everything go.

She described this particular situation as

For a start you just open the door and you go in and there is this huge phone book and last years and the year before and there's just all the junk mail that comes through is just thrown in a heap and you go into the sitting room and there's clothes. I don't even know, its an unbelievable house....The cobwebs, its like a film really. The cobwebs hanging down on the walls, its just amazing. I don't even know what's lying around, but just everything accumulates over the years, its never been moved, its never been touched.....The kitchen is awful. Although having said that I've seen him washing his dishes and he's quite particular about the cup being clean after he's used it. The cooker doesn't work at all. That was part of the problem with him not eating well.....because he couldn't even heat soup or anything like that.

The DN reported that Mr W was the most extreme case of self-neglect that she had ever come across. She suggested that his self-neglect could be understood as him not looking after his appearance and his living conditions. She also believed that this lifestyle was one which was chosen by Mr W

Well I can't say he's got no choice to his life. He does have a choice. I think he has chosen to live like this, although it may be that now, at this stage in his life, he would be less able to organise something. To sort out his house and sort out his things, but I think over the years he has let himself go. When he was fitter, when he could have done something about it he chose not to....Well I think he's mentally, he seems to be able to make his own decisions, he's not confused. He seems to know exactly what it is he wants.

The DN could not explain why Mr W neglected himself. She argued that he could afford to provide for himself and his old routine of a hotel meal everyday was given as evidence of his willingness to provide for himself when he chose to do so.

The DN had been visiting Mr W for around four years. These visits started when the DN service was required to provide incontinence pads for Mr W, after he had been diagnosed as being incontinent. This intervention had been successful and was no longer seen as a problem by the DN. She thought that he was coping well with this form of incontinence management. This pattern of compliance with prescribed treatment was also mentioned by the DN in connection with medication

You know at times he had a urine infection and he's got anti-biotics and he takes them regularly. I would say he does comply with anything like that. There was one time he had to get a dressing done and there was no problem with that.

Currently Mr W was receiving monthly visits from the DN. This arrangement was made by the DN team but the DN could give no rationale for these monthly visits

In think that generally people feel that if we didn't go there wouldn't be anyone else going....You know he's refused social workers and home care and anything like that. It just seems reasonable to go in once a month otherwise he's not on the telephone and he wouldn't contact a doctor or anybody that he might need unless things were really desperate.

Mr W was reluctant to accept any treatment or interventions apart from the DN and meals-on-wheels. The DN thought that this may, in part, be a response to the good nurse-patient relationship which had developed. She described him as a pleasant man

He's quite easy to get along with. I don't find him difficult to get along with. He was in hospital recently and he didn't get on well in hospital and the people in hospital...their perception of him was aggressive and just very difficult. I could well imagine that he would be in hospital if people were telling him what to do and have a bath and to do all that. ..we're seeing him in his own home and you can't do that then he's very easy to get along with. He's not somebody you could get close to just the same. You don't feel that he's always quite as pleasant.

The DN recognised that he would refuse other services, especially social workers and offered an explanation of why she didn't get rejected

I think he definitely doesn't like people. He's a very nice man but he definitely doesn't like people telling him what to do and organising his life. I think he feels that nurses are less of a threat. I suppose social workers have a, well, get a bad press for perhaps going in and organising people and forcing them to do things or taking out court orders or whatever but nurses are not involved in that sort of thing.

When asked about what would constitute a successful treatment outcome the DN replied

I think that you have to accept that you won't have success as you perceive it ever for him. I don't know. Well you would want that person to be able to make his own choices but I'm not sure that he will always feel that he has really got the power to make any different choices or to change things, you know. As he becomes less able and less mobile, less well. He was probably happier some time ago when he was able to go out and walk into town and that sort of thing. He's not able to do that now.

The DN was aware that Mr W did not have a great deal of social support. There was a daughter who occasionally visits for an overnight stay. The DN had not heard Mr W speak about any of his relatives other than this daughter. The main source of support was thought to be

The people in the local shop who are very good to him. They act as the bank and everything and you know they cash cheques for him and do anything like that for him. The shop is open late at night so he goes in there and gets whatever. So they're really good to him, I think.

Mr W did not have any other friends and did not get involved in any activities other than watch the television all day. He therefore appeared a distant and isolated man.

4.6.5.1 **Within-Case Analysis**

This man's lifestyle, personality and behaviours are very similar to those ascribed to the Diogenes Syndrome (Clark et al 1975). It appeared that the DN did in fact think that this problem, which she defined in terms of his poor hygiene and poor household cleanliness, was the worst she had come across. In general she described two types of self-neglect; self-neglect of health and self-neglect of house and hygiene. This is also consistent with Orem's (1991) distinction between health-deviation and universal self-care deficits.

The GP initially described Mr W's problem as "*refusing to seek professional help*". The GP did describe the household and personal hygiene deficits of Mr W but these were secondary to the primary definition of refusing to seek professional help for health-related problems. The major problem faced by Mr W, according to the GP and Mr W, was a mobility limitation. MacMillan and Shaw (1966) also found that 50% of those with severe self-neglect had mobility problems.

Mr W did not think that hygiene and household cleanliness constituted a problem for him, although he did accept that others may not think that this was the case. He reported that his major problem was a mobility impairment caused by a painful foot which prevented him going to the shop and climbing the stairs. His rejection of the self-neglect label, in-spite of the fact that the picture painted was remarkably similar to the classic Diogenes Syndrome, opens up a major philosophical challenge to the whole notion of the Diogenes Syndrome and also Orem's notion of self-care deficits.

Orem (1995), in common with the proponents of the Medical Model which underpins much of the recent work on self-neglect (Johnson and Adams 1996), operate from a realist philosophy. This realist philosophy, although accepting that individuals have a subjective view, believe that there is an *a priori* reality. In this *a priori* reality standards and criteria exist against which behaviours and beliefs can be judged. This is evident in Orem's (1995) limiting factors in engaging in self-care which include "refusal to make a decision once a desirable and suitable course of actions identified and understood" and "dispositions and orientations that result in perceptions, meanings, and appraisals of situations that are not in accord with reality". In essence this challenge can be summed up in the question `if standards of hygiene and other self-care behaviours are acceptable to an individual and are part of a preferred lifestyle can this lifestyle be used as evidence that this individual has a self-care deficit or a medical syndrome?'

Orem (1991) does deal with culture and social reality in her theories but may not deal with these notions in any substantive manner. In fact it can be argued that Orem relegates culture and social reality, along with many other concepts, to a secondary role as Basic Conditioning Factors. In effect they exert an effect through their influence on another construct, namely self-care agency.

All participants thought that Mr W's lifestyle was intentionally chosen, although the GP implied that some unspecified deep-seated psychological problem may be at work. This view is very similar to Ungvari and Hantz's (1991a) notion that primary severe self-neglect is a variation of Atypical Adjustment Disorder. In the Atypical Adjustment Disorder hypothesis patients have a premorbid personality characterised as suspicious, aloof, and quarrelsome. When such individuals are faced with a problem such as the loss of a close confidant a downward spiral of self-neglect occurs. Whilst some aspects of Mr W's history fit into this picture some other aspects are inconsistent. These include his ability to work in a responsible occupation dealing with people, his close friendship with a group of fellow professionals and his good relationship with the DN. It may also be the case that Mr W's compliance with prescribed medical and nursing care is also inconsistent with this hypothesis.

The GP claimed that no treatment could realistically be offered and would not be accepted if one were available, and that the best solution was for Mr W to die peacefully. The DN also thought that treatment

options were limited but appeared to suggest more active interventions which included visits and maintaining a good relationships. She did not hold out much hope that any intervention would be successful. O'Rawe (1982) described a similar case in which an individual who had previously rejected assistance from health care agencies went on to develop a "valuable relationship" with a nurse who had consciously and deliberately set out to foster such a relationship. Mr W did not want much in the way of treatment and in fact suggested that he refused treatment as this would be the slippery slope that would allow officials to meddle in his affairs.

All agreed that Mr W was an independent person who had little in the way of social contacts. He was described by all as a loner who had a somewhat abrasive manner. In-spite of that the DN had a good relationship with him and the GP was a past personal friend. Mr W had a history of broken marriages and was not disappointed at having lost contact with his only son. His daughter was the only family member who maintains some contact. Most recent support came from his relationship with the local shopkeeper who provided a range of support activities for Mr W.

4.7 **Across-Case Analysis**

The five cases just described will be analysed across cases to provide answers to the four discrete research questions. This level of analysis will focus on both similarities and differences between cases in order that the full complexity of self-neglect can be explored.

Research Question 1 - Do patients, relatives and professional carers have similar perceptions of self-neglect?

The working hypothesis developed from case one (Mrs H) was that all participants would share the same perspectives on whether self-neglect was present or not. In the case of Mrs H there was agreement between her son and the DNs that she was self-neglectful, the features of this self-neglect and the reasons for this self-neglect. Mrs H's self-neglect was thought to be directly related to her dementia. The degree of congruence between participants' perceptions of self-neglect varied across subsequent cases. In the case of Ms D there was also agreement between all participants that she was self-neglectful in terms of not caring for health-related factors but that she was not self-neglectful in terms household and personal hygiene. In fact she was very houseproud and had high standards of personal cleanliness. There was some disagreement between the patient and the GP on the one hand and the DN on the other as to the cause of her self-neglect. The GP also seemed to have a construction of self-neglect which related to the demands or lack of demands placed on him by patients in general and Ms D in particular. In Ms D's case and most others poor dietary status seemed to play a significant role in constructions of self-neglect. Dietary problems ranged from being overweight, not eating enough and not being able to prepare meals. This is not consistent with the fact that altered nutrition did not feature prominently in the list of nursing diagnoses in stage one. This is consistent though with Adams and Johnson's (1998) finding that diet plays a major role in nurses' constructions of self-neglect.

In the case of Mrs S both she and the CPN did not think she was self-neglectful. The CPN thought that whilst Mrs S had a disorganised life this was no greater than many other people. The DN and the GP thought she was self-neglectful in terms of her household and lifestyle circumstances (universal self-care requisites). There seemed to be a sense in which her social background played a part in these perceptions. In addition the GP also constructed Mrs S's problem in terms of the demands that her constant self-referrals placed on his workload.

A similar pattern emerged in the case of Ms E, who did not think she was self-neglectful but the DN and CPN did think she was. All participants reported that her problems, self-neglect and otherwise, were directly related to the family circumstances. It was thought that her sense of family duty meant that she cared for family members at the expense of caring for herself. There was also a sense in which the social background of Ms E played some part in her being described as self-neglecting. Johnson and Adams (1996) suggest that class, gender and ethnicity may be significant factors which influence the way self-neglect is perceived. This lends support to the social constructionist model of self-neglect in which judgements about neglect are influenced by a range of professional, social and cultural variables. It is not clear from this stage of the main study which variables or group of variables exert most influence on judgements of self-neglect. This problem will be investigated in stage three of the main study.

Two of the cases were people from large and well known ex-travelling families. Taylor (1991) describes how travelling families do not demonstrate positive health-maintaining behaviours. Rose (1990) identified the specific deficits in health-maintaining behaviours as alcohol use, poor ante-natal care, maintaining a good diet and proper dentition. In part this is attributed to the medical profession's lack of understanding of how to deliver culturally sensitive care. Thiederman (1986) comments on the link between cultural values and health care behaviours when suggesting that a breakdown in cross-cultural understanding stems from the tendency of health-care professionals to project their culturally specific values and behaviours and also suggests that this failure contributes to patient non-compliance.

Self-neglect may have a very different meaning in different sub-cultures with their own norms and values. Sub-cultural differences may also include issues related to class and occupational sub-groups such as general nurses and psychiatric nurses. It can be suggested that Orem (1991), whilst accepting that social class may influence self-neglect and its impact on the relationship between patient and professional carer, does not fully accept the constructionist position that social class itself is involved in the manufacture of professionals' judgements of self-neglect. The meanings of self-neglect as reflected in judgements of self-neglect and the factors which influence such judgements in different groups of nurses will be investigated in stage three.

There was also disagreement between professional carers and Mr W as to whether he was self-neglecting or not. He thought that his way of living was a personal choice and did not present any problem for him. The professional carers believed him to be the worst case of self-neglect that they had come across. His self-neglect was understood as neglect of personal and household hygiene but somewhat paradoxically he would take great care to comply with certain prescribed health-care regimes. This divergence of perspectives raises fundamental philosophical questions around whose perspective of self-neglect represent the truth? In terms of a social constructionist position his constructions of his own behaviour are as true as the constructions of professional carers and therefore to that extent he cannot be regarded as having a disorder called Diogenes Syndrome.

The Medical Model and Orem's Theory of Self-Care seem to operate from the position that there is some objective *a priori* self-care category, which individuals may have their opinions on, but nevertheless these opinions are subjective perspectives of an objective reality. Both theoretical perspectives provide an answer to the question of which perspective is to be taken as truth as both perspectives would suggest that there is an objective *a priori* state called self-neglect or problems called self-care deficits which can be diagnosed by medical and nursing professionals.

Research Question 2 - Is self-neglect intentional or unintentional?

The issues of freedom and choice are central to the Medical Model and to wider economic-political discourses on the place of the individual in capitalist cultures. Gerhardt (1989) argues that medical constructions of disease and illness have a political and cultural dimension. To neglect the `self` is to deny one of the major projects of liberal humanism, that is, care of self. Self-neglect must be seen against a backcloth of capitalist values of personal achievement and the self-neglecting individual's inability to engage in productive activities. In essence the Medical Model would propose that in certain circumstances, such as when an individual has a psychiatric disorder, they have a limited capacity to choose to engage in self-care actions. With respect to the relationship between self-neglect and dementia it was clear Mrs H did not choose to neglect herself. In the case of the man with severe self-neglect he himself admitted that his life-style was intentionally chosen and yet it was assumed that this was a result of undiagnosed deep-seated psychological problems.

Self-care (Orem 1991) and self-neglect (Clark 1980) have been regarded as intentional patterns of behaviour. In the case of Mrs H her dementia meant that she had little control over her actions and thus her self-neglect was not intentional. The working hypothesis from this case was that self-neglect was not intentional. In the cases of Mrs S and Mr W it was agreed that their behaviours were a matter of personal choice and to that extent were intentional, although the GP indicated that psychological problems limited Mr W's capacity to behave intentionally.

In the case of Ms E her choices were more difficult, in the sense that her ideas on family duty placed primacy on caring for other family members at the expense of self-care. Her self-neglect was not a preferred lifestyle choice and appeared to be a response to her brother's obsessional behaviour which meant that she and her mother had to eat, sleep, eliminate and live in the kitchen. She had very recently been allocated her own house had been able to exercise more choice and can now bathe and toilet in a way and at a time of her choosing. Johnson and Adams (1996) open up the question as to whether cases such as Ms E are more appropriately regarded as neglect inflicted by others. In the case of Ms D she chose not to contact health care professionals when she was ill but went to extra-ordinary lengths to care for herself, to the extent she self-treated two large varicose ulcers for many months.

Although he was thought by professional carers to be severely self-neglecting Mr W was still able to actively participate in aspects of his prescribed care

"*You know at times he had a urine infection and he got anti-biotics and he takes them regularly. I would say he does comply with anything like that. There was one time he had to get a dressing done and there was no problem with that.*" (DN)

Therefore it seems that some people who are described as severely self-neglecting may at the same time be able to manage their treatment

regime and thus non-compliance and self-neglect may be different concepts. It was also evident in the cases of Mrs S and Ms W that they would actively seek out health care and or social care resources and would manage these to what they perceived as to their advantage. Thus in this sense they were active or even pro-active in managing their care.

Again a picture emerges of a complex and heterogeneous phenomenon. There is no single straightforward answer to this question. In the case of major mental illness (dementia) the patient did not choose to live the way she did as her capacity to make choices were greatly diminished. Mr W (the worst case of self-neglect ever seen by the DN) self-expressedly did choose to live this lifestyle. In the other cases patients did choose to live their lifestyle but these choices were not obvious to them or there were other factors, such as sub-culture, family and gender, which made lifestyle choice at the very least difficult.

Research Question 3 - What is the relationship between psychiatric disorders and self-neglect?

In the case of Mrs H there was perceived to be a clear-cut relationship between her self-neglect and the presence of dementia. This dementia meant that her memory and capacity to function on her own was seriously impaired. Therefore the working hypothesis from this case was that there is perceived to be a clear-cut causal-relationship between psychiatric disorder and self-neglect. In the case of Mrs S she had been given the diagnosis of schizophrenia. The GP also thought that her major problem was her neurotic anxiety about her health

status. He ascribed her attention/reassurance seeking behaviours as stemming directly from her anxiety. The GP did not indicate how her schizophrenia was related to her self-neglect. The DN did not suggest any such link and the CPN could not in find any evidence for Mrs S having a mental illness in the first place. Mrs S herself did not think she had any mental illness nor was she self-neglecting. Therefore on close inspection no perceived causal-link between psychiatric illness and self-neglect was found in this case.

In the case of Ms E, who had been diagnosed as suffering from manic depression, no participant suggested there was a direct link between this psychiatric illness and self-neglect. In fact the link with mental illness was an indirect one in which her brother's obsessional behaviours created circumstances in which Ms E found it difficult to care for herself in the way she may have wished.

In the case of Ms D she had not been formally diagnosed as having a mental illness but her pattern of not seeking professional health-related advice was ascribed to the 3-D phobia (Dentist, Doctor and Dietician). This pseudo-diagnosis operated as an explanation rather than as a diagnosis and was offered by her doctor and subsequently taken up by the patient and her GP. It is open to question whether this lady did in fact suffer from a phobic state as specified in the ICD-10 criteria (ICD 1992). In the case of Mr W, who also did not have a formally diagnosed psychiatric illness, the GP offered the explanation that his self-neglect may have been caused by some deep-seated psychological problem. This explanation may be true, although not

offered by the DN or the patient, although admittedly the DN commented on his rather abrasive personality. It also may be the case that this explanation is a tautology. Faced with a puzzling problem a explanatory label is sought, the evidence of which is the symptoms of the problem itself: the symptoms being defined by the explanatory label.

All five patients had been diagnosed as having some mental health/psychological component to their self-neglect, albeit the 3-D phobia originated as a label of convenience for a doctor. Nevertheless the presence of mental health problems did not, with the exception of dementia, have a clear causal-relationship with self-neglect. Previous research (Shah 1992, Cooney and Hamid 1995) may have taken for granted that the presence of mental illness in a self-neglecting person indicates a causal-relationship. On closer investigation it is not quite as clear-cut and in fact the relationship may be an attributional one in which professionals are more likely to diagnose self-neglect when a mental illness is present irrespective of any objective relationship between self-neglect and mental illness.

Research Question 4 - How do professional carers and patients treat self-neglect and what constitutes success in terms of this treatment?

The working hypothesis generated from Miss E's case was that practitioners had no clear plan of treatment and there was no expectation that treatment would be successful. In all subsequent cases, with the exception of Ms D, there was a clear sense of

therapeutic pessimism. Professional carers were not hopeful that any treatment would work, if in fact a treatment was available. An extreme example this was found in the case of Mr W whose GP thought that the best solution would be for him to die peacefully. Patients themselves also expressed a sense of therapeutic pessimism and Mr S and Ms E had detected that their professional carers were pessimistic about treatment.

Most patients were able to manage their own treatment regime to some degree and professionals frequently reported that compliance to a nursing/medical regime was acceptable. The exceptions were Mrs S who thought she was managing and complying with her treatment regime, as did the CPN, but the GP thought she was not compliant. The other exception was Mrs H whose memory impairment made it impractical for her to take any real responsibility for her treatment. Therefore it seems that patients who were described as self-neglecting were also able to manage aspects of their treatment regime and thus compliance and self-neglect may be linked but may also be different concepts. It was also evident in the case of Mrs S and Ms E that they would actively seek out health care and or social care resources and would manage these to what they perceived as to their own advantage. Thus in this sense they were active or even pro-active in managing their care. There appeared to be some confusion in the case of Ms E about whether the CPN or DN was best suited to play the key role in her care. In other cases also there were concerns expressed about the level of co-operation between social and health services.

In the case of Ms D's treatment, its effectiveness and the level of positive thoughts of future success was much higher than in other cases. This was the only case in which only health-care deficits were present and thus interventions had a definite focus in the sense that treatment was organised around observable physical events. In addition professional carers were also sensitive to the need to develop a relationship in which Ms D could feel happy to stay in the treatment system and seek treatment in any future situation on her own volition. The need to develop a trusting relationship was commonly reported by professionals and the requirement to operate from the principle of compromise as an integral element in any good relationship was apparent. Developing a trusting relationship with travelling families may be attained by offering nursing care which is responsive to and accommodates the values of these families (Bodner and Leininger 1992).

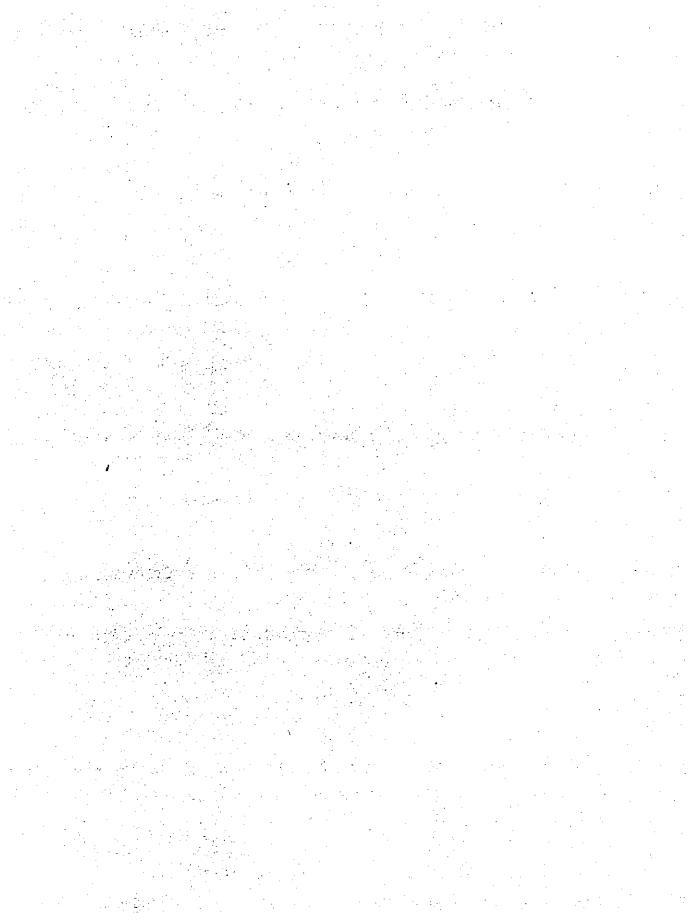
In the cases of Mr W, Ms D and Mrs S there were informal social support systems that played some role in supporting these individuals. These support mechanisms included the local pub, the local corner shop and the local chemist shop. In the case of Mrs S and Ms E who both came from large ex-travelling families there appeared, in terms of numbers of family members available, to be the potential for good levels of social support. In-spite of this both of these women played the central role in the family network and accepted the burden for caring for other family members to the extent where they would offer more support than they would receive in return.

4.8 **Summary**

Self-neglect in the five cases investigated was a very complex and heterogeneous phenomenon. Cases showed a number of similarities which if one was working from a methodological perspective which sought to impose order and identify patterns self-neglect could be defined in terms of these similarities. Nevertheless there appeared to be more differences than similarities between cases. This brings into sharp relief the very nature of a concept of self-neglect. It is suggested that it remains a poorly understood concept which in practice is interpreted in a number of different ways. It is suggested that behaviours which are regarded as self-neglectful are linked within a cultural and professional framework of values and norms. These values and norms provide the frame of reference when professionals make judgements about self-neglect. In essence it is suggested that self-neglect is not an objective diagnosis of a medical syndrome but is in fact a social judgement. These social judgements revolve around cultural, social and professional values about health-care prevention, cleanliness, hygiene and choice of lifestyle. Such judgements are dressed up in the language and concepts of scientific medicine. In the next stage of the main study the process of making social judgements and the factors which influence these judgements will be investigated further.

One interesting reflection on the qualitative analytic method used in the case studies was the difficulty in analysing data in which one of the explicit aims was to seek out diversity and contradiction. Instead of the

usual analytical process of seeking to impose order by identifying unifying themes, a process which may mimic the way in which people think, the difficulties faced in maintaining a sense of both order and disorder was very difficult for a single researcher. Thus the use of only five cases may actually be close to an upper limit in research studies carried out by a single researcher using this analytic strategy.



CHAPTER 5: STAGE THREE

A FACTORIAL SURVEY OF NURSES' JUDGEMENTS OF SELF-NEGLECT

5. **Introduction**

In earlier stages of the main study evidence emerged which suggests that self-neglect is a concept which lacks conceptual clarity. It is used in different ways by different people and it is possible therefore that they are influenced by different factors or combinations of factors when making judgements about self-neglect. It is also unclear whether self-neglect is thought to be an active or passive lifestyle choice. In this third stage of the main study the issues as to whether different groups of nurses do in fact have different notions of self-neglect and also the extent to which these groups think self-neglect is a lifestyle which has been actively chosen by patients was investigated.

The lack of agreement on what is or is not self-neglect is well illustrated in the case of Mr W who was described by the District Nurse and the GP as the worst case of self-neglect they had ever come across (Section 4.6.5). Mr W reported that his lifestyle was acceptable to him and he could see no reason for this to be regarded as a problem needing professional intervention. In stage two it was also found that behaviours which were regarded as self-neglecting included failing to seek medical help (the 3-D Phobia) (Section 4.6.4), forgetfulness and disorientation in late stage dementia (Section 4.6.1), and severe household and personal hygiene problems (Section 4.6.5). This lends support to the view that there is a lack of conceptual clarity and that diagnostic criteria for a self-neglect medical syndrome are too diverse to produce a meaningful category of behaviour.

The literature on self-neglect, the Medical Model and Orem's Theory of Self-Care contain what are inconsistent, or at the least unclear, accounts about the extent to which people who are said to self-neglect do so as an active choice of a particular lifestyle. The Medical Model and Orem's Theory of Self-Care (1991) imply that choice and responsibility are limited when an individual is suffering from some form of medical disorder (Section 1.1). The question of choice is illustrated in the case studies which included a person with late stage dementia whose ability to make choices is very different from the man who decided he wanted to live a `self-neglecting` existence.

It is suggested that judgements regarding self-neglect may be social judgements influenced by professional socialisation, normative values and cultural values. In the third stage of the main study the proposition that different groups have different ideas on self-neglect will be investigated and the factors which influence these judgements was explored using a research design developed for this purpose. The inclusion of nursing students allows some picture to emerge as to whether judgements of nurses who are in the early stages of their career path are different from nurses at a later stage of their career.

5.1 **Social And Professional Judgements**

In their work on measuring social judgements Rossi and Anderson (1982) suggest that humans continually make evaluative judgements about their world and that these judgements have both a social and a personal component. In effect, social judgements are neither entirely independent nor entirely idiosyncratic. Judgements may be relatively

structured and individuals rely on a limited number of characteristics when making judgements.

Individuals approach problems with preconceived schematic frameworks which provide reference points within which inferences are made (Brown 1996). Brown suggests that people begin to make judgements by using a limited amount of information to develop naive hypotheses about causes of behaviour and then they seek to develop simple confirmatory explanations. In situations where individuals have no clear beliefs or expectations they rely on scanning new situations which are then mapped onto cognitive frameworks constructed for similar phenomena (Driver and Erickson 1983).

In the light of the complexity of judgements social scientists must uncover the underlying order to these judgements (Rossi and Anderson 1982). Rossi and Anderson suggest that answers require to be found to questions such as `what information is used in making judgements?`, and `how do individuals differ in the ways in which information of different sorts is combined?`. The type of questions identified by Rossi and Anderson are essentially those which were investigated during this stage.

5.2 **Research Aims**

To compare judgements of self-neglect made by psychiatric nurses, general nurses, and student nurses.

To compare judgements of lifestyle choice made by psychiatric nurses, general nurses, and student nurses.

To identify the patient characteristics which influence judgements of self-neglect.

To identify the patient characteristics which influence judgements of lifestyle choice.

5.3 **Research Design And Method**

Rossi and Anderson (1982) have developed the factorial survey as a design specifically developed to answer the type of questions outlined above. The strengths of this design include the facts it is able to be administered to a large sample, and the vignettes employed may be more accurate representations of real life than the type of generalised questions usually asked in interview studies (Abbot and Sapsford 1993). In essence a factorial survey provides a high degree of rigour by providing an opportunity for control, manipulation of variables, orthogonality of variables, and inclusion of large numbers of subjects.

Rossi and Nock (1982) describe the factorial survey as

> *factorial surveys consist of providing individuals with contrived hypothetical situations/objects which are to be evaluated according to some process being studied. The construction of such situations/objects follows factorial experimental protocols which ensure the orthogonality of all components of the situations/objects. Individuals then respond to a sample of all possible contrived situations/objects* (p 10).

The factorial design allows the researcher to manipulate a number of independent variables to randomly construct vignettes. Love et al (1996) suggest that a factorial design is suitable for investigating normative beliefs, which they define as "*those shared values or beliefs that characterise a particular social group regarding an area of common interest*" (p 372).

The factorial survey combines elements of both the simple survey and the experiment (Love et al 1996). The distinction between experimental and non-experimental designs is critical. In multivariate experimental designs the researcher controls levels or conditions in more than one variable. In addition the researcher randomly assigns subjects to levels of the independent variable and controls for other factors by holding them constant or counterbalancing their influence. Thus scores on the dependent variable should be expected to be the same within the parameters of random variation, except for the effect of the

independent variables (Tabachnick and Fidell 1989). Thus a rating of self-neglect in a particular case history (vignette) would remain relatively constant over time and would only change significantly when an independent variable was changed, for example when the patient history was changed from depicting a minor to a major psychiatric illness. This quality has the advantage of possessing the internal validity of the experiment with the external validity of the survey (Rossi and Anderson 1982).

Love et al (1996) claim the factor orthogonality of the factorial survey allows this design to distinguish the separate effects of the independent variables on the construct of interest, in this instance judgements of self-neglect. Orthogonality has been described as perfect non-association of variables (Tabachnick and Fidell 1989). In other words the correlation between variables is zero. Orthogonality in factorial designs allows causal relationships to be clearly attributed to specific effects and interactions (Tabachnick and Fidell 1989). If variables are orthogonal each independent variable adds in a linear style to predictions of the dependent variable. Thus for example if 50% of the variance in judgements of self-neglect are predicted by functional ability and mental illness then 20% may be attributable to functional ability and 30% to mental illness. It also allows the researcher to capture the real life complexity of phenomena by investigating a number of dimensions without the problems of multicollinearity which bedevil surveys.

Multicollinearity refers to situations in which variables are highly correlated. If variables are highly correlated it becomes difficult to measure how much each variable uniquely contributes to variance. Rossi and Anderson (1982) give the example of expensive housing which is more likely to be large, have a larger plot, be in better repair, and more likely to have double glazing than a very inexpensive house. These features tend to be associated in real life, when one finds one the others are likely also to be present, leaving the researcher unable to measure each variable separately. This problem presents both logical and statistical difficulties (Tabachnick and Fidell 1989). If we include redundant variables we weaken the analysis by decreasing the degrees of freedom. It also causes statistical instability by providing large numbers in the inverted matrix. Thus numbers in the matrix show wide fluctuations with even small changes in the size of a correlation.

Liker (1982) suggests that real life judgements are not as free as some would suggest as they are constrained by situational factors. Situational factors may include organisational culture, peer-group pressure and professional codes of conduct. Thus to the extent that this holds the factorial survey may offer a more accurate representation of an individual's beliefs than could be inferred from observing how that particular individual responds to a real life situation.

Factorial surveys employ short vignettes to obtain data on the dependent variable (Rossi and Anderson 1982, Rossi and Nock 1982). Vignette methods investigating how individuals understand and react to situations have been employed to study how nurses respond to

abused women (Dickson and Tutty 1996), nurses' memory of patient's pain (McDonald 1996), beliefs about the efficacy of complementary medicine (Furnham and Rawlinson 1996), responses to patients assaulting nurses (Lanza and Carafio 1991) and developing nursing diagnoses (Vincent and Coler 1990).

Vignettes involve the use of short descriptions or case histories of situations or phenomena. Subjects are required to read these vignettes and make a judgement on some dimension about these vignettes (Lanza and Carifio 1990). A factorial survey design using vignettes is able to uncover the belief structure which underlies these normative judgements. This design is also suited to studies which seek to measure the relative weights that subjects attach to the variables linked to the occurrence of a behaviour.

5.3.1 **Validity and Reliability**

Lanza et al (1997) suggest that the standardisation of vignettes, manipulation of variables and control of confounding variables makes the vignette design one which has a strong claim to having internal validity. Liker (1982) argues that the random assignment of variables to vignettes has many of the statistical properties of laboratory experiments. He suggests that this maximises the internal validity of this methodology.

Content validity in the form of face validity was evaluated through the use of expert groups (Lanza 1988). In the current study an expert group of nurse educators, who had knowledge and experience of

nursing in a range of settings, were used during the pilot phase, to ascertain whether the vignettes represented plausible depictions of self-neglect. With the exception of one or two minor gender related points the vignettes were thought to be realistic, and representative of `real` life patients.

Rossi and Anderson (1982) describe how if the first few vignettes presented to a subject are sufficiently alike, subjects may resort to shifting frames of reference and alternating judgements between generous and strict. This they refer to as serial order dependency. Thus the order in which vignettes are presented to subjects may influence their judgements as to the level of self-neglect and choice of lifestyle subjects assign to this vignette. To control for effects of presentation order it is necessary to vary the order of vignette presentation to subjects (Burgio et al 1995). Vignettes were randomly selected and compiled but in the few instances where two consecutive and thus very similar vignettes were sampled for a given package these were placed in a different order in the same vignette package. This did not compromise the principle of random sampling.

5.3.2 **Procedures**

All subjects received a package containing an accompanying letter which explained the purposes of study, a randomly selected sample of 10 vignettes, and where necessary a return-addressed envelope. Subjects were required to read each vignette and rate the degree of self-neglect which they thought applied to each vignette and also rate how

much choice they thought the patient depicted in each vignette had over the lifestyle they were leading.

5.3.3 **Sample**

The target population comprised student nurses, psychiatric nurses and general nurses. The incorporation of student nurses allowed some insights into the development of professional judgements about self-neglect across the career pathway. The selection of general and psychiatric nurses permitted comparisons to be made about similarities and differences in judgements of sub-groups of nurses. The student nurse element of the sample consisted of the 1997 cohort undertaking the Diploma in Higher Education (Nursing) at a Scottish University. A sample frame for this population was obtained from the University Registry Department. The psychiatric nurse element consisted of a random sample of Registered Nurses (RN) practising in the Mental Health Unit of a Community NHS Trust. The general nurse sample comprised a random sample of Registered Nurses practising in a medium-sized District General Hospital. No community nurses were included in this stage of the main study due to a range of problems outwith the control of the researcher. These problems include the fact that a large number of District Nurses in the area had been involved in earlier stages of the study, a number of other District Nurses were involved in another study being conducted concurrently by the researcher, and the practical difficulties of obtaining access and ethical permission from relevant committees to include nurses in another Health Board within the timescale of the study.

Randomisation was achieved by means of the random number facility in SPSS programme. The sample frame for psychiatric nurses contained 193 RNs, in the general nurse sample frame there were 337 RNs (areas such as paediatrics, maternity were excluded as self-neglect in children is a very different concept to self-neglect in adults), and in the student sample frame there were 65 students. The entire cohort of student nurses were selected for inclusion in the study along with 100 subjects from each of the RN groups. Acceptable return rates of 98% (N=64) for students, 59% (N=59) for general RNs, and 67% (N=67) for psychiatric RNs were achieved. This resulted in 1894 returned vignette ratings, a small number of which had missing data (See Section 5.5.2).

Sample characteristics are reported in Table 5.1. The mean age of the sample was 35.2 yrs (sd 9.1). The age of students ranged from 18-51 yrs (mean 28.5), general nurses from 24-53 yrs (mean 38.7), and psychiatric nurses from 25-53 yrs (mean 39). The mean age of each element of the sample showed significant differences ($F = 382.443$, $df = 2$, $P = 0.0001$). Numbers of males were small with the largest number, as expected, in the psychiatric group.

Table 5.1 Sample Characteristics

	Students	General RN	Psychiatric RN
	N=64	N=59	N=67
Female (N)	58	54	54
Male (N)	6	5	12
Age (Mean)	28.5	38.7	39
SD	8.2	7.4	7.2

5.4 **Instrumentation**

Vignettes used were specifically constructed for the purposes of the study. The vignettes were constructed using dimensions which were believed by the researcher to influence how people judge self-neglect. There are a large number of possible dimensions which could have been included in the vignettes but the number selected was restricted to six; socio-economic status (SEC), psychiatric status (Psychi), self-care status (S/Care), stated preference for lifestyle (Lifestyle), gender, and functional ability (ADL). The factors were selected as those most likely to influence such judgements, and were selected after close consideration of findings of earlier stages of the main study, existing research and the self-neglect literature. In addition pragmatic considerations also played a part in the decision to limit the number of dimensions to six. The six dimensions were further divided into 17 levels. All possible combinations of levels gave a total of 432 unique vignettes. Adding even one more dimension with three levels would have increased this number by a factor of three.

Thus within the constraints of the study it was decided to limit the complexity of the vignettes to a manageable number. There are also important statistical reasons for limiting the number of variables included in multivariate regression analysis (Tabachnick and Fidell 1989). Tabachnick and Fidell argue that including more variables may slightly improve the solution but at the expense of reducing the degree of freedom and thus diminishing the power of the analysis. In addition they suggest that too many variables in relation to the sample may

provide a good solution to the study sample but this may not generalise to the population. This is the so-called overfitting problem. Tabachnick and Fidell conclude that one should use as few variables as possible.

Dependent variables

Two dependent variables are used in this study; judgements of self-neglect; and judgements of the choice in leading a lifestyle. These judgements were measured on a seven point anchored-visual analogue scale. The first dependent variable was a rating of participants' judgements of self-neglect which moved from point 1 - *not self-neglect* through to point 7 - *severe self-neglect.* The second dependent variable was participants' judgements of whether patients had chosen to lead their lifestyle. This was also measured on a seven point visual analogue scale moving from point 1 - *has chosen to lead lifestyle* through to point 7 - *has chosen no aspect of lifestyle.*

Independent Variables

There were six independent variables. The independent variables (dimensions) which have been used to construct the vignettes had been identified during earlier stages of the main study. Each dimension contains a number of levels, with the number of levels varying between dimensions.

Dimension 1 - Socio-Economic Status

It has been suggested that professional groups are over-represented in self-neglect cohorts (Clark et al 1975). Occupational categories are

based on the descriptive groups outlined in the General Health Survey (Foster et al 1993). These occupational groups have been conflated to give three occupational groupings which are regarded as proxy measures of social class.

Levels

1. Professional/Employer/Manager: University Lecturer, Chief Executive, Sales Manager, Senior Civil Servant, Lawyer, Doctor, Accountant
2. Non-Manual: Army NCO, Accounts Clerk, Nursery Teacher, Enrolled Nurse, Salesman, Bank Clerk, Joiner, Master Butcher, Chef
3. Unskilled/Semi-Skilled Manual: Sales Assistant, Petrol Pump Attendant, Window Dresser, Labourer, Unemployed

Dimension 2 - Self-Care Status

This variable was developed as a synthesis of Orem's (1991) concepts of Health-Deviation Self-Care Requisites and Universal Self-Care Requisites and the literature on hygiene and cleanliness behaviours characteristic of self-neglect as defined in the self-neglect literature. The levels have been developed to represent the main self-care patterns found in cases described in stage two. Level 1 captures both the classic picture of the Diogenes Syndrome (MacMillan and Shaw 1966), and Mr W (Section 4.6.5). Level 3 represents the case of Ms D (Section 4.6.4).

Levels

1. Severe accumulation of dirt, food waste and hygienic waste in the house. Personal hygiene very poor with infested hair, long curling nails and urine-smelling clothes
2. Untidy house with clothes lying on the floor and little evidence of attempting to keep the house tidy. Has an unkempt and dishevelled appearance
3. Does not look after personal health in areas such as dental hygiene, diet and will not seek medical attention even when ill
4. Seeks medical help when ill but fails to comply with medical and nursing treatment

Dimension 3 - Stated Preference for Lifestyle

There is a suggestion in the literature, and one which was supported in the case study stage, that many people who are described as self-neglecting may express an opinion that this is a lifestyle of choice for them (Mr W). This variable has been developed to capture stated preference for lifestyle.

Levels

1. Wishes to lead this lifestyle
2. Wishes to lead another lifestyle

Dimension 4 - Psychiatric Status

The literature on self-neglect within the medically-based literature suggests that many self-neglecters suffer from a mental illness (Post 1985). The levels will allow some picture to emerge about the relative

influence of different severities of mental illness or absence of psychiatric illness on judgements of self-neglect and choice in lifestyle.

Levels

1. Has a major mental illness (schizophrenia, dementia, manic-depression)
2. Has a mild mental disorder (mild-depression, alcohol abuse)
3. No mental illness

Dimension 5 - ADL Status (Functional Ability)

In stage one it was found that there were no significant differences in the proportions of subjects who were dependent and independent in ADL functioning between the group classified as self-neglecting and the group classified as non self-neglecting. Nevertheless there did appear to be differences in the number of patients classified as self-neglecting who had functional impairments in the activities of feeding, continence and toileting.

Levels

1. Dependent in all areas of activities of daily living (bathing, dressing, toileting, continence, feeding, mobilising) and requires a lot of assistance from others
2. Dependent in activities of feeding, toileting and continence and requires some assistance from others
3. Is independent in all activities of daily living .

Dimension 6 - Gender

In stage one of the main study a larger number of men were identified by District Nurses as self-neglecting than one would have expected in

an age group cared for by these District Nurses. This runs counter to the dominant image of the elderly self-neglecting woman (Clark et al 1975). Therefore the role played by gender in judgements requires to be investigated.

Levels
1. Female
2. Male

5.5 **The Database**

Data were managed using the SPSS 8.0 statistical package. Data were initially screened and examined for errors using frequency and explore techniques. Input errors, all keying errors, were discovered by comparing the data set with coding book. Data were examined to ascertain whether they met certain assumptions which underpin and determine the type of statistical analyses which could legitimately be carried out on these data. These assumptions included the level of measurement, presence of outliers, normality, linearity, multicollinearity and singularity. No evidence of multicollinearity, singularity or outliers was found. Vignette ratings of choice and neglect were treated as continuous measurements. There is some disagreement as to whether this type of response format is to be treated as a discrete (dichotomous, ordinal) or a continuous measurement (interval, ratio). Berk and Rossi (1982) have demonstrated that in vignette studies respondents treated this type of response category as though it were formed on an equal interval scale. This convention has been the norm in most factoral survey analysis

(Rossi and Anderson 1982, Rossi and Nock 1982, Love et al 1996). All other data were treated as categorical measurements. Ratings of choice and neglect were found to have a non-normal distribution (Tables 5.2; 5.2.1). Therefore a regression technique (CATREG) which makes no assumptions about normality nor requires continuous level measurement was selected.

5.5.1 **Data Analysis**

Data were examined using a range of descriptive and inferential statistical tests. Inferential statistics comprised of parametric tests (ANOVA, t-test, Pearson's Test) and non-parametric tests (CATREG). The decision to use parametric or non-parametric tests was dependent on the level of data measurement and, when appropriate, the distribution of data. Multivariate analysis was performed using a categorical data technique. Categorical Regression (CATREG) is a form of multiple regression technique for ordinal and categorical variables. CATREG is one of a class of techniques for non-linear analysis of categorical variables (Van de Geer 1993). This class of methods are often described as the GIFI system after the collective name of a group of mathematicians from the University of Leiden. In non-linear analysis the classical multivariate assumptions of a normal sampling distribution and continuous level measurement are not held. Van de Geer (1993) reports the comparative reliability of these techniques. CATREG was performed to examine the relationship between the dependent and independent variables. The vignette dimensions of gender, socio-economic category, psychiatric illness status, self-care

status, activity of daily living status, and stated preference for lifestyle were included in the regression analyses.

5.5.2 Missing Data

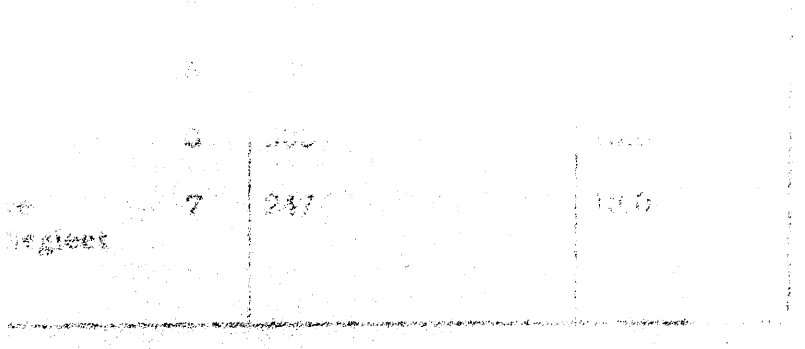
Missing data can create problems within multivariate analysis. The dependent variables of choice and neglect ratings had missing data of 0.5% and 0.4% respectively, and occupational group had 0.1% missing data. The levels of missing data were low enough not to present problems during data analysis. It is appropriate in these circumstances to delete cases with missing data from the analysis (Tabachnick and Fidell 1989)

5.6 Findings

5.6.1 Choice and Neglect Ratings

Judgements of choice and neglect in each vignette were rated on an anchored scale ranging from 1-7. The distribution of ratings in both variables displayed a non-normal distribution although scores were generally well spread across rating points (Table 5.2; Table 5.2.1). This suggests that the scale provides sufficient response points to discriminate degrees of respondents' judgements. Choice ratings showed a non-normal distribution and were positively skewed with the mode rating in the lowest point of the scale. Thus the most popular response was that patients were judged to have chosen to lead a particular lifestyle. Neglect ratings also showed a non-normal distribution with a slight negative skew. The smallest percentage of neglect ratings (9.3%) were found in the lowest point of the scale. Respondents therefore judged that most vignettes displayed some

degree of self-neglect. This may be a source of error produced by expectation that in a study of self-neglect vignettes must have some degree of self-neglect. Alternatively the suggestion that self-neglect lies on a continuum of behaviours may be supported by this finding.



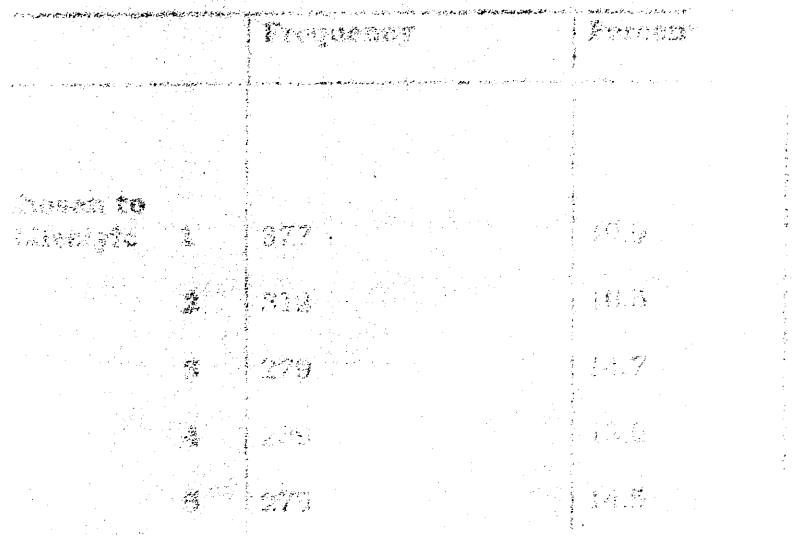


Table 5.2. Subjects Ratings of Neglect in Vignnetes

		Frequency	Percent
Not Self-Neglect	**1**	177	9.3
	2	247	13.0
	3	302	15.9
	4	266	14.0
	5	348	18.4
	6	300	15.8
Severe Self-Neglect	**7**	247	13.0

Table 5.2.1 Subjects Ratings of Choice in Vignnetes

		Frequency	Percent
Has Chosen to Lead Lifestyle	**1**	377	19.9
	2	312	16.5
	3	279	14.7
	4	239	12.6
	5	275	14.5
	6	267	14.1
Has Chosen No Aspect of Lifestyle	**7**	136	7.2

The mean score for neglect ratings was 4.19 (sd 1.87) and the mean score for choice was 3.57 (sd 1.95). The modal score for neglect was 5 and for choice was 1 (Table 5.2.2). There was little correlation between the level of neglect and the degree to which patients had exercised some choice over the lifestyle they had led (r -0.063, P = 0.006, Pearson's Product Moment Correlation Test: Two-Tailed). The absence of any notable relationship between judgements of self-neglect and choice in this lifestyle lends no support to either the active or passive choice hypotheses. The active hypothesis proposes that self-neglecters choose to self-neglect. The passive hypothesis proposes that self-neglect is a consequence of disease or impairment and the individual has no choice in this lifestyle. It may be the case that there are a number of distinct sub-groups within the self-neglect group some of which (dementia patients) have a clear negative relationship whilst others (no mental illness patients) have a positive relationship. For example patients with late stage dementia may be judged not to have the intellectual capacity to make considered choices about the type of lifestyle they lead. In other words the combination of self-neglect and major psychiatric illness leads nurses to judge that less choice had been exercised by patients in the lifestyle they were leading. Alternatively self-neglecters with no mental illness may be judged to have chosen to lead this lifestyle. Combining the two groups obscures these relationships. This issue will be explored later in this Chapter in the categorical regression analysis (Section 5.6.4).

Table 5.2.2 Descriptives Of Neglect And Choice Ratings

		NEGLECT	CHOICE
N	Valid	1887	1885
	Missing	7	9
Mean		4.19	3.57
Median		4.00	3.00
Mode		5.00	1.00
Std. Deviation		1.87	1.95
Variance		3.49	3.79
Skewness		-.117	.184
Std. Error of Skewness		.056	.056
Kurtosis		-1.111	-1.233
Std. Error of Kurtosis		.113	.113
Range		6.00	6.00

5.6.2 **Ratings Of Neglect by Occupational Group**

Student nurses' data had a mean rating of 4.20 (sd 1.8), psychiatric nurses a mean rating of 4.20 (sd 1.9) and general nurses had a mean rating of 4.18 (sd 1.89) (Table 5.3). The differences between groups was not significant (F = .023, df = 2, P = 0.977). The boxplot of neglect ratings indicates that all three groups of nurses have a very similar spread of ratings (Figure 5.1)

Table 5.3 Mean And Modal Ratings Of Neglect By Speciality

Group	All	Student	Psych RN	Gen RN
Mean	4.19	4.20	4.20	4.18
Mode	5	5	5	5
SD	1.87	1.8	1.9	1.89

5.6.3 **Ratings of Choice by Occupational Group**

Student nurses' datahad a mean rating of 3.69 (sd 1.95), psychiatric nurses had a mean rating of 3.63 (sd 1.9), and general nurses had the lowest mean rating of 3.37 (sd 1.98) (Table 5.3.1). There was a significant difference between groups (F = 4.263, df = 2, P = 0.014).

Table 5.3.1 Mean And Modal Ratings Of Choice By Speciality

Group	All	Student	Psych RN	Gen RN
Mean	3.57	3.69	3.63	3.37
Mode	1	1	1	1
SD	1.95	1.95	1.9	1.98

The boxplot of choice shows marked differences in the spread of ratings between groups (Figure 5.2). Psychiatric nurses and students' ratings tail off towards the lower quartile. Psychiatric nurses and student nurses are more inclined to believe that patients had exercised less choice in the lifestyle they led. In contrast general nurses ratings trail off towards higher quartile. General nurses therefore are more inclined to believe that patients had chosen to lead a particular lifestyle.

Figures 5.1 Boxplot Of Neglect Ratings By Speciality

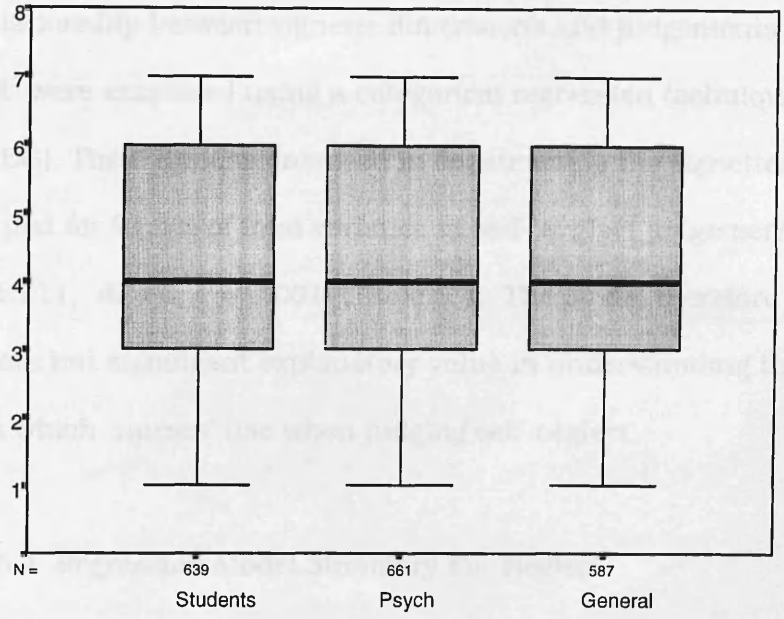
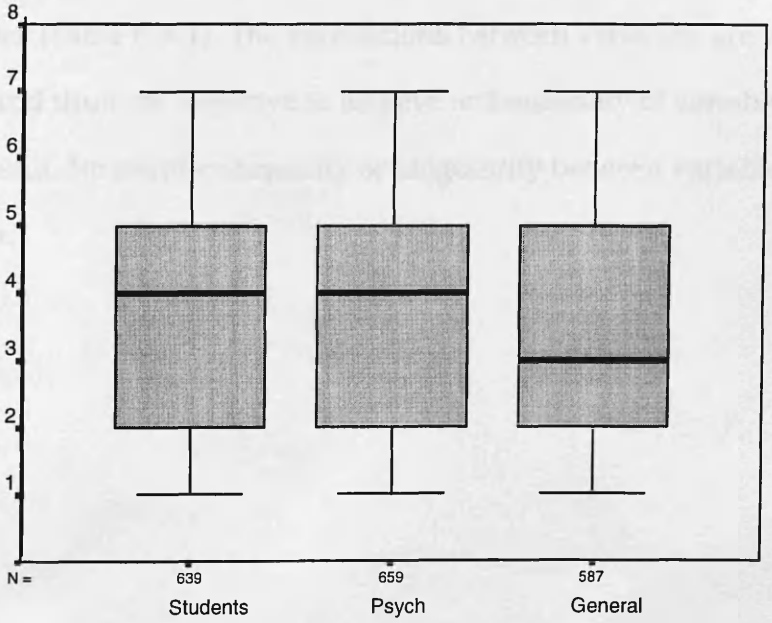


Figure 5.2 Boxplot Of Choice Ratings By Speciality



5.6.4 **Categorical Regression Analyses**

The relationship between vignette dimensions and judgements of self-neglect were examined using a categorical regression technique (CATREG). The 6 dimensions used in constructing the vignettes accounted for 21.4% of total variance in self- neglect judgements ($F = 84.211$, $df = 6$, $P = 0.001$) (Table 5.4). The model therefore has a moderate but significant explanatory value in understanding the factors which nurses' use when judging self-neglect

Table 5.4 Regression Model Summary For Neglect

Multiple R	R Square	Adjusted R Square
.462	.214	.211

The correlation coefficient table displays the correlation between variables (Table 5.4.1). The correlations between variables are very small and thus the objective to achieve orthagonality of variables was successful. No multi-collinearity or singularity between variables is present.

Table 5.4.1 Correlations Of Original Predictors

	1	2	3	4	5	6
1. Gender	1.00					
2. ADL	-0.04	1.00				
3. Psychi	0.02	0.06	1.00			
4. S/Care	0.02	0.02	-0.01	1.00		
5. Lifestyle	0.04	-0.05	-0.01	-0.01	1.00	
6. SEC	0.01	-0.04	-0.01	0.04	-0.03	1.00

The regression coefficient table displays the standardised regression coefficients, and semi-partial correlations (sr^2)(Table 5.4.2). This indicates that self-care status (sr^2 -0.436) is the dominant dimension in ratings of neglect. Other dimensions had very small coefficients. The importance of self-care status in judgements of self-neglect is consistent with earlier findings from stages one and two of the main study that self-care may be the central concept in formal (Section 3.6.6) and tacit constructions of self-neglect (Section 4.6.5.1). It also suggests that formal constructions of self-neglect found in the literature (O'Rawe 1982, Moore 1989) are consistent with the tacit constructions held by nurses.

Table 5.4.2 Regression Coefficients For Neglect

Variable	Beta	R	Sr^2	Importance	Tolerance
Gender	2.743E-02	.043	.031	.006	.995
SEC	-8.40E-02	-.096	-.094	.038	.995
Psychi	9.677E-02	.103	.108	.047	.993
S/Care	-.431	-.436	-.436	.879	.996
Lifestyle	6.834E-02	.062	.077	.020	.996
ADL	-5.04E-02	-.047	-.057	.011	.990

ANOVA tests were performed to test if there were any significant differences between levels in the self-care dimension. Although data were not normally distributed ANOVA can still be used as it is robust with respect to normality, especially when there are sufficient number of cases (Erickson and Nosanchuck 1992). Level 1 `*Severe accumulation of dirt, food waste and hygienic waste in the house. Personal hygiene very poor with infested hair, long curling nails and urine smelling clothes*` had the highest mean rating of 5.28 (sd 1.83) (F = 110.815, df = 3, P = 0.0001) (Table 5.4.3 ; Figure 5.3). Level 4 `*seeks medical help when ill but fails to comply with medical and nursing treatment*` had the lowest mean rating of 3.51 (sd 1.62). This develops the finding in an earlier stage of the main study that non-compliance is regarded as a feature of self-neglect. Non-compliance was judged to be on the lower end of the self-neglect continuum.

Table 5.4.3 Descriptives Of Vignette Levels Within Self-Care Status Dimension

Self-Care Levels	N	Mean	Std Deviation
1	468	5.28	1.83
2	507	3.57	1.76
3	464	4.42	1.67
4	447	3.51	1.62
Total	1887	4.19	1.87

Figure 5.3 Mean Plot For Self-Care Status

A CATREG analysis was also carried out on judgements of choice. The dimensions of gender, socio-economic status, self-care status, psychiatric status, ADL status, and stated preference for lifestyle were included in the regression model. The vignette dimensions accounted for 23.2% of total variance (F = 93.676, df = 6, P = 0.0001) (Table 5.5). The model therefore has a moderate but significant explanatory value

in understanding the factors which nurses use when judging the level of choice patients made in the lifestyle they were leading.

Table 5.5 Regression Model Summary for Choice

Model Summary

Multiple R	R Square	Adjusted R Square
.482	.232	.230

The correlation coefficient table displays the correlations between variables (Table 5.5.1). The correlations between variables are very small and thus the objective to achieve orthagonality of variables was achieved. No multi-collinearity or singularity between variables is present.

Table 5.5.1 Correlations of Original Predictors

	1	2	3	4	5	6
1. Gender	1.00					
2. ADL	-0.04	1.00				
3. Psychi	0.02	0.06	1.00			
4. S/Care	0.02	0.02	-0.01	1.00		
5. Lifestyle	0.04	-0.05	-0.01	-0.01	1.00	
6. SEC	0.01	-0.04	-0.01	0.04	-0.03	1.00

The regression coefficient table indicates (Table 5.5.2) that stated preference for lifestyle(sr^2 -0.353), psychiatric status (sr^2 -0.265), and ADL status (sr^2 -0.230) had highest correlations with judgements of choice.

Table 5.5.2 Regression Coefficient Table For Choice

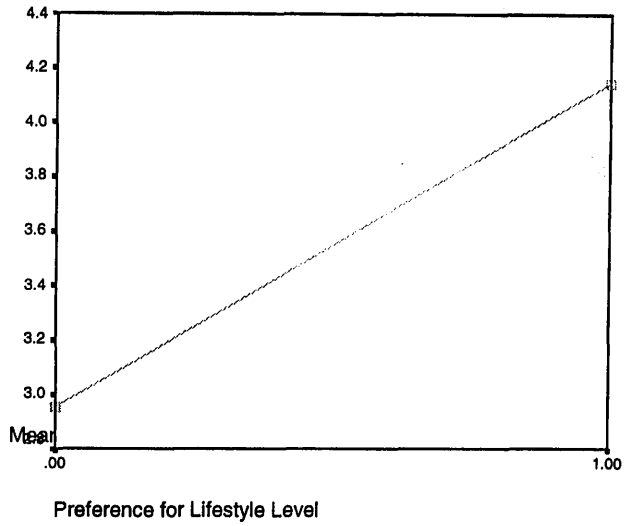
Variable	Beta	R	Sr^2	Importance	Tolerance
Gender	-1.13E-03	.0415	-.001	.000	.997
SEC	4.578E-02	.067	.052	.013	.997
Psychi	-.242	-.252	-.265	.262	.995
S/Care	-.135	-.135	-.152	.078	.999
Lifestyle	-.332	.319	-.353	.456	.994
ADL	-.208	-.213	-.230	.191	.991

ANOVA and t-tests were performed to examine differences between levels of the dominant three dimensions. In the stated preference for lifestyle dimension the level `*wishes to lead another lifestyle*` had the higher mean rating of 4.15 (sd 1.82) (T = 13.940, df = 1883, P = 0.0001) (Table 5.5.3; Figure 5.4).

Table 5.5.3 Descriptives For Levels Within Stated Preference For Lifestyle Dimension

Stated preference for lifestyle	**N**	**Mean**	**Std Deviation**
1	**917**	**4.15**	**1.82**
2	**968**	**2.96**	**1.88**
Total	**1885**	**3.57**	**1.95**

Figure 5.4 Mean Plot For Lifestyle Preference Status

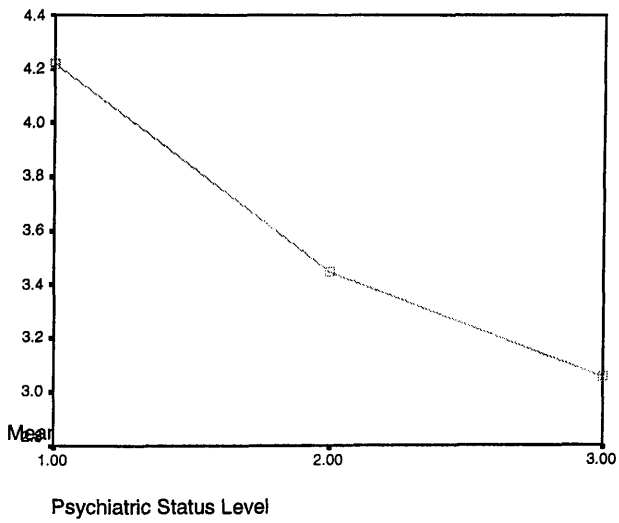


In the psychiatric status dimension the level `*major mental illness*` had the highest mean ratings score of 4.2 (sd 1.93) (F = 62.191, df = 2, P = 0.0001) (Tables 5.5.3; 5.5.4). The level `*minor mental illness*` had a mean rating of 3.45 (sd 1.82) and the `*no mental illness*` level had lowest mean rating of 3.06 (sd 1.90). This supports the finding that patients with dementia are judged to have less choice in the lifestyle they lead. It also lends support to the suggestion from stage two that patients with dementia may be a sub-group of self-neglect which present certain philosophical problems regarding choice and capacity for intentional self- neglect (Section 4.7).

Table 5.5.4 Descriptives For Levels Within The Psychiatric Status Dimension

Psychiatric Levels	N	Mean	Std Deviation
1	620	4.2	1.93
2	617	3.45	1.82
3	648	3.06	1.90
Total	1885	3.57	1.95

Figure 5.5 Mean Plot For Psychiatric Status

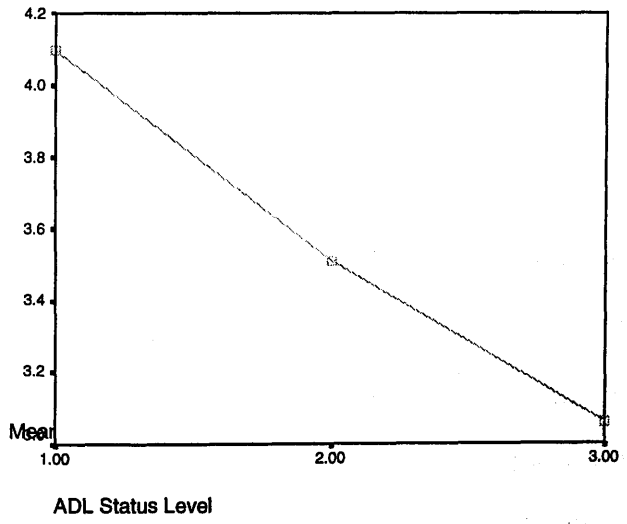


In the ADL status dimension the level `*dependent in all ADLs*` had the highest mean rating of 4.10 (sd. 1.99) (F = 46.344, df = 2, P = 0.0001). *Dependent in three ADLs* had a mean rating of 3.51 (sd1.86) and *independent in all ADLs* had the lowest mean rating of 3.06 (sd 1.85) (Table 5.5.4; Figure 5.6).

Table 5.5.4 Descriptives Of Levels Within ADL Status Dimension

ADL Levels	N	Mean	Std Deviation
1	642	4.10	1.99
2	641	3.51	1.86
3	602	3.06	1.85
Total	1885	3.57	1.95

Figure 5.6 Mean Plot For ADL Status



5.7 **Discussion**

There were four aims specified for this stage of the main study and the discussion will be organised around these aims.

Aim 1

To compare judgements of self-neglect made by general nurses, psychiatric nurses, and student nurses.

There were no significant differences in the mean ratings of self-neglect held by psychiatric nurse, general nurse and student nurse groups. In addition the spread of ratings and mode were similar for all groups. Ratings were relatively well spread across the scale which suggests that self-neglect is judged to be a continuum of behaviours. It would appear that all groups operate from similar conceptual schemata when making decisions about self-neglect. This is not consistent with the findings of the case studies in which different groups of nurses, in some cases, held different views on self-neglect (Section 4.7). There are a number of possible explanations for this finding including the fact that no community nurses were included in the factorial survey but were included in the case studies. It may be the case that removing self-neglect from a `real` context may obscure those very elements which differentiate nurses' judgements. Alternatively this finding may be an methodological artefact and may lend support to Rossi and Anderson's (1982) hypothesis that judgements have a social and an individual dimension. The factorial survey may elicit social judgements and have an inherent tendency to force consensus across a group

whereas case studies and semi-structured interviews may tap into individual components of judgements with all the idiosyncratic features of individual schemata (Eisenhardt 1989). One further possible explanation is that deeply held general views may be difficult to sustain when one meets a real case in its real context. Thus it is possible for one to believe something is true as a general rule but to have this belief challenged when actually meeting an individual contrary case.

This finding raises issues at paradigmatic, theoretical and methodological levels (See sections 1.4.2 and 5.3 for a discussion on these issues). At the paradigmatic level ideas about what is the truth about self-neglect and how are we to know truth regarding self-neglect arise. A paradigm refers to the entire repertoire of beliefs, values, laws, theory methodologies, and principles of a discipline (Meleis 1985). The constructionist position is able to reconcile seemingly contradictory positions as it allows for plurality of truth, that is there are many ways of understanding self-neglect, and thus what may appear contradictory findings may represent the reality of a plural world.

At a theoretical level most theories are not framed within paradigmatic boundaries (Polit and Hungler 1991). Thus theories are complex, multidimensional and require methods of verification and testing which reveal different ways of understanding self-neglect. At the methodological level different methods look at the problem in different ways and can give different findings. Hough et al (1991) used a combination of survey and case studies to explore family coping and adjustment. They found that each method produced seemingly

contradictory results. Similarly in the main study case study methods and survey methods focus on different ways in which self-neglect is constructed. The issues raised in this section lead one to the conclusion that the way we conceptualise, investigate and understand self-neglect will produce a particular construction of self-neglect which is bounded within certain paradigmatic, theoretical and methodological assumptions. In essence we see what we want to see. The multi-layered processes in which a particular construction of self-neglect is legitimised is discussed in an earlier section (Section 1.4).

The student group had completed one year of a three year course. During this year they had undertaken 18 weeks of clinical placement. The fact that there was general consensus between students and qualified nurses suggests that professional judgements of self-neglect may be developed during a socialisation process which takes place over a relatively short period of time or it may also be the case that such judgements are rooted in deeper lay beliefs about self-neglect, hygiene and dirt held within contemporary British culture (Section 1.4.2). The question of whether and in what way nurses' judgements are influenced over their career pathway by cultural values is one which requires further investigation.

Aim 2

<u>To compare judgements of lifestyle choice made by general nurses, psychiatric nurses, and student nurses.</u>

The overall pattern of ratings of choice showed a different pattern than judgements of self-neglect. Ratings were skewed towards the lower end

of the scale. The most common rating indicated that patients had chosen to lead all aspects of their lifestyle. There was little correlation between self-neglect and choice. This finding is consistent with the case study finding that people with self-neglect can be regarded both as having chosen to lead a self-neglecting lifestyle or in other cases have chosen not to lead a self-neglecting lifestyle (Section 4.7).

General nurses were more likely to believe that patients had choice in the lifestyle they led. It has been suggested previously that the Medical Model and Orem's Theory of Self-Care (1991) propose that an individual's capacity to exercise choice is impaired by disease and illness (Section 1.1). Thus to this extent psychiatric nurses and student nurses are more likely to judge in a fashion which is more consistent with these constructions than are general nurses. The implications of this are important inasmuch as if one accepts that a patient has exercised choice in the lifestyle they are leading one may conclude that they do not suffer from a diseased state but have opted for a lifestyle in much the same way as anyone else, even if this does lead to other problems. If one judges that the patient has not chosen this lifestyle but have had this enforced on them through a disease process then this lifestyle is seen as a disordered state which requires treatment. Alternatively the notions of choice and blame may be conflated here with self-neglecters being blamed for this lifestyle. They are dirty not ill may be the dictum. This may provide an explanation of the different perspectives of self-neglect and the various treatments offered in the case of Mrs S (Section 4.6.3). The CPN thought Mrs S was not self-neglectful and did not need a depot tranquilliser, whereas the

DN may have implied that Mrs S was to blame and that she needed treatment-punishment. Therefore the socialisation process which influence choice may have a direct impact on the way nurses respond to patients in the clinical environment.

It was interesting that student nurses and psychiatric nurses had significantly different ratings than qualified general nurses. This suggests that socialisation into the Medical Model may take place during later stages of training when students move from a common foundation to a branch-specific education or that this sub-cultural socialisation takes place post-qualification. The corollary position is that psychiatric nurse specialist education or socialisation into that particular sub-culture has a judgement neutral effect. It merely sustains and supports views already held by student nurses that people who self-neglect are likely not to have chosen to lead aspects of their lifestyle.

Aim 3

To identify patient characteristics which influence judgements of self-neglect

The six variables used in the construction of patient vignettes accounted for 21.4% of the variance in professionals' judgements of self-neglect. Thus most of the variance is explained by other factors. Adams and Johnson (1998) may be correct when they imply that the concept of self-neglect may be too complex and heterogeneous to be reduced to a few common features. This finding also raises pragmatic questions about the clinical usefulness of the concept self-neglect.

Findings from stage one support the notion of heterogeneity in the types of medical and nursing diagnoses found in those patients identified by District Nurses as being self-neglectful (Sections 3.6.3: 3.6.4). It may be a concept which is used in ways which are not helpful in communicating a clear sense of the behaviours which are incorporated into the category of self-neglect. It is suggested that we need to have a clearer sense of what we mean by self-neglect at a conceptual level and also in terms of how such a concept would be operationally defined.

The dominant dimension in the regression model was self-care status. Self-care status accounted for more variance than the other five dimensions combined. This lends support to the tentative model of self-neglect which began to emerge in stage one in which self-care was a central concept (Section 3.8). The formal construction of self-neglect which has self-care as a central concept is therefore consistent with the tacit construction held by nurses. This may not be surprising as constructions of self-neglect are sub-culturally and culturally-bound inasmuch as ideas of self-neglect have been framed within a discourse dominated by the Medical Model (Section 1.4.2).

Within the self-care dimension the level `severe accumulation of dirt, food waste and hygienic waste in the house, personal hygiene very poor with infested hair, long curly nails and clothes smell of urine` was, as expected, the dominant level. This level represents the image of severe self-neglect syndromes portrayed in the nursing and medical literature

(MacMillan Shaw 1966, Moore 1989) (Section 1.2). The level which links seeking nursing/medical regimes and non-compliance to these regimes had the lowest mean score of self-neglect. Reed and Leonard (1989) believe that non-compliance and self-neglect are closely related. In stage one non-compliance was a common nursing diagnosis in the self-neglect group (Section 3.6.4). In stage two of the main study participants did report a seemingly different view when claiming that self-neglecters would comply with prescribed treatment when they thought it was in their interest to do so (Section 4.7). The findings in this stage would appear to suggest that whilst non-compliance is thought to be a indicator of the presence of self-neglect it is judged to be indicative of self-neglect at the lower end of the continuum.

Aim 4

<u>To identify patient characteristics which influence judgements of choice in leading a lifestyle</u>

The most common rating was that patients had chosen to lead all aspects of their lifestyle. The least popular was that patients had no choice in leading a particular lifestyle. In this sense nurses were found to have been inclined to believe that people, even within the limitations created by impaired ADL status, impaired psychiatric status, impaired self-care status, still had the capacity to make choices about their lifestyle. Judgements about choice and blame are commonly used in an interchangeable fashion (Yalom 1980). Thus in essence nurses may be saying `that I am rather disgusted at the state you (the self-neglecter) are in and I think that you (the self-neglecter) must accept some of the blame for this state - in-spite of the fact that you (the self-neglecter)

are intellectually and physically incapable of fully caring for yourself'. This idea touches on a rich seam of sociological literature, some of it specifically nursing, regarding attributions of blame. Mischel (1993) describes the way in which people make judgements about others even when they have little knowledge of them. Abraham and Shanley (1992) believe that understanding the characteristics we use to represent others, permits people to build up a set of expectations because they help to explain causes of events. They further argue that there is evidence suggesting that people have a general tendency to explain behaviour in terms of patients' characteristics instead of situational factors. They state that people with "less socially acceptable" illnesses are thought to have more rigid and resistant personalities and patients who are non-complaint are regarded as bad. Bad patients may receive poorer treatment from nurses (Kelly and May 1982).

The second CATREG also included the six variable vignettes and these accounted for 23.2% of the variance in judgements of choice in lifestyle. This finding is similar to the 25% variance in judgements of responsibility in elder self-neglect cases made by adult protective workers in USA (Byers and Zeller 1995). In their model the independent variables were age, household income, disability, family presence and involvement, form and consequence of self-neglect. The vast majority of variance was accounted for by disability and this led Byers and Zeller to conclude that judgements of responsibility were unidimensional. The findings from the current study, using different variables in the model, suggest that for nurses such judgements are not unidimensional. The dominant dimensions in this regression

model were, in order of importance, stated preference for lifestyle, psychiatric status, ADL status. In the stated preference for lifestyle dimension the level expressed desire to lead another lifestyle was dominant. This finding is difficult to interpret but MacMillan Shaw's (1966) distinction between passive and active choices in self-neglect may be of some relevance. Patients who express a desire to lead a lifestyle other than that which they are leading appears to represent a passive position. It is passive in the sense that although they wish to change a lifestyle they do not or are perceived not to be able to change their lifestyle. Thus this finding may offer a challenge to the active choice hypothesis. The active hypothesis is one which is not consistent with the Medical Model with its ideas on loss of control and passivity of patients (Abraham and Shanley 1992). The view held by these nurses is that of passivity and loss of control over one's life. A seemingly contradictory finding from stage two was that Mr W the most serious case of self-neglect was clearly thought to have actively chosen his lifestyle. Thus the active choice hypotheses receives support in that case (Section 4.6.5) .

The complexity of the active and passive choice hypotheses is further illustrated in the finding that in the psychiatric status dimension, major mental illness was the dominant dimension. This was expected in the light of what may be regarded as the generally held view that patients with a major mental illness have an impaired ability to make choices about their life (Orem 1991). In ADL status the dominant dimension was 'dependent in all ADLs'. This was also expected in the light of the generally held view that when one is dependent in all basic

ADLs one's ability to change ones life is proportionately reduced (Orem 1991). Both the presence of psychiatric and ADL status are important variables in nurses' decision making process. This is consistent with the Medical Model, Dependency Theory and Orem's Theories (1991), whose propositions on the relationship between disease and choice are widely known to nurses (Section 1.1).

The relationship between ADL, psychiatric status and choice lends support to the case study findings (Section 4.7). The case studies do though present a more differentiated picture in which some cases (i.e. dementia) are linked to lack of choice whilst others, including the man with the worst case of neglect seen by the District Nurses, were thought to have choice in their lifestyle. Therefore it is not the self-care aspect of self-neglect which influences attributions of choice but a combination of stated preference, ADL status accompanied by a major mental illness, which were the main influences on such judgements. The issue of choice brings one back to a central problem in this thesis, that problem being the lack of conceptual clarity of self-neglect (Section 1.1). If self-neglect is to be understood as failure to engage in adequate self-care actions the question of ability, both cognitive and physical, to engage in self-care acts arises. Self-neglect appears to be used in cases in which patients have the ability, do not have the ability or are judged by practitioners as having or not having the ability to engage in self-care acts. The label self-neglect seems appropriate to describe those who have the ability but choose not to care for themselves. It is appropriate in the sense that there are a group of individuals who may simply be 'anti-social'. They are anti-social in the sense that they do

not conform to social norms. Professionals can choose to accept this behaviour or control this behaviour, through treatment or through legal actions (Section 1.2.4). The latter response to self-neglect is the so called policing function of the medical hygiene police (Foucault 1980) (Section 1.4.2). Those who do not have the ability, as a consequence of many factors including dementia, do not have that sense of agency which allows one to do something. Therefore if one cannot do something one cannot choose not to do this thing.

If we are to accept that self-neglect is a continuum then we are faced with the prospect of a complex picture of self-neglect with varying degrees of severity. This raises questions about the distinction between a pathological and non-pathological state. If the distinction is quantitative where is the cut-off point? Is self-neglect a discrete medical syndrome in which only severe self-neglect can legitimately be a pathological state? The distinction between normal and non-normal is a qualitative one and in one sense this makes diagnosis of a syndrome technically easier, although the conceptual problem of whether it really exists remains.

5.8 **Limitations**

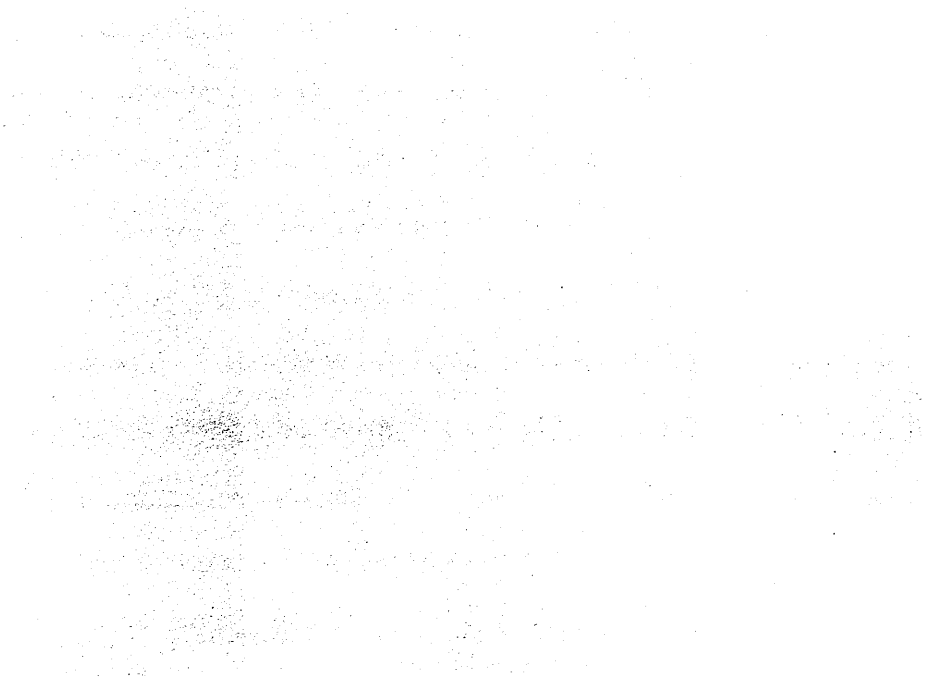
Using a single question to measure an attitude has been suggested to produce inconsistent and thus unreliable results (Oppenheim 1993). This is a consequence of factors such as question wording and context (Moser and Calton 1971, Oppenheim 1993). This may be less of a problem in stage three as the focus was not on an attitude in the general sense but on a social judgement of a specific concrete case.

The problem of sensitivity has been recognised as a problem in response formats (Wilkin et al 1992, Oppenheim 1993). This may mean that the seven-point scale used in this stage of the main study was not sensitive to real but fine differences in judgements. Another problem with this form of response format is the tendency to avoid extreme scores and to place judgements around the mean (Moser and Calton 1971). This did not appear to be a major problem in stage three and in fact the modal rating of choice was at the lowest end of the scale.

Berk and Rossi (1982) highlight the problem of truncation in vignette studies. Truncation refers to the possibility that a variable may be characterised by a floor-ceiling effect outwith which no observations can be made. Truncation was not observed in the distribution of neglect ratings but was evident in the choice ratings when 20.2% of ratings were in the lowest category. A relatively large number of responses cluster around boundaries. This leads to problems in many multivariate regression techniques by producing inconsistancies and bias in these techniques. In stage three this problem was overcome by using a categorical regression method which is not influenced by truncation type distributions.

There are number of limitations when using vignette-based methods. These include the fact that due to the artificial nature of vignettes one cannot assume that subjects' responses would be the same in an actual event. This creates problems for the external validity of findings (Lanza and Carifio 1990). Lanza and Carifio (1990) also suggest that there are threats to the internal validity of the study. Changes in the

independent variable must produce changes in the dependent variable. They suggest that researchers seldom have sufficient control to make such causal inferences. They argue that the failure to use strict control conditions is a major methodological weakness in much vignette based research. They advocate the use of control vignettes as a means of enhancing both internal and external validity. This criticism applies to vignette studies which use a few researcher developed vignettes. The randomisation and control which is a feature of the factorial survey design in stage three overcame the methodological limitations identified by Lanza and Carifio (1990).



CHAPTER 6

SUMMARY AND CONCLUSIONS

6. SUMMARY AND CONCLUSIONS

6.1 Theoretical Background to the Study

The theoretical background and the philosophical assumptions which underpin the three stages that comprise the main study changed over course of the study. This development was in response to the study aims which dictated that self-neglect can and in fact should be understood in very different ways. Broadly speaking the main study moved from a synthesis of Orem Theories and the Medical Model orientation of stage one, through to the social constructionist orientation of stages two and three.

The implicit theoretical orientation of much self-neglect research has been the Medical Model with its notions of causality, objectivity, disease and symptomatology. This orientation is implicit rather than explicit as the theoretical framework for studies is seldom reported in the research literature. It can be suggested that many of these researchers are operating from the belief that the tenets of the Medical Model are so truthful that they can be taken as givens rather than as a set of concepts and propositions which need to be tested. The few case studies found in the nursing literature used Orem's Theory of Self-Care (1991) as a guiding framework (Section 1.3.2). The rationale for using this theory was not provided by the authors and again one is given the impression that the relationship between self-care and self-neglect is almost taken for granted. One theory explicitly developed to understand self-neglect is the Adaptive Compensation Theory (Rathbone-McCuan and Bricker-Jenkins 1992) (Section 1.1). This

theory is very under-developed and in its published form is not suitable for use as a theoretical framework for research, although it opens up possibilities for future research (see Chapter 1 for a discussion of the theoretical basis for self-neglect research).

The lack of any consensus with regards to the theoretical basis for self-neglect resulted in a number of concepts and propositions (one of which is stated in the form a research hypothesis) being identified from the literature which would form a conceptual framework for stage one. The concepts included disease/illness (operationalised by nursing diagnoses and medical diagnoses), functional ability, self-care and self-care agency. These concepts were of varying value in clarifying our understanding of self-neglect. The hypothesised relationship between self-care agency and self-neglect was supported and thus self-care and self-care agency may be useful concepts in understanding self-neglect (Section 3.6.6).

Dependency Theory and the Medical Model both suggest that disease and illness and impaired functional ability increase an individual's susceptibility to self-neglect. There was a suggestion that psychiatric diagnoses and the nursing diagnoses of ineffective management of therapy and non-compliance may be features of self-neglect. Nevertheless the concepts of medical and nursing diagnoses proved of limited use in distinguishing self-neglect patients from other patients cared for District Nurses. Likewise the functional ability of patients was broadly similar in both groups, with some exceptions, and thus functional status did not clarify the construct of self-neglect. Gruman

et al's (1997) support for the Dependency Theory of Self-Neglect was not fully supported. Dependency Theory may explain why a sub-group of people, who have dementia and are fully dependent in all ADLs, self-neglect. Dependency Theory fails to explain why people who are independent in all ADLs will self-neglect and also why people with similar levels of functional ability may or may not self-neglect. Dependency Theory can be suggested to be too simplistic a theory to fully explain the complexity of self-neglect.

Hudson (1989) suggests that there is no extant theory of self-neglect, but what some authors claim to be a theoretical perspective is best described as a taxonomy of behaviours. This criticism is not warranted in relation to the use of Orem's construct of self-care agency in stage one. Self-care agency was employed, for what may be the first time in a study of self-neglect, to provide the theoretical links between disease and illness, functional ability and self-neglect. In essence individuals who have some form of disease or illness, with its concomitant reduction in functional ability, experience a reduced level of self-care agency. Self-care agency is that theoretical construct which explains the process and abilities individuals require in order to decide and act upon self-care requisites. When self-care agency is not sufficient to meet self-care requisites, self-neglect can appear. This finding offers up not only the potential to advance our theoretical understanding of self-neglect but also the potential to develop nursing interventions directly targeted at increasing self-care agency.

The limitations of the theoretical framework and philosophical assumptions underpinning stage one are outlined in Chapter 3. These limitations and the aims of stages two and three suggested that another theoretical approach to the study of self-neglect be adopted in these stages. The theoretical approach chosen was social constructionism. Social constructionism is an approach which can be placed within the rubric of sociological theories. Social constructionism proved a useful approach as it legitimates the explication of the many constructions of self-neglect held by various social actors. These constructions are rooted in a wider cultural and professional discourse on hygiene and cleanliness. The focus moved from describing an objective syndrome called Diogenes Syndrome to focusing on the dynamic way in which self-neglect is judged and understood by individuals within a given cultural and professional context. Attribution theory would suggest that professional carers use a few patient characteristics to build up a set of expectations about cause-effects of illnesses. In stage three the relative importance of a number of factors was investigated (Section 5.6.4). It was found that nurses were more likely to be influenced by some patient characteristics than others when determining levels of self-neglect. These findings do lend support to the basic proposition of attribution theory just outlined.

Rogers (1991) in his critique of socio-psychological theories claims that such theories present the view that constructions of disease are the products of human thinking which are then projected onto the external world. He proposes that a dialectical approach considers constructions to have both an internal and external basis. Dialectical

theories accept that constructions are influenced by external factors such as social norms and cultural values and practices. Rogers further adds that a dialectical approach would place constructions of disease in an historical context. A dialectic approach to self-neglect would provide an explanation for the way in which constructions involve an interaction between an individual, professionals and the external world of cultural values on cleanliness and self-care. The post-modern notion of dominant discourses could explain why a particular construction of self-neglect has been reified in the form of a medical diagnosis such as the Diogenes Syndrome. A dialectic theory of self-neglect would suggest that self-neglect is a category label which is a consequence of an interplay between competing discourses, cultural values, professional norms and language, and personal circumstances. This is not to say that self-neglect does not exist, in the sense that there are relationship, lifestyle and health-related problems for patients, relatives and professionals, but the focus is on how self-neglect has been constructed and how the application of a diagnostic label impacts on individuals (Section 1.4.5).

The notion of a social constructionist perspective of self-neglect highlights the very tenuous nature of self-neglect. It also highlights the ways in which values and beliefs influence how and when this label is applied. Using a social constructionist perspective allows one to draw parallels between self-neglect and a wide range of other phenomena such as attention-deficit disorder, post-traumatic stress disorder and deafness. Each of these phenomena are socially constructed in a way which legitimises a construction of these problems as medical

disorders which are amenable to medical treatments. The process by which a medical construction has come to dominate has been explicated in the case of self-neglect using Berger and Luckman's (1967) notion of legitimation. This process of legitimation can conceivably be suggested to apply equally to these other socially constructed phenomena.

6.2 **Discussion**

The main study, in a sense mirrors self-neglect inasmuch as both have qualitative and quantitative dimensions, are complex and multi-faceted, and can be understood within very different theoretical perspectives. The first stage was rooted in the dominant constructions of self-neglect found in extant literature; the Medical Model and Orem's Theory of Self-Care. The assumptions which emerge from these constructions include an acceptance that self-neglect exists independent of any cultural and historical context, self-neglect is a discrete medical syndrome which can be described objectively (usually from the viewpoint of the professional) and that this syndrome is caused by an underlying medical disorder.

The quantitative methodology underpinning the first stage did in fact demonstrate support for a number of claims in the extant literature which suggested self-neglecters frequently have a psychiatric disorder (Section 3.6.3) and frequently live alone (Section 3.2.1). The use of Orem's concepts of self-care and self-care agency did provide a meaningful way of conceptualising aspects of self-neglect. Self-neglecters were shown to have low levels of self-care agency (Section

3.6.6). Self-care agency in Orem's Theories plays a crucial part in explaining why and how individuals engage in self-care. Individuals who have low levels of self-care agency will not have the capacity to care for themselves and therefore may in certain circumstances develop self-neglect. Self-care may be a central concept in a nomothetic approach to this phenomenon which aims to develop a general theory of self-neglect (See section 4.2 for a discussion of nomothetic and idiographic approaches to self-neglect).

Nevertheless although stage one began to produce a description of self-neglect which contributed to our understanding of self-neglect, it was also clear that in a number of ways people who were reported to self-neglect defied clear description and showed similarities to people who were reported not to self neglect (Section 3.7). Quantitative methodology with its tendency to deal with populations obscures differences and contradictions (Section 3.9). In addition the circularity of the professional understanding of self-neglect, rooted in privileged cultural values and norms, in which we see what we set out to see may perpetuate a construction of self-neglect which is at odds with the constructions of self-neglect held by other social actors. Thus what first appeared to be a homogenous phenomenon turned out to be a heterogeneous and poorly conceptualised phenomenon.

The complexity and heterogeneity of self-neglect was explored in the multiple-case studies described in stage two (Chapter 4). The theoretical and philosophical assumptions underpinning this stage were different from those underpinning stage one. The philosophical

orientation of stage two can best be described as idealist (Section 4.2) and the theoretical underpinning was social constructionism. Social constructionism implies that reality is located within a social, cultural, sub-cultural, political, and personal context. Consequently different social actors have different constructions of a phenomenon, in this instance self-neglect. Some constructions, such as the Medical Model, are given a privileged position and are regarded as having a special access to the `truth`.

Stage two permitted the various constructions of patients and professional carers to be uncovered. The proposition that there are different constructions at work in many cases of self-neglect was supported. In addition it was shown how the conceptual label of self-neglect was applied by professionals to a wide range of behaviours (Section 4.7). These behaviours included the failure to seek nursing and medical assistance when this was needed, an inability to undertake activities of daily living, and poor personal and household hygiene. The perceived link between psychiatric diagnoses and self-neglect varied between and also within cases of self-neglect (Section 4.7). In the case of dementia there was a clear attributional causal link but in other cases the relationship was not clear-cut.

It is suggested that psychiatric illness and self-neglect may co-exist but may not necessarily have a causal link. It is further suggested that the presence of a psychiatric illness may make it more likely that professionals' judge that an individual is self-neglecting. The process of social judgements of self-neglect was investigated in stage three. The

findings of stage two strongly suggest that self-neglect is a poorly conceptualised phenomenon which may lead different practitioners to categorise the same types of behaviours in very different ways. If self-neglect is to be understood as a continuum of behaviours how are we to objectively measure when self-neglect becomes pathological and thus warrants the application of a medical diagnoses? Any such judgement involves notions of what is normal and acceptable. Consequently self-neglect is not an objective *a priori* status but involves a complex set of social judgements.

The implications of this may be profound for people who come to be labelled as suffering from a self-neglect medical syndrome. Such individuals, when diagnosed as diseased, can now be legitimately treated by the nursing and medical professions. These treatments range from drug therapy, with questionable benefits, through to forcible removal to hospital or even prison. The whole issue of treatment and prognosis for self-neglecting patients was brought into sharp relief during stage two. There was a general sense, shared by patients, nurses and medical practitioners, that this type of patient had a poor prognosis (Section 4.7). What seemed to be missing from this equation was a genuine attempt to understand the world from the patient's perspective. The treatment of patients with self-neglect was fragmented and professionals were unclear whose responsibility it was. There was some confusion between District Nurses and CPN's about who was most competent to care for this group of patients. Professional perspectives of care were characterised by pessimism and lack of hope. The exception was the case of Miss D whose care was described in

terms of primarily physical treatments (Section 4.6.4). It may be that conceptualising a problem in terms of concrete physical events allows professionals to focus on easily observable symptoms which are directly amenable to professional interventions.

The treatment-punishment of self-neglect may be understood in terms of what Foucault (1980) describes as the noso-political phenomena of a general police of healing. This policing project emerged from the 18th century concerns in capitalist societies about threats to their ability to accumulate men to wage war and for mass production of goods. Thus uncleanliness has come to be reconstructed as a syndrome and a harbinger of disease. In this reconstructive process the individual is to be regarded as an object; a disease category. If professionals were aware of the complex dialectical process in which constructions of self-neglect are socially constructed and how these constructions govern our response, they may take the first step to overcoming this sense of therapeutic nihilism. When the nurse recognises that there are many ways of understanding self-neglect, the corollary position that there are many possible solutions becomes obvious. This opens up the possibility that there are a range of responses available to professional carers one of which may meet the needs of self-neglecters and/or their families.

The third stage investigated the factors which influence nurses' judgements of self-neglect and the degree of choice self-neglecters are believed to exercise in the lifestyle they lead. This stage was also underpinned by the social constructionist theoretical perspective. The

methods used in stage three allowed the various factors which had been previously identified as influencing judgements to be examined. The judgements of self-neglect made by general, psychiatric and student nurses showed no significant difference across groups (Section 5.6.2). Thus notions of self-neglect may be very powerful and shared within a given cultural and professional context. Judgements of self-neglect between groups showed marked similarities and thus constructions of self-neglect are widely held in nursing and the evidence from the student group indicates that these constructions are quickly inculcated during the educational process, or alternatively are held by students prior to commencement on training. This may be a topic worthy of future study.

The major factor which influenced judgements of self-neglect was self-care status (Section 5.6.4). This provides support for the central role played by the concept of self-care in both the more formal constructions of self-neglect found in the literature and the tacit constructions of self-neglect held by nurses. This was not unexpected as the post-modern perspective describes the way in which particular constructions dominate within a culture and exert their influence not only on everyday ideas of cleanliness and hygiene but on the way these behaviours are framed within nursing and medical discourse.

Professional judgements of choice are central to both defining self-neglect and responding to self-neglect (Longres 1994). Longres asks the question '*Where does self-determination end and self-neglect begin?*' (p 3). It is evident that for Longres the central factor which determines

when someone moves from being a very untidy and dirty person to being self-neglectful in a statutory and medical sense is a judgement about choice and the capacity to make choices. Longres has shown how elder abuse professionals in the USA did use judgements of competence and non-competence to determine whether an individual fell into the category which required statutory intervention. This relationship between judgements of choice and self-neglect did not apply to nurses in stage three as there was no significant relationship between choice and neglect ratings. If UK nurses do, in practice, use judgements of choice (choice being a proxy measure of self-determination) to make diagnostic decisions on self-neglect, the validity of this decision making process is open to doubt.

There were significant differences between general nurses, psychiatric nurses and student nurses regarding the level of choice that self-neglecters were believed to have exercised in the lifestyle they were leading (Section 5.6.3). General nurses were more likely than both psychiatric nurses and student nurses to believe that individuals had exercised more choice in the lifestyle they lead and were therefore more inclined to accept the active hypothesis of self-neglect. It is not clear whether choice was interpreted in the existential sense of being the uncontested author of an event or whether it was used in the more prosaic sense of blaming the patient. This is a topic worthy of further study.

The factors which influenced judgements of choice were stated preference for lifestyle, dependent in all ADLs, and having a major

psychiatric disorder (Section 5.6.4). This was not altogether unexpected as the image, and in many cases a reality, of somebody who fits this picture is of a person who has limited choices in the lifestyle they lead. In essence the Medical Model would propose that in certain circumstances, such as when an individual has a psychiatric disorder, they have a limited capacity to choose to engage in self-care actions. With respect to self-neglect and dementia is was clear that the participant did not choose to neglect themselves. In the case of the man with severe self-neglect he himself admitted that his life-style was intentionally chosen and yet it was assumed that this was a result of undiagnosed deep-seated psychological problems. Longres (1994) suggests that the professional's judgement of the self-neglecter's capacity to choose to lead a lifestyle influences whether self-determination or the doctrine of *parens patriae* is accepted as the guiding principle of treatment (See section 1.2.4).

Dingwall (1976) suggests that the Medical Model exonerates individuals from responsibility for their own condition. Reed and Leonard (1989) on the other hand, believe that individuals are responsible for their own self-neglect. The notion of responsibility and choice are used in a number ways which lead to some confusion about what is meant by these terms. Foucault's (Dreyfus and Rabinow 1982) concept of governmentality refers to modes of action which structure the potential fields of action of others. Ideas of freedom and choice are explicit here as he suggests that institutions, in this case medicine, have the power to define, regulate and punish categories of behaviour. In this sense an individual's freedom to choose to live a

particular lifestyle is limited, and those who choose to live a particular lifestyle can have this choice categorised as undesirable, a process which sets up possibilities of treatment-punishment. The everyday understanding of responsibility and choice is a more prosaic one and revolves around notions of blame. This notion does not distinguish between cannot do, will not do and finds it difficult to do. It is the degree of disjuncture between the various notions of responsibility and choice that is of particular interest in the current study.

The issues of freedom and choice are central to the Medical Model and to wider economic-political discourses on the place of the individual in capitalist cultures. Gerhardt (1989) argues that medical constructions of disease and illness have a political dimension. Self-neglect must be seen against a backcloth of capitalist values of personal achievement and the self-neglecting individual's inability to engage in productive activities. To neglect the `self' is to deny one of the major projects of liberal humanism, that is, care of self.

The findings of the three stages of the main study contribute in original ways to the scientific and practice-based communities' understanding of self-neglect. The conceptual framework developed for stage one and the use of Orem's notion of self-care agency to understand self-neglect have not previously been employed. In addition the description of the functional ability and the type of nursing diagnoses associated with those patients categorised as self-neglecting has not previously been documented. In stage two the explication of the various constructions of self-neglect, most notably the constructions of patients, has been

previously missing from the literature. The explication of the pessimism expressed by health care professionals when faced with caring for self-neglecting patients is a timely and practical reminder to professionals. The range of patients labelled as self-neglecting clearly supports the claims made in some sections of the literature on the lack of conceptual clarity of the label self-neglect. The research design used in stage three to investigate judgements of nurses has not been documented in the published literature, certainly in UK. Finally the critical examination of the Medical Model, a nursing theory, and the various constructions of social actors in understanding self-neglect and the practical implications of these constructions is new and original.

6.3 **Implications**

1. The findings of the main study support the contention that self-neglect is underconceptualised and illustrate the need for greater theoretical development. The dominant construction in the medical literature, that self-neglect is a medical syndrome and is an objective reality which can be defined from the professional's perspective, has been challenged. In addition that circularity of the medicalisation of self-neglect through professional doctrine and through professional journals strongly suggests that this theoretical development requires to include theoretical perspectives rooted in different philosophical perspectives which challneg this doctrine.

2. The issue of philosophical and theoretical perspectives of self-neglect also raises questions of research methodology. It has been shown that

there are radically different ways to understand a phenomenon, in this case self-neglect, and these dictated that different methods be used to study this phenomenon. Each method may provide a picture which complements other methods, but, equally as likely, may uncover inconsistencies and contradictions. Triangulation from this perspective should be understood as a comprehensive account of a pluralist world. This is in contrast to the positivist perspective in which inconsistencies and contradictions are viewed as products of technical limitations in the research design and are thus are questions of validity and reliability. If one accepts the tenets of idealism-constructionism then one would expect to find inconsistencies and contradictions in a pluralist world where there is no single version of truth. This problem ceases to be a limitation but is in fact a virtue as it permits the uncovering of the richness of a complex world.

3. At the patient-professional interface there are likely to be different and sometimes competing constructions of the problem. The first task facing the practitioner is to enter into a dialectical process in which a shared definition of the problem emerges. This dialectical process involves a complex set of skills which may not be well understood at the moment but which still require to be taught.

4. The therapeutic orientation of professionals appeared to be generally pessimistic with District Nurses and CPNs unsure who had the responsibility for treating the self-neglecter. There needs to be a clear understanding of the goals of treatment, if indeed treatment is necessary. The problem of role ambiguity needs to be addressed with

community nurses if we are to be clear as to who has responsibility for this type of patient whose problems do not easily fit into mental health, physical health or social health categories. The interventions needed by each individual require to be transparent and any goals and interventions need to be acceptable to patients. This may seem obvious but was not evident in the observed practice.

5. Education should explicitly deal with the way in which nurses make value judgements and identify the factors which nurses take into account when making these value judgements. This should involve not simply general admonishments to be non-judgmental and objective. Specific concrete phenomenon should be the focus of learning. The use of case studies as vehicles for teaching self-neglect and judgements of self-neglect can be recommended to teachers.

6.4 **Ethics**

The study was submitted to the Local Health Board Research Ethics Committee and, for matters relating to nursing students, to the Department of Nursing and Midwifery Ethics Committee for ethical approval. The issues of confidentiality, anonymity and informed consent were addressed to the satisfaction of these committees (Appendix 6). The Health Board Committee, in addition, identified the following ethical issue "..the question of the researcher's responsibility should the condition of the elderly person give serious cause for concern. It was felt that, in this situation, the researcher would be morally obliged to try and pursuade the patient or their carer to consult their GP". It was agreed that in cases where the researcher

judged that the patient's health gave rise to concerns about their safety attempts would be made to persuade the patient and/or their carers to consult the GP.

6.5 **Future Studies**

In the light of the conceptual and theoretical under-development of the concept of self-neglect it would appear that further empirical and theoretical work needs to be undertaken to clarify what is and what is not self-neglect. This would include clarification of the concepts of choice and agency. These studies would by design explicitly take into account the cultural context within which self-neglect is being investigated.

The role of language and the iconography of self-neglect in constructing professional and lay beliefs about cleanliness and hygiene and the impact these beliefs have on labelling self-neglect is an area of potential research. This type of study would use genre analysis or discourse analysis methods which should transcend various academic disciplines such as Nursing, Literary Studies, Film and Media Studies and English Language Studies.

The three stages which comprise the main study could be extended and widened. In stage one a random sample could be drawn from a GP's patient list. The criteria for identifying self-neglect could either be operationally defined or a number of professionals could identify self-neglecters independently, thus providing examples of different judgements. Stage two could be extended to include more cases. This

would provide for a greater range of perspectives or alternatively one could take a very different methodological approach by employing grounded theory methods aimed at developing a theory of self-neglect. Stage three could be developed by including a wider range of occupational groups in the sample and also by refining the six variables model.

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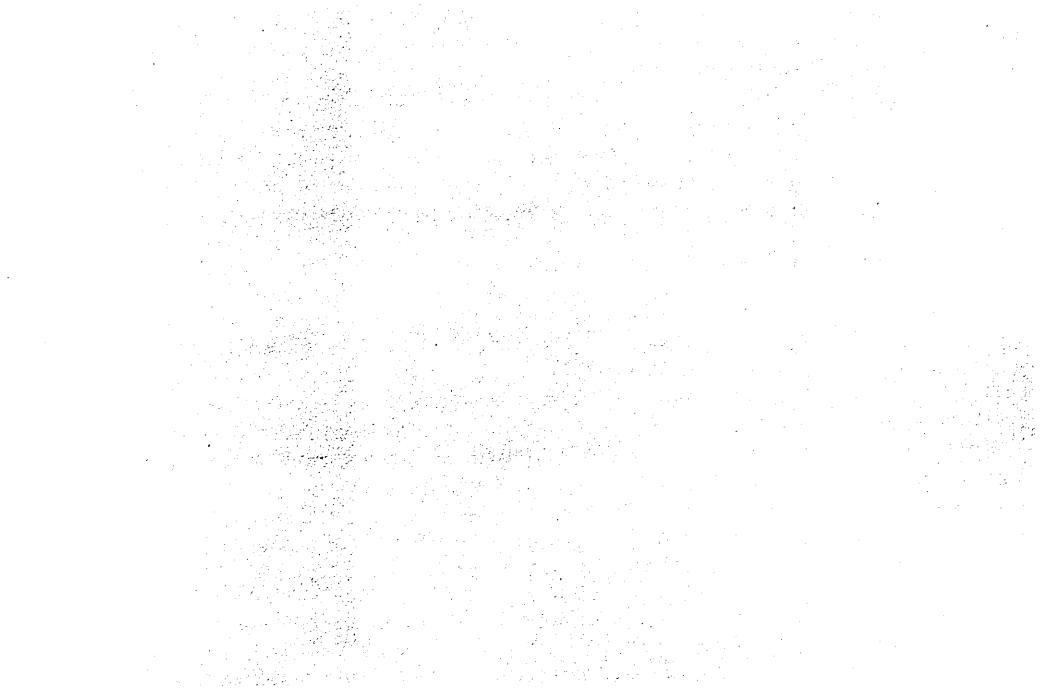

APPENDICES

Appraisal of Self-Care Agency Scale

Developed by: Brouns, Evers, Smeets, Isenberg, Philipsen

A.S.A. form B (appraisal of another)

Study ID:

Date:

Directions:

A list of statements which people have used to describe themselves are given below. Please read each statement and then circle the appropriate number to the right of the statement to indicate how much you agree or disagree with the statement as a description of the person under consideration. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to be most descriptive of the person under consideration.

		Totally Disagree	Disagree	Neither Disagree Nor Agree	Agree	Totally Agree
1.	As circumstances change, makes the needed adjustments to stay healthy.	1	2	3	4	5
2.	Rarely checks whether the measures taken to stay healthy are adequate.	1	2	3	4	5
3.	When mobility is decreased, makes the needed adjustments.	1	2	3	4	5
4.	Takes measures to maintain sanitary conditions in personal environment.	1	2	3	4	5
5.	When needed, sets new priorities in the measures that are taken to stay healthy.	1	2	3	4	5
6.	Often lacks the energy to care for self in the way he/she would like.	1	2	3	4	5
7.	Looks for better ways to care for self.	1	2	3	4	5
8.	To maintain personal hygiene, adjusts the frequency of bathing and showering to the circumstances.	1	2	3	4	5
9.	Eats in a way that maintains body weight at an appropriate level.	1	2	3	4	5
10.	When needed, manages to be alone.	1	2	3	4	5

	Totally Disagree	Disagree	Neither Disagree Nor Agree	Agree	Totally Agree
11. Often talks about including a program of exercise and rest in daily routine, but never gets around to doing it.	1	2	3	4	5
12. Over the years has developed a circle of friends that can be called upon when help is needed.	1	2	3	4	5
13. Rarely gets enough sleep to feel rested.	1	2	3	4	5
14. When receiving information regarding health, seldom asks for clarification of language that isn't understood.	1	2	3	4	5
15. Seldom examines self to determine the presence of any bodily changes.	1	2	3	4	5
16. When taking new medication, obtains information about the side-effects.	1	2	3	4	5
17. In the past has changed some old habits in order to improve health.	1	2	3	4	5
18. Routinely takes measures to insure the safety of self and family.	1	2	3	4	5
19. Regularly evaluates the effectiveness of things being done to stay healthy.	1	2	3	4	5
20. In daily activities seldom takes time to care for self.	1	2	3	4	5
21. Is able to get the information needed when health is threatened.	1	2	3	4	5
22. Seeks help when unable to care for self.	1	2	3	4	5
23. Seldom has time for self.	1	2	3	4	5
24. Due to limited mobility, is not always able to care for self in a way that he/she would like.	1	2	3	4	5

Maastricht, 18 May, 1987
MI/HP/3446

SCORING INSTRUCTIONS FOR APPRAISAL OF SELF-CARE AGENCY (ASA) SCALE.

1. Recode nine items: #2, #6, #11, #13, #14, #15, #20, #23, and #24.

   To recode: Reverse score each item 1=5, 2=4, 3=3, 4=2, 5=1.

   Example: If subject circles a "2" in response to item #6, recode the response by reverse scoring the "2"; the resulting recoded score is "4".

2. Scoring of unanswered items: If a subject does not answer an item on the ASA-Scale, score the item as a "3". On the ASA-Scale response "3" means neither disagree or agree.

   Note: If, however, a subject leaves more than three items on the scale unanswered, then the validity and in turn, usefulnessness of the subject's overall ASA-Score is questionable.

3. Determine overall score: After recoding items, determine the overall score by summing the scores for the 24 items.

   lowest possible score = 24
   highest possible score = 120

4. Determine factor scores: The scale was developed with the intent of yielding factor scores as well as an overall score. However, the development of this aspect of the scale is not yet completed.

4/87 MA ISENBERG

INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

EVALUATION SCALE

INDEX OF INDEPENDENCE IN ACTIVITIES OF DAILY LIVING

The Index of independence in Activities of Daily Living is based on an evaluation in the functional independence or dependence of patients in bathing, dressing, going to the toilet, transferring, continence, and feeding. Specific definitions of functional independence and dependence appear below the index.

A - Independent in feeding, continence, transferring, going to the toilet, and bathing.

B - Independent in all but one of these functions.

C - Independent in all but bathing and one additional function.

D - Independent in all but bathing, dressing and one additional function.

E - Independent in all but bathing, dressing, going to the toilet and one additional function.

F - Independent in bathing, dressing, going to the toilet, transferring, and one additional function.

G - Dependent in all six functions.

Other - dependent in at least two functions, but not classifiable as C, D, E, F.

Independence means without supervision, direction, or active personal assistance, except as specifically noted below. This is based on actual status and not on ability. A patient who refuses to perform a function is considered as not performing the function, even though he is deemed able.

Bathing (Sponge, Shower, or Tub)

Independent: assistance only in bathing a single part as in back or disabled extremity) or bathes self completely.

Dependent: assistance in bathing more than one part of the body: assistance in getting in or out of the tub or does not bathe self.

Dressing

Independent: gets clothes from closets and drawers; puts on outer garments, braces; manages fasteners; act of tying shoes is excluded.

Dependent: does not dress self or remains partly undressed.

Transfer

Independent: moves in and out of bed independently and moves in and out of chair independently (may or may not use mechanical supports)

Dependent: assistance in moving in or out of bed and/or chair; does not perform one or more transfers.

Continence

Independent: urination and defecation completely self-controlled.

Dependent: partial or total incontinence in urination or defecation; partial or total control by enemas, catheters, or regulated use of urinals and /or bedpans.

NAME.....DATE OF EVALUATION.....

For each area of functioning listed below, check description that applies. (The word "assistance" means supervision, direction or personal assistance). Please tick appropriate box.

Bathing-either sponge, tub bath, or shower.

☐	☐	☐
Receives no assistance (gets in and out of tub by self if tub is usual means of bathing).	Receives assistance in bathing only one part of the body (such as back or leg)	Receives assistance in bathing more than one part of body (or not bathed)

Dressing-gets clothes from closets and drawers-including underclothes outergarments and using fasteners (using braces if worn).

☐	☐	☐
Gets clothes and gets completely dressed without assistance.	Gets clothes and gets dressed without assistance except for assistance in tying shoe laces.	Receives assistance in getting clothes or in getting dressed, or stays completely or partly undressed.

Toileting-going to the "toilet room" for bowel and urine elimination; cleaning self after elimination; and arranging clothes.

☐	☐	☐
Goes to the "toilet room", and arranges clothes without assistance (may use object for support such as cane, walker or wheelchair and may manage night bedpan or commode, emptying the same in morning).	Receives assistance in going to "toilet room" or in cleansing self or in arranging clothes after elimination or in use of night bedpan or commode.	Does not go to room termed "toilet" for the elimination process.

Transfer-

☐ Moves in and out of bed as well as in and out of chair (may be using object for support such as cane or walker).

☐ Moves in or out of bed or chair with assistance.

☐ Does not get out of bed.

Continence-

☐ Controls urinary and bowel movement completely by self.

☐ Has occasional "accidents".

☐ Supervision helps keep urine or bowel control; catheter is use; or is incontinent.

Feeding-

☐ Feeds self without assistance.

☐ Feeds self except for getting assistance in cutting meat or buttering bread.

☐ Receives assistance in feeding or is fed partly or completely by using tubes or intravenous fluids.

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Facsimile:01463 713471

PROFESSIONAL CONSTRUCTIONS OF SELF-NEGLECT STUDY

This study is designed to elicit **your** views on self-neglect and how much choice people exercise in leading a particular lifestyle. Permission has been obtained from your manager to ask you to participate in this study. Any information you will provide is anonymous and no individual can be identified.

Please complete the attached biographical information sheet and complete the rating scales on the 10 case histories that have been provided. When you have completed these please return via internal mail in the envelope provided. This is likely to take between 5-10 minutes.

Thank you very much for your co-operation and assistance. The information you provide will prove beneficial in furthering our understanding of self-neglect.

Thank you in anticipation

W Lauder

William Lauder
Lecturer
Department of Nursing and Midwifery

PERSPECTIVES OF SELF-NEGLECT

Thank you for taking part in this study. Your responses will be treated as confidential and anonymous. The purpose of the study is to explore **your judgement** of what does or does not constitute self-neglect and how much choice each individual exercised in producing their particular lifestyle. Self-neglect refers to an individual not undertaking those self-care actions which promote a health body, mind, and/or lifestyle.

INSTRUCTIONS

There are randomly numbered 10 case histories in the package you have been given, please read these one at a time and on the basis of each case history please rate the degree of self-neglect you think is present in each case and also the extent to which each individual has had a choice in the type of lifestyle they lead.

REMEMBER IT IS YOUR JUDGMENTS THAT ARE IMPORTANT. THERE ARE NO RIGHT OR WRONG ANSWERS

BIOGRAPHICAL DETAILS

Question 1 What is your age.....

Question 2 Female ☐ Male ☐

Question 3
What is your professional background?
(Please tick appropriate box)

Qualified Nurse	☐
Qualified Medical Practitioner	☐
Qualified Social Worker	☐
Nursing Student	☐
Medical Student	☐
Social Work Student	☐
Education Student	☐

Question 4
If you are a qualified nurse or medical practitioner what is your speciality?
(Please tick one box only)

General Practice	☐
District Nursing	☐
Psychiatric Nursing	☐
Acute General	☐
Elderly Non-Acute	☐
Learning Difficulties	☐

CASE HISTORY 1

FEMALE.

LAWYER.

IS DEPENDENT IN ALL AREAS OF ACTIVITIES OF DAILY LIVING (BATHING, DRESSING, TOILETING, CONTINENCE, FEEDING, MOBILISING) AND REQUIRES A LOT OF ASSISTANCE FROM OTHERS TO UNDERTAKE THESE ACTIVITIES.

IS CURRENTLY DIAGNOSED AS HAVING SCHIZOPHRENIA.

SEVERE ACCUMULATION OF DIRT, FOOD WASTE AND HYGIENIC WASTE IN THE HOUSE. PERSONAL HYGIENE VERY POOR WITH INFESTED HAIR, LONG CURLING NAILS AND CLOTHES SMELL OF URINE.

WISHES TO LEAD THIS LIFESTYLE NO MATTER WHAT IMPACT IT HAS ON HER LIFE.

SELF-NEGLECT AND CHOICE RATING

PLEASE PUT CROSS ON APPROPRIATE NUMBER WHICH BEST REPRESENTS YOUR JUDGEMENT ON SELF-NEGLECT AND CHOICE IN THIS VIGNETTE.

A)

NOT SELF-NEGLECT 1-------2-------3-------4-------5-------6-------7 SEVERE SELF-NEGLECT

B)

HAS CHOSEN TO LEAD LIFESTYLE 1-------2-------3-------4-------5-------6-------7 HAS CHOSEN NO ASPECT OF LIFESTYLE

CASE HISTORY 2

FEMALE.

DOCTOR.

IS DEPENDENT IN ALL AREAS OF ACTIVITIES OF DAILY LIVING (BATHING, DRESSING, TOILETING, CONTINENCE, FEEDING, MOBILISING) AND REQUIRES A LOT OF ASSISTANCE FROM OTHERS TO UNDERTAKE THESE ACTIVITIES.

IS CURRENTLY DIAGNOSED AS HAVING DEMENTIA.

UNTIDY HOUSE WITH CLOTHES LYING ON THE FLOOR AND LITTLE EVIDENCE OF ATTEMPTING TO KEEP THE HOUSE TIDY. HAS A DIRTY APPEARANCE.

WISHES TO LEAD THIS LIFESTYLE NO MATTER WHAT IMPACT IT HAS ON HER LIFE.

SELF-NEGLECT AND CHOICE RATING

PLEASE PUT CROSS ON APPROPRIATE NUMBER WHICH BEST REPRESENTS YOUR JUDGEMENT ON SELF-NEGLECT AND CHOICE IN THIS VIGNETTE.

A)

NOT SELF-NEGLECT 1-------2-------3-------4-------5-------6-------7 SEVERE SELF-NEGLECT

B)

HAS CHOSEN TO LEAD LIFESTYLE 1-------2-------3-------4-------5-------6-------7 HAS CHOSEN NO ASPECT OF LIFESTYLE

CASE HISTORY 3

FEMALE.

SALES MANAGER.

IS DEPENDENT IN ALL AREAS OF ACTIVITIES OF DAILY LIVING (BATHING, DRESSING, TOILETING, CONTINENCE, FEEDING, MOBILISING) AND REQUIRES A LOT OF ASSISTANCE FROM OTHERS TO UNDERTAKE THESE ACTIVITIES.

IS CURRENTLY DIAGNOSED AS HAVING MANIC-DEPRESSION.

DOES NOT LOOK AFTER PERSONAL HEALTH IN AREAS SUCH AS DENTAL HYGIENE, DIET AND WILL NOT SEEK MEDICAL ATTENTION EVEN WHEN ILL.

WISHES TO LEAD THIS LIFESTYLE NO MATTER WHAT IMPACT IT HAS ON HER LIFE.

SELF-NEGLECT AND CHOICE RATING

PLEASE PUT CROSS ON APPROPRIATE NUMBER WHICH BEST REPRESENTS YOUR JUDGEMENT ON SELF-NEGLECT AND CHOICE IN THIS VIGNETTE.

A)

NOT SELF-NEGLECT 1-------2-------3-------4-------5-------6-------7 SEVERE SELF-NEGLECT

B)

HAS CHOSEN TO LEAD LIFESTYLE 1-------2-------3-------4-------5-------6-------7 HAS CHOSEN NO ASPECT OF LIFESTYLE

Appendix 4

Figure 4.2 Case Study Methodology (adapted from Eisenhardt 1989)

STEP	ACTIVITY	RATIONALE
Getting started	Define research question	Focus efforts
Selecting Cases	Theoretical sampling	Focuses efforts
Instrumentation	Multiple data collection methods; qualitative and quantitative data	Triangulation Fosters divergent perspectives
Entering the field	Overlap data collection & analysis: flexible data collection methods	Speeds analysis and allows for adjustments to data collection
Data analysis	Within-case analysis	Gain familiarity with data and emergent theoretical formulation
	Across-case analysis	Forces researchers to contrast and compare cases
Shaping hypotheses	Iterative tabulation of evidence for each theme; search for evidence of `why' behind each relationship	Sharpens construct definition, and validity Builds internal validity
Enfolding literature	Comparison with conflicting literature	Raise theoretical level, builds internal validity, sharpens construct definitions
	Comparison with similar literature	Improves construct definition, increase generalisability, raises theoretical level
Reaching closure	Theoretical saturation when possible	Ends process when marginal improvement is minimal

APPENDIX 5

Interview Topics - Multiple-Case Studies

1. Definition of the problem
2. What is self-neglect
3. How do you treat/care for this person (carer)
4. What care/treatment do you receive (patient)
5. Relationships between services
6. Relationship with DN, GP, CPN
7. Mental health problems
8. Choice in lifestyle
9. Social support networks
10. Definitions of success in treatment

APPENDIX 6

HIGHLAND HEALTH BOARD
ETHICS COMMITTEE

Chairman: Mrs A. Macpherson

Reay House
17 Old Edinburgh Road
Inverness IV2 3HG
Tel: 01463 239851
Fax: 01463 235189

28 June 1995

Mr William Lauder,
Highland & Western Isles College of Nursing & Midwifery,
Raigmore Hospital,
Inverness.

Dear Mr Lauder,

An Evaluation of Health and Social Services for the Elderly
With Self-Neglect Problems Who Are Living in the Community

Thank you for the response to the points raised by the Ethics Committee on the above proposal.

I am pleased to say that having considered your amended proposal by Chairman's Action we are now able to grant it ethical approval.

May I remind you that any proposed amendments to the submitted application should be referred to this Committee for further approval and that we should be advised of any adverse or unforeseen developments.

Yours sincerely,

Moira Pat

M Angela Macpherson
Chairman

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Chairman
Department of Nursing and Midwifery
Ethics Committee
University of Stirling

26 April 1998

Dear Chairman

I have enclosed details of a pilot study and a main study which I intend to undertake during May-August 1998. As intended subjects include staff and students in this department I have submitted an outline proposal to your committee for ethical approval.

I hope that this is satisfactory and that this matter can be expedited as soon as your internal procedures permit.

Yours sincerely

William Lauder
Lecturer

HIGHLAND & WESTERN ISLES
COLLEGE OF NURSING & MIDWIFERY

(INVERNESS CAMPUS)

MR R COOPER
RGN RFN RCT RNT BA
ACTING DIRECTOR OF NURSE EDUCATION

TEL NO. 0463 704000
EXT 4484
FAX No. 0463 713471

RAIGMORE HOSPITAL
INVERNESS
IV2 3UJ

YOUR REF

12 December 1995

Mrs Christine Gilmour
Clinical Services Manager
Highland Communities Care Unit
Royal Northern Infirmary

Dear Christine

Re: Research into District Nursing

You may be aware that I am undertaking a PhD study investigating District Nursing and patients with self-neglect problems. I am now at the stage of study that necessitates collecting information from District Nurses. This study has received approval from Highland Health Board's Ethics Committee and I hope that you will also agree to the study taking place in areas under your management.

I intend to ask District Nurses in the Inverness, Culloden, Loch Ness West and Badenoch/Strathspey/Stratherrick areas to participate. This involvement is likely to stretch to a 10 minute interview and the completion of 2 questionnaires at time of the DNs convenience.

I would be grateful if it could be arranged that I give a brief outline of the study to DNs in these areas, possibly at their weekly/monthly meetings. It is hoped that this will take place in January and that the data collection take place in February/March.

I hope that this brief outline is satisfactory, and if not I will be happy to discuss this matter further.

Yours sincerely

William Lauder

Nurse Teacher/NBS Research Training Fellow

HIGHLAND & WESTERN ISLES
COLLEGE OF NURSING & MIDWIFERY

(INVERNESS CAMPUS)

MR R COOPER
RGN RFN RCT RNT BA
ACTING DIRECTOR OF NURSE EDUCATION

RAIGMORE HOSPITAL
INVERNESS
IV2 3UJ

TEL NO. 0463 704000
EXT 4484
FAX No. 0463 713471

YOUR REF

12 December 1995

Mr Brian Lamont
Clinical Services Manager
Highland Communities Care Unit
Royal Northern Infirmary

Dear Brian

Re: Research into District Nursing

You may be aware that I am undertaking a PhD study investigating District Nursing and patients with self-neglect problems. I am now at the stage of study that necessitates collecting information from District Nurses. This study has received approval from Highland Health Board's Ethics Committee and I hope that you will also agree to the study taking place in areas under your management.

I intend to ask District Nurses in the Inverness, Culloden, Loch Ness West and Badenoch/Strathspey/Stratherrick areas to participate. This involvement is likely to stretch to a 10 minute interview and the completion of 2 questionnaires at time of the DNs convenience.

I would be grateful if it could be arranged that I give a brief outline of the study to DNs in these areas, possibly at their weekly/monthly meetings. It is hoped that this will take place in January and that the data collection take place in February/March.

I hope that this brief outline is satisfactory, and if not I will be happy to discuss this matter further.

Yours sincerely

William Lauder

Nurse Teacher/NBS Research Training Fellow

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INVERNESS IV2 3FG
Telephone:01463 704315
Facsimile:01463 713471

Mr Nigel Hobson
Director of Nursing and Quality
Raigmore NHS Trust

30 June 1998

Dear Mr Hobson

Re: Professional Constructions of Self-Neglect Research Study

I am currently undertaking a series of studies investigating self-neglect/diogenes syndrome. The study I am working on at the moment is to measure the variables which influence judgements of self-neglect of professionals (GPs, Nurses, Social Workers) and students (psychology, social work, medical, nursing).

I wonder if you would agree to me approaching qualified nurses in Raigmore with a view to participation in the study. The participation would consist of administering a small number of randomly constructed vignettes (case studies) and the completion of two rating measures for each vignette. This should take between 5-10 minutes. It is intended to collect data in Autumn this year.

I intend to collect data from a random sample of nurses practising in Raigmore. Data will be collected by means of a postal administration of a vignette package. If you agree to this request I can contact the relevant administration person for a list of all staff in Raigmore which will act as my sample frame. Staff and managers can be assured that this information will remain confidential and will not be used for purposes other than this study. The staff list will be returned when the sample is selected. It is even possible that such a sample frame will not need to be removed from Raigmore premises and sample selection can be carried out on-site. In addition subjects will be assured of anonymity. The study has been approved by the relevant ethical committees.

I hope that my request is not too onerous and I will be happy to provide any information you feel is necessary

Yours sincerely

William Lauder
Lecturer

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INVERNESS IV2 3FG
Telephone:01463 704315
Facsimile:01463 713471

Mr T Veitch
Patient Services Manager
Craig Dunain Hospital

30 June 1998

Dear Mr Veitch

Re: Professional Constructions of Self-Neglect Research Study

I am currently undertaking a series of studies investigating self-neglect/diogenes syndrome. The study I am working on at the moment is to measure the variables which influence judgements of self-neglect of professionals (GPs, Nurses, Social Workers) and students (psychology, social work, medical, nursing).

I wonder if you would agree to me approaching qualified nurses in CDH with a view to participation in the study. The participation would consist of administering a small number of randomly constructed vignettes (case studies) and the completion of two rating measures for each vignette. This should take between 5-10 minutes. It is intended to collect data in Autumn this year.

I intend to collect data from a random sample of nurses practising in CDH. Data will be collected by means of a postal administration of a vignette package. If you agree to this request I can contact the relevant administration person for a list of all staff in CDH which will act as my sample frame. Staff and managers can be assured that this information will remain confidential and will not be used for purposes other than this study. The staff list will be returned when the sample is selected. It is even possible that such a sample frame will not need to be removed from CDH premises and sample selection can be carried out on-site. In addition subjects will be assured of anonymity. The study has been approved by the relevant ethical committees.

I hope that my request is not too onerous and I will be happy to provide any information you feel is necessary

Yours sincerely

William Lauder
Lecturer

CLIENT INFORMATION SHEET

The research study that you have been asked to participate in is an evaluation of the effectiveness of the social and health services that have been offered to you. Your views on the problem and how successful services have been are central to the study method. Therefore you will be asked to describe your health status, describe the services that you are offered by health and social services and also asked to give an opinion on how effective these services have been in meeting your needs.

Your views will be collected by means of an interview or by completing a short questionnaire. This information will be confidential and anonymous and no individual will be identifiable in any findings. It is likely that if you are to be interviewed that this will take place on one or at most two occassions only.

Taking part in the study will not affect your treatment in any way and your General Practicioner and District Nurse will be informed of your participation.

The principal researcher is Mr William Lauder, who is a Nurse Teacher and Research Training Fellow at the Highland and Western Isles College of Nursing and Midwifery, Raigmore, Inverness (Telephone: Inverness 704000, ext 4484). If you have any further questions about this research study please contact Mr Lauder at the above address.

VERBAL EXPLANATION

research study that you have been asked to participate in is an
luation of the effectiveness of the social and health services that
been offered to you. Your views on the problem and how successful
ices have been are central to the study method. Therefore you will
sked to describe your health status, describe the services that you
offered by health and social services and also asked to give an
ion on how effective these services have been in meeting your
ds. The patient's and relative's view of problems and the services
are offered are frequently marginalised in research investigating
effectiveness of services. The reverse is the case in this
dy as your views are given a central place.

views will be collected by means of an interview or by completing
ort questionnaire. This information will be confidential and
ymous and no individual will be identifiable in any findings.
s likely that if you are to be interviewed that this will take
e on one or at most two occasions only.

ng part in the study will not affect your treatment in any way and
General Practicioner and District Nurse will be informed of your
icipation.

principal researcher is Mr William Lauder, who is a Nurse Teacher
esearch Training Fellow at the Highland and Western Isles College
rsing and Midwifery, Raigmore, Inverness. The study is part of
ctor of Philosophy Degree being undertaken by myself at the
ersity of Abertay Dundee. The findings of the study may be useful
e future design of health and community services for people such
urself.

International Journal of Nursing Practice 1999; 5: 58–63

SCHOLARLY PAPER

The medical model and other constructions of self-neglect

William Lauder DipN, RMN, RCNT, RNT, DipEd, MEd
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Accepted for publication October 1998

Lauder W. *International Journal of Nursing Practice* 1999; 5: 58–63
The medical model and other constructions of self-neglect

Nurses frequently encounter patients who neglect their personal hygiene and household cleanliness. Self-neglect is usually understood within the parameters of the medical model, with its need to objectify and categorize. The medicalization of self-neglect obscures the fact that patients and professionals may have different ideas about what self-neglect is and what it is not. This paper explores how the medical construction of self-neglect has come to dominate the self-neglect discourse and will also explore other possible ways of understanding self-neglect.

Key words: medical model, self-neglect.

SELF-NEGLECT

The first reported empirical study of self-neglect was undertaken by MacMillan and Shaw.[1] This study developed from the researchers' intuitive recognition of a group of patients with similar symptoms who could be grouped together as suffering the same illness. Macmillan and Shaw provide a description of the putative syndrome which they tentatively labelled 'Senile Breakdown'.

> *The usual picture is that of an old woman living alone, though men and married couples suffering the condition are also found. She, her garments, her possessions, and her house are filthy. She may be verminous and there may be faeces and pools of urine on the floor* (p. 1032).

This picture of self-neglect has had a major impact on our understanding of self-neglect since it was first published over 30 years ago. The present paper sets out to challenge the notion that there is one way of understanding self-neglect and will explore how the medical construction of self-neglect has come to dominate at the expense of other constructions of self-neglect.

In Europe, the medical model has been the dominant force in the development of a professional construct of self-neglect. This construct has operated from the assumption that there is a discrete self-neglect medical syndrome which can be objectified and measured. Variants of a self-neglect medical syndrome have been variously labelled as the Diogenes syndrome, senile squalor, senile self-neglect and the social breakdown syndrome.[2]

The problem of who defines self-neglect is a conceptual and practical issue of some importance. Johnson and Adams argue that objective and subjective perceptions of self-neglect may vary between different professional groups and between professional groups and those who they categorise as self-neglecting.[3] Possibly an even more fundamental challenge is the claim that there is little evidence to support the existence of a self-neglect syndrome.[2,3]

Correspondence: W. Lauder, Lecturer, Department of Nursing and Midwifery, University of Stirling, Highland Campus, Old Perth Road, Inverness IV2 3FG, United Kingdom. Fax: +01 4637 13471 Email: <william.lauder@stir.ac.uk>

The legitimation of self-neglect as a medical syndrome

It is necessary to explore how, in spite of limited supporting evidence, self-neglect as a medical syndrome has come to be the predominant perspective. Berger and Luckman argue that legitimization is a key process in the acceptance of a particular way of constituting reality, in this instance self-neglect.[4] Legitimation of self-neglect as a medical syndrome has been supported by the use of language and symbols, the impact of everyday explanations, explicit theory of self-neglect and through the worldview which underpins self-neglect theory.

Legitimation of self-neglect: Language and symbols

The medicalization of self-neglect has been developed and sustained by the use of language and images. Language is embedded in a discourse and does not exist in a social vacuum.[5] Wittgenstein[6] proposed that language has no fixed meaning and that the meaning of words lies in the way in which words are used. Language is a strategic resource in power relationships and the language used to describe and give meaning to ideas and practices reflects the dominant discourses.[7] Turner[8] suggests that a Foucauldian analysis would claim that:

> *. . . we know, or see, what our language permits, because we can never naively apprehend or know reality outside our language* (p. 11).

The terms self-neglect, social breakdown and Diogenes syndrome are not neutral but convey a set of meanings. These meanings reflect the values of those who employ such terms, namely health and social care professionals. For example, the language used to describe people who are described as self-neglecting, such as 'lack of shame', conveys a sense of moral judgement as much as it describes a clinical symptom. The medical nomenclature of self-neglect and the language used to describe its key characteristics, such as syllogomania, desperate state of domestic disorder, troublesome behaviour, and refusal of treatment, give the impression of revealing some underlying reality. In fact, such language may actually define and create a reality which does not exist outside the language used to create it.[7] Daignault[9] believes language allows us to become aware of the distinction between the body and what happens to the body:

> *Nouns are used to designate bodies: actions and passions. All of that exists; all of that is body. But what happens to the body, the event, does not exist; it is expressible only as language, but it is attributed to the body insofar as it is expressed as a verb* (p. 207).

The way in which we come to conceptualize a disease involves the use of images as well as written text.[5,10] Gilman[10] argues that these representations eventually become the disease anthropomorphized. This process is evident in the self-neglect literature when MacMillan and Shaw's original description of 'self-neglect' came to be seen as the syndrome itself.[1] This description has been further entrenched through the photographs of self-neglecting patients published in the literature.[11] These photographs use dramatic images to entrench and further establish the definition of self-neglect which they purport to objectively illustrate.

The language and imagery of self-neglect is disseminated across the academic and clinical community in many ways, the principal way being the professional journal. Foucault described how knowledge/power is exercised to limit and control a discourse through hierarchical observation.[7] Hierarchical observation is the process of sustaining power by institutionalizing a particular branch of knowledge. This is, in part, achieved through professional journals which play a key role in legitimizing a particular construction as the truth. Thus, some professional journals, with their own limited conventions of truth, science and language, may be instrumental in portraying self-neglect in a specific way. This, in part, explains the self-sustaining and mutually reinforcing style of the literature of self-neglect. There are nearly as many reviews of the literature as there are original research studies. The self-sustaining quality of the literature can be seen when the same literature is cited by many reviews, and, having cited this literature, find themselves cited in future articles. This is problematic when ideas become established as fact rather, than as tentative and provisional, as most must be regarded in the light of the lack of empirical data.

The process of establishing ideas as fact is evident in the recycling of Clark *et al.*'s suggestion that self-neglect is causally related to an underling personality disorder.[12] Gannon and O'Boyle[13] claim that personality problems do exist in serious self-neglect and they cite Cybulska and Rucinski[14] in support of this claim. In the Cybulska and Rucinski article, no new evidence about the relationship between personality and self-neglect is presented. In fact, Cybulska and Rucinski cite the original Clark *et al.*[12] article as evidence of such a relationship.[14] This somewhat incestuous and circular process in which authors cite a

small number of articles, and are themselves cited in future articles, is clearly evident in the self-neglect literature. Thus, tentative, intuitive ideas become received wisdom and are regarded as givens. Consequently, our understanding of self-neglect has not developed as it would have if mainstream ideas had been exposed to critical analysis, which may have prompted insights and a corresponding advance in our response to self-neglect. However, it must be acknowledged that authors such as Johnstone and Adams have recently begun to articulate such a challenge to the disease model.[3]

If we can move beyond the technical meaning of language to the values which inform that language, we can expose the value-ladeness of the medicalization of self-neglect. This realization is a necessary prerequisite if nurses are to seriously challenge their approach to such people. If nurses are aware that our response to people is based on value judgements, they are more likely to adjust their responses to self-neglect than if a particular construction of self-neglect is regarded as an unquestionable truth.

Legitimation of self-neglect: The impact of everyday experience

Foucault explored the way medicine has increasingly exercised power over many aspects of our daily lives.[7] Medicine in general, and medical psychiatry in particular, is not simply concerned with pathophysiological states but has extended the professional gaze to everyday aspects of life, such as cleanliness, sleeping and eating. This may have a continuing relevance to behaviours thought to be central to self-neglect.

Self-neglect is inextricably bound up with notions of cleanliness and hygiene. Hygiene and cleanliness are, in the context of a self-neglect syndrome, no longer matters of personal preferences and values but are symptomatic of a disorder. Foucault placed this debate in a historical context when describing how in the 18th century matters of hygiene became enmeshed in systems of social control.[7] Thus, medicine gained power over personal hygiene and was given the authority to control and dominate hygiene practices and engage in authoritarian medical interventions to maintain personal hygiene. The type of authoritarian medical intervention described by Foucault has its modern day manifestation in the statutory legislation which allows medical practitioners to forcibly hospitalize people who are self-neglecting.

Body cleanliness is central to the discourse on contemporary notions of disease and modern day attitudes to cleanliness have become more pervasive and visible.[5] These attitudes, in the opinion of Lupton, border on the obsessive and can be seen in the nightly bombardment of television images of bright blue chemicals being released into the lavatory each time we flush.[5] The metaphors of war and conflict are commonly used to describe the 'battle' between cleanliness and dirtiness. One consequence of this is that people who are 'dirty', 'unclean', and 'unhygienic' in Western cultures are regarded as disordered, unhealthy and to be vanquished. Cleanliness and dirt appear to be almost pathognomic of self-neglect. It can be suggested that values in this respect may differ between cultures and socio-economic groups within the same culture. In some cultural groups, such values may be sufficiently different from western cleaniliness values that self-neglect, as understood in Western medicine, may not exist.

Another consequence of placing cleanliness at the core of a self-neglect syndrome is that the psychosocial dimensions of the patient experience have been largely overlooked. People who self-neglect may have problems developing relationships and it could be the case that this dimension is of more significance to the patient than the more observable aspects of this phenomena.

Legitimation of self-neglect: The medical model

The type of legitimation identified by Berger and Luckman uses an explicit theoretical framework and its attendant processes and procedures.[4] It has been argued that the medical model is the dominant construction of self-neglect[3] and when a discourse is bounded by the medical model, self-neglect will inevitably be constructed within the same parameters. The principal method of the medical model is the diagnostic process. Diagnoses are the medical model's most important source of professional legitimation as diagnoses promote a professional agenda to the public.[8] Rogers[15] describes how medicine turns ideas and constructions into 'real' things by a process of reification:

> *Reification is the process of taking a complex and amorphous mixture of observed events, experiences, accounts and ideas, conceptually turning them (or having them turned) into a 'thing' and then giving that 'thing' a name (e.g. anorexia, premenstrual tension and post-traumatic shock syndrome)* (p. 19).

Rogers also suggests many medical diagnoses are not made with reference to objective operational definitions but with reference to value judgements. Mental illness, fre-

quently linked to self-neglect,[13] has been described as a label for a problem with living in accord with professional, ethical and legal norms.[16] The diagnostic process in general, and the diagnosis of a self-neglect syndrome specifically, is based on the concept of normality. In the case of a medical syndrome of self-neglect, at issue is what are normal and abnormal levels of cleanliness and hygiene? Thus, self-neglect exists when medical and nursing professionals judge that individuals do not conform to expected behavioural norms with respect to cleanliness and hygiene. Deleuze and Guattari[17] reject any suggestion of 'transcendent interpretation' in which the significance of a phenomenon, such as self-neglect, is made with reference to external norms. The psychiatric–psychoanalytic causal explanations for self-neglect are products of an interpretation machine which translates what the patient says into another language of classification and control. Nurses have participated in the construction of self-neglect as a medical syndrome, by extending and reconstructing self-neglect and nurses' response to this phenomenon, using Orem's Theory of Self-Care as a theoretical framework.[18,19] Self-neglect or, more accurately, those aspects of self-neglect which have become nurses' territory, is regarded as a set of self-care deficits.

Labelling someone as suffering from a self-neglect syndrome is a normative process in which value judgements are made about an individual's behaviour relative to some norm. The internal contradiction implicit in such a stance involves believing that medicine espouses objectivity and operational definitions but, when faced with the complexity of human behaviour in the swamplands of practice, resorting to normative judgements.

Worldviews as a source of legitimation

The final way that the medical construction of self-neglect is legitimized is when health professionals adopt the worldview that underpins the medical model. The medical model is dependent on a post-positivist worldview for legitimation. Post-positivism proposes that phenomena, such as self-neglect, are real and can be measured objectively, known with a degree of proabability and explained in a general theory. Many authors and theorists do not fully explicate or even acknowledge the philosophical assumptions underpinning their position with respect to self-neglect. Nevertheless the literature on self-neglect is almost exclusively rooted in the post-positivist tradition and, therefore, any discussion of self-neglect must take account of this worldview.

If post-positivism is to be the basis for our understanding of self-neglect, it follows that when self-neglecters believe their lifestyle is deliberately chosen, and this lifestyle is to their liking, they can be diagnosed as suffering from a medical syndrome. Such a diagnosis is justified on the basis that the individual displays a number of behaviours which match a predefined list of behaviours characteristic of a category of disease. Because these categories have been prescribed by professional groups, most notably the medical profession, the protests of patients that this is how they want to live can be disregarded as, at best, a subjective and misguided opinion and, at worst, evidence of the patients' disturbance.

Clark alludes to the subjectivity of patients' views, as opposed to the assumed objectivity of the professional view, when he claims that individuals who self-neglect have a propensity to distort reality.[11] Clark's presumption is that reality is not defined by the self-neglecter, but by others. Post-positivist constructions of self-neglect attempt to uncover general immutable laws which transcend individual perceptions, historical forces and cultural values. The core of self-neglect, from this standpoint, has an existence independent of context and must necessarily be a universal experience which is essentially similar in all cultures.

A practical science of self-neglect

This notion of an objective and measurable reality which can be captured in the language of science has been challenged by postmodernism. Postmodernism explicitly rejects the existence of grand narratives such as the medical model. Postmodernism proposes that understanding a phenomena is the process of making explicit a number of explanatory systems.[15] According to Turner, postmodern epistemology claims that constructions of disease are products of an historically and culturally located discourse.[8] Rogers makes a similar point when arguing that illness is not simply a physical or psychological fact, but is a process of social definition.[15]

Postmodernists believe that disease is an open text amenable to a variety of interpretations.[8] This dictum, if applied to self-neglect, would suggest that claims of the medical model to having access to the truth about self-neglect must be rejected. In fact, postmodernists would argue that this explanatory system is no more true than the perspectives of people who are thought to self-neglect. Consequently, formulating a universal theory of self-neglect may not be possible and instead we should

attempt to understand self-neglect in its historical, cultural and interpersonal context.

Toulmin asserts that the problem facing the academic community is how to reconcile 16th century humanism with 17th century empiricism,[20] in effect reconciling the universal with the particular, uncertainty with certainty and practice with abstractions. Toulmin admonishes us to rediscover the Aristotelian quest for the practical and the humanist desire for uncertainty by finding room for the practical, local and contextual in our theorising.[20] Emerging from Toulmin's position, there are important consequences of understanding self-neglect. The use of theoretical frameworks, such as the medical model, constrain understanding of self-neglect by creating objects of their own making. In effect, if we begin with an *a priori* view that self-neglect is a medical syndrome or self-care deficit, then that is what we are likely to find. Thus, we impose limits on the possible range of constructions of, and solutions to, what is common human experience.

Another consequence of seeking *the* theory of self-neglect is that, in the drive for universality, researchers seek to uncover patterns and similarities common to all cases of self-neglect. This, as Toulmin suggests, means that elements of the self-neglect experience of individuals that do not fit into a general pattern tend to be omitted. Diversity is sacrificed on the altar of uniformity. A postmodern interpretation of self-neglect would reject the notion of an all-encompassing theory with assumptions of uniformity and objectivity. A postmodern perspective of self-neglect would propose that, in place of a single theory of self-neglect that presents a uniform view of this phenomenon, self-neglect is essentially a fragmented phenomenon. We should seek to understand the concrete and particulars of self-neglect as it appears to different groups. Sarup summarizes this position with the axiom, 'big stories are bad, little stories are good'.[21] Sarup offers the metaphor of montage to explain this position:

> *Montage presupposes fragmentation of reality; it breaks through the appearance of totality and calls attention to the fact that it is made up of reality fragments* (p. 148).

Toulmin[20] accepts the proposition that generalization is problematic, but deviates from the usual postmodernist position adopted by Sarup[21] when he (Toulmin) suggests that a synthesis of the polarities of general and particular is needed.

> *The Platonist drive towards universal theory [must], thus, reach a balance with an Aristotelian attention to the times and places, circumstances and occasions of biological events in which their sheer variety creates practical problems . . .* (p. 181).

In the context of self-neglect, it is necessary then to explore both similarities between cases and to recognise the essentially unique and personal experience of every single case of self-neglect. Deleuze and Guattari[17] believe that the most appropriate mode of analysis is 'immanent interpretation', which takes account of internal norms and values. They argue that any analysis must recognise that reality is complex and not susceptible to universal explanations. Thus, it is necessary to utilize research methods which allow each case to be explored as a unique entity, while at the same time seeking amongst cases any patterns that may be of practical use for nurses and medical practitioners.

Rediscovering the practical and timely solution to the problems faced when dealing with self-neglect, however this is defined, may overcome the conceptual problem of the self-neglect continuum. Such a recognition suggests that, in the light of the contextual nature of self-neglect and the way it is constructed and experienced by participants, it is neither necessary nor possible to find a cut-off point that allows judgements to be made about when poor hygiene changes from personal lifestyle preference to self-neglect. This judgement can only be made by participants in the context of each individual's life. Thus, what a nurse describes as a serious case of self-neglect may, in the light of the 'self-neglecter's' rejection of this label and their wish to continue to lead this lifestyle, be a 'less serious' case than another case which objectively appears less dramatic but which causes the 'self-neglecter' distress. The synthesis of universal and particular aspects of self-neglect reconciles both and allows for the professional judgements needed when a nurse is faced with responding to a complex human experience like self-neglect.

Self-neglect should not be regarded as an abstraction that is amenable to capture in a single theory, nor can it be defined by some operational definition. Self-neglect is a human experience, understood within a particular historical context that has its own cultural values and interpersonal practices. Accepting that this phenomenon may be understood in radically different ways by patients and professionals and among different groups of professionals has important implications. The nurse's first tasks are to uncover the patient's constructions of self-neglect and

enter into a process of defining the problem and agreeing what goals need to be set. Nurses are required to see past the label and deal with the problem in human terms in a way that is sensitive to the values held by the patient. It is not surprising that there seems to be a consensus in the medical literature that this group of patients is difficult to treat. If patients do not believe they have a self-neglect syndrome why would they accept treatment? However, nurses can successfully respond to this problem by recognizing their own preconceptions and accepting alternative ways of perceiving self-neglect behaviour.

CONCLUSION

In summary, the predominant construction of self-neglect is that of a medical syndrome. This notion of a medical syndrome of self-neglect can be challenged on the basis that it is a normative judgement which revolves around the norms of cleanliness and hygiene. Nurses need to be aware that there may be a number of different constructions of self-neglect and nurses should be prepared to explore the 'patient's' own construction.

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A survey of self-neglect in patients living in the community

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Summary

- Self-neglect is a familiar concept to all community nurses. Nevertheless there have been few empirical studies undertaken in this area over the last 30 years.
- The study of self-neglect has been hampered by inadequate conceptualization and a lack of theoretical frameworks.
- This article reports a study of patients who did and did not self-neglect, drawn from district nursing caseloads.
- Patients with self-neglect had lower levels of operable self-care agency than patients in a comparison group.
- Only self-neglecting patients had the nursing diagnoses 'ineffective management of therapy' and 'non-compliance'.

Keywords: orem, self-care, self-care agency, self-neglect.

Introduction

The problem of self-neglect is one which has not been subjected to a great deal of research, although recently there has been an upsurge of interest in this phenomena (Johnson & Adams, 1996). A range of labels have been applied to self-neglect such as Senile Breakdown (MacMillan & Shaw, 1966), Diogenes Syndrome (Clark & Gray, 1975), and Social Breakdown (Ungvari & Hantz, 1991). Nevertheless descriptions of self-neglect are instantly recognizable to nurses and other care professionals practising in the community (Snowdon, 1987). The first published description of self-neglect is one which still captures the essence of serious self-neglect:

> The usual picture is that of an old woman living alone, though men and married couples suffering the condition are also found. She, her garments, her possessions, and her house are filthy. She may be verminous and there may be faeces and pools of urine on the floor (Macmillan & Shaw, 1966, p. 1032).

Case reports of self-neglect found in both the medical and nursing literature have been notable by their faithfulness to the description of serious self-neglect described in Macmillan & Shaw's landmark study (O'Rawe, 1982; Moore, 1989; Ungvari & Hantz, 1991; Shah, 1992). Lack of social support has also been a feature of many reports on self-neglect, with patients usually living alone (Cybulska & Rucinski, 1986).

Although there seems to be a sense in which these descriptions are recognizable to practitioners, there is also a widespread consensus that self-neglect is a vague and poorly conceptualized phenomenon (Hudson, 1989; Fabian & Rathbone-McCuan, 1992, Johnson & Adams, 1996). There is also no single accepted model of the causal processes which result in a person neglecting themselves (Gannon & O'Boyle, 1992; Cooney & Hamid, 1995). A variety of causes have been proposed, including dementia of the frontal lobe type (Gregory & Hodges, 1993), personality disorder (Klosterkotter & Peters, 1985; Post,

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1985; Howard & Bergmann, 1993), interaction of personality, environment and disease (Clark *et al.*, 1975; Radebaugh *et al.*, 1987, Cooney & Hamid, 1995) and aetiological heterogeneity (Cybulska & Rucinski, 1986; Gannon & O'Boyle, 1992). It has been suggested that there is a close association between psychiatric illness and serious self-neglect (Shah, 1992; Wrigley & Cooney, 1992).

Johnson & Adams (1996) in their review of the literature concluded that self-neglect is a concept which should be applied to a wide range of behaviours rather than simply being restricted to serious self-neglect. Johnson and Adams take this line of argument further when suggesting that the evidence supporting a specific syndrome is scant and unconvincing. Consequently the current study will add to an understanding of a phenomenon familiar to nurses. This is because there is presently little empirical data on the functional status of this patient group, and the nursing problems with which self-neglecting patients present have not been well documented. In addition the use of an explicit theoretical framework provides an opportunity to advance the theoretical basis of nursing practice.

The conceptual framework for the study was Orem's Theory of Self-Care (1985). Orem proposes that self-care is essential to prevent disease and promote health. In this theory the capacity to engage in self-care activities is a function of self-care agency. Self-care agency is defined as those capabilities and dispositions which enable one to engage in self-care activities. In the current study self-neglect was conceptualized as being the failure to engage in the necessary self-care actions required to promote health and well-being. Thus it is hypothesized that individuals who self-neglect will have lower levels of self-care agency than those individuals who are not self-neglecting.

RESEARCH AIMS

The research aims were specified in the form of two research objectives and one research hypothesis:

Research objectives

What are the most common medical and nursing diagnoses in patients identified as self-neglecting?
What is the functional status of patients identified as being self-neglecting?

Research hypothesis

Patients who have been identified as self-neglecting will have lower levels of self-care agency than patients in a comparison group.

Method

The study method was a survey of patients categorized by district nurses as self-neglecting. In addition a comparison group was drawn from the caseload of participating district nurses. District nurses were asked to list medical and nursing problems experienced by subjects. These problems were then re-classified by the researcher using the North American Nursing Diagnoses Association Typology (NANDA, 1988). Ethical approval was sought and obtained from the Health Board Research Ethics Committee.

SAMPLE

Subjects were selected from the case-loads of district nurses practising in two geographical areas within a single Health Board Region. Selecting a sample in research with low visibility populations is not an easy procedure, especially when there is no widely accepted operational definition of the disease or syndrome (Tantam, 1984; Abrahamson, 1990). Faugier & Sargeant (1997) believe that when researching difficult to locate populations 'innovative sampling techniques' need to be used. They recommend that insider information from people who have knowledge of these low visibility populations is the best way to recruit samples. Nevertheless the problem of bias is one that must be acknowledged.

PROCEDURES

District nurses practising in the two geographical areas were interviewed by the researcher. Access to district nurses was obtained through the appropriate nurse manager. During the interview the purpose of the study was outlined and it was explained that the survey would focus on people with self-neglect. District nurses were told that self-neglect in general terms referred to patients who, for whatever reason, did not engage in self-care actions with the purpose of adequately caring for themselves and/or their home. District nurses were then asked to identify each patient on their caseload and make a professional judgement as to whether that patient was self-neglecting or not. When all patients has been categorized in this way the study group was selected by district nurses identifying two patients who best represented what they regarded as self-neglect. On one occasion a district nurse could identify only one self-neglecting subject. The comparison group was randomly selected from non-neglecting patients on each district nurse's caseload who were in a similar 5-year age range.

MEASURES

Biographical data

Biographical data were collected for each patient by means of a biographical data sheet prepared for the study. Data were collected on age, sex, housing, marital status, medical and nursing problems. Nursing problems were classified using the North American Nursing Diagnoses protocol (NANDA, 1988). Medical problems were classified using a modification of the International Classification of Diseases format (ICD, 1992).

Self-care

Self-neglect was conceptualized as the failure to engage in adequate self-care actions necessary for health and well-being. Orem (1985) suggests the concept of self-care agency to explain the link between self-care needs and self-care actions. Self-care agency comprises two interdependent elements, power components and self-care operations, which together determine whether an individual will engage in necessary and appropriate self-care actions (Aish & Isenberg, 1996). Self-care agency was operationalized by the Self-Care Agency Scale (ASA: Isenberg, 1987). The Self-Care Agency Scale can be completed by the subject (ASA-A) or by another (ASA-B). The ASA-B Scale used in the current study consists of 24 items each of which are scored on a 5-point Likert scale, with 15 positive items and nine negative statements. All items in the scale are scored and then summed to give an overall scale score with a theoretical range 24–120, with the higher score representing a higher level of self-care agency (Lorenson *et al.*, 1993).

The test-retest reliability of the scale has been given as 0.87 with dieting subjects (Kristal *et al.*, 1990), and 0.91 with myocardial infarction patients (Aish & Isenberg, 1996). Internal consistency has been given as 0.62 (Kristal *et al.*, 1990); 0.74 and 0.71 (Aish & Isenberg, 1996); 0.77 and 0.86 with cardiac patients (Isenberg, 1987); 0.72 with elderly patients (Evers, 1987); 0.72 (ASA-A), and 0.82 (ASA-B) with elderly patients in rehabilitation and living independently at home (Lorensen *et al.*, 1993). Discriminant validity was demonstrated by Lorensen *et al.* (1993), who reported that the ASA Scale can discriminate between elderly patients receiving institutional rehabilitation care and elderly patients living at home.

Functional ability

The Index of Independence in Activities of Daily Living was originally developed as a measure of the effectiveness of medical and nursing treatments (Katz *et al.*, 1970). The scale is a Guttman-scaled, rank-ordered ordinal scale measuring six activities (bathing, dressing, toileting, transfer, continence and feeding). There are three levels of performance for each activity. Each activity is scored in turn and aggregated and converted into an overall grade, ranging from A-G. This final part of the procedure is not Guttman-scaled (Wilkin *et al.*, 1992). Katz *et al.* (1970) report on the validity and reliability of the scale.

DATA ANALYSIS

Data were analysed using the Minitab statistical analysis package. Both descriptive and inferential statistical analysis were employed, with differences between groups being analysed using *t*-tests, chi-square tests and Fisher's exact test: one-tailed. Correlations between groups were analysed using Pearson's product moment test. The significance level for the study was set at $P < 0.05$.

FINDINGS

The sample consisted of 63 patients, of whom 41 (22 female, 19 male) were recruited to the study group and 22 (19 female, 3 male) were recruited to the comparison group. The study and comparison groups were matched for age. The ages of the study group ranged from 40 to 96 with a mean age of 70.8 years (SD 14.1). The ages of the comparison group ranged from 44 to 93 years with a mean age of 74.6 years (SD 14.1: not significant, $t-1.02$, $P = 0.31$, d.f. = 43). In the study group 38 were unmarried and 3 married, whilst in the comparison group 16 were unmarried and 6 were married (significant. $P = 0.04009$, Fisher's exact test: one-tailed).

MEDICAL PROBLEMS

Subjects in both study and comparison groups had a wide range of medical diagnoses (Table 1). The joint most common diagnoses in the study group were disorder of the coronary circulation ($N = 7$) and peripheral vascular disease ($N = 7$). In the comparison group disorder of the coronary circulation was the most common medical diagnosis ($N = 5$).

Medical diagnoses related to psychiatric/psychological disorders (organic mental, psychoactive substance abuse, schizophrenia and mood disorder) were more commonly reported in the study group ($N = 10$) than in the comparison group ($N = 1$), although individual psychiatric disorders were not amongst the most commonly reported disorders.

Table 1 Medical problems of study and comparison groups as reported by district nurses

	Study (n = 41)	Comparison (n = 22)
Tumours	4	1
Anaemia	3	2 (5 =)
Diabetes mellitus	6 (3 =)	1
Obesity	3	0
Organic mental	4	1
Psychoactive substance abuse	3	0
Schizophrenia	1	0
Mood disorder	2	0
Extrapyramidal disorder	1	0
Demyelinating disease of CNS	2	0
Episodic/paroxysmal disorder	1	0
Glaucoma	2	1
Disease of ear	1	1
Disorder of coronary circulation	7 (1 =)	5 (1 =)
Cerebro-vascular disorder	6 (3 =)	1
Peripheral vascular disease	7 (1 =)	3 (3 =)
Chronic respiratory disorder	2	3 (3 =)
Disease of GU system	1	1
Arthritis	5 (5 =)	5 (1 =)
Amputation of lower limb	1	2 (5 =)
Paraplegia	2	0
Disease of GI system	0	1
Subarachnoid haemorrhage	0	1

Rank in brackets.

NURSING DIAGNOSES

A wide range of nursing diagnoses was found in both study and comparison groups (Table 2). The two most common nursing diagnoses found in each group were bathing/hygiene deficit (study group N = 17; comparison group N = 7) and impaired tissue integrity (study group N = 13; comparison group N = 5). Ineffective management of therapy (N = 10), and non-compliance diagnoses (N = 8) were found in the study group but not in the comparison group. Nursing diagnoses which explicitly included the concept of deficit in the diagnostic label (knowledge deficit, instrumental self-care deficit, feeding deficit, toileting care deficit, dressing/grooming deficit, bathing/hygiene deficit) were more commonly reported in the study group (N = 33) than in the comparison group (N = 10).

FUNCTIONAL ABILITY

In the study group 17 (41.5%) subjects and 12 (54.5%) subjects in the comparison group were independent in all activities of daily living (Table 3). Dependency in one area of functioning was found in 11 (26.8%) subjects in the study group and five (22.7%) subjects in the comparison group. Dependency in two areas of functioning was found in 10 (24.4%) subjects in the study group and four (18.2%) subjects in the comparison group.

When IADL grades A–G were collapsed into two categories, independent and dependent, it was found that in the study group 17 subjects were independent in all areas of functioning and 24 subjects had between one and six areas of functioning in which they were dependent to some degree. In the comparison group 12 subjects were independent in all areas of functioning and 10 had between 1 and 6 areas of functioning in which they had some degree of dependence (not significant: chi-square = 0.986, d.f. = 1).

The most common activity in which subjects were dependent in both study group (N = 16) and comparison group (N = 9) was bathing (Table 4). This is consistent with the finding that a bathing/hygiene deficit was the most common nursing diagnosis in each group. The ranking of activities in each group was very similar and the most noticeable differences between the study group and comparison group related to subjects who had some degree of dependency in continence, toileting and feeding. In the study group 14 (31.1%) subjects had problems related to continence/toileting, whilst three (13.6%) subjects in the comparison group were dependent in this area of functioning. Feeding problems were the least common activity in which subjects were assessed as having

Table 2 Nursing diagnoses of study and comparison groups as reported by district nurses

	Study (n = 41)	Comparison (n = 22)
Impaired gas exchange	1	0
Ineffective airway clearance	0	2
Impaired tissue integrity	13 (2)	5 (2)
Impaired skin integrity	4	0
Impaired verbal communication	1	0
Impaired social interaction	1	0
Social isolation	1	0
Risk of loneliness	0	1
Ineffective individual coping	2	0
Ineffective management/therapy	10 (3)	0
Non-compliance	8 (4 =)	0
Impaired physical mobility	5	3 (5)
Bathing/hygiene deficit	17 (1)	7 (1)
Dressing/grooming deficit	5	1
Toileting care deficit	1	0
Chronic confusion	2	0
Altered nutrition – more	2	0
Mood disturbance	0	1
Altered nutrition – less	5	1
Sensory/perception altered	1	1
Faecal elimination; altered pattern	1	0
Knowledge deficit	5	0
Surveillance/monitoring	6	4 (3 =)
Urinary elimination; altered pattern	8 (4 =)	4 (3 =)
Feeding self-care deficit	2	1
Instrumental self-care deficit	3	1

Rank in brackets.

some degree of dependence (study group N = 4; comparison group N = 0).

SELF-CARE

The ASA-B scores of the study group ranged from 43 to 96 with a mean score of 66.5 (SD 10.6), and ASA-B scores of the comparison group ranged from 67 to 107 with a mean score of 89.1 (SD 10.2: significant, t=8.32, P = 0.0001, d.f. = 44). The relationship between age and ASA-B was analysed using Pearson's product moment correlation test. The correlation between age and ASA-B scores in the study group showed a weak negative correlation (r = − 0.084, P > 0.05). In the comparison group there was a moderate negative correlation (r = − 0.379, P < 0.05).

Table 3 Index of independence in activities of daily living for study and comparison groups

	Study (n = 41)	Comparison (n = 22)
Independent	17	12
Dependent in one area	11	5
Dependent in two areas*	10	4
Dependent in three areas	1	1
Dependent in four areas	1	0
Dependent in five areas	0	0
Dependent in six areas	1	0

*Categories C and G in IADL index classification aggregated.

Table 4 Functional ability requiring some degree of assistance in study and comparison groups

	Study (n = 41)	Comparison (n = 22)
Bathing	16 (1)	9 (1)
Dressing	9 (3)	4 (2)
Toileting	6 (4)	1 (5)
Transfer	4 (5 =)	2 (4)
Continence	14 (2)	3 (3)
Feeding	4 (5 =)	0 (6)

Rank in brackets.

Discussion

Patients in both groups experienced a wide range of medical diagnoses. The types of diagnoses found were similar to those found by Gannon & O'Boyle (1992). When aggregated as a category of diagnoses, psychiatric disorders were more common in study group. This is consistent with the literature, which suggests that psychiatric disorders are commonly found in cases of extreme self-neglect (Shah, 1992). Nevertheless it remains the case that only a minority of the study group had psychiatric diagnoses. This contrasts with the claim that 50% of patients with extreme self-neglect have a psychiatric disorder (Post, 1985). This finding may be explained by the possible under-reporting of psychiatric disorders by district nurses and the fact that the study group may include patients with less severe forms of self-neglect. The relationship between medical diagnosis and self-neglect is unclear; does a particular medical diagnosis, or pattern of medical diagnoses, cause self-neglect? Or alternatively does self-neglect result in an increased likelihood of a medical diagnoses subsequently developing?

Both study and comparison groups had the same two most common nursing diagnoses (bathing/hygiene deficit, impaired tissue integrity). The most obvious difference between the study and comparison group was the relatively high number of study group patients with ineffective management/therapy and non-compliance nursing diagnoses. It may be the case that non-compliance and ineffective management of therapy are important characteristics of self-neglect. Reed & Leonard (1989) in their analysis of self-neglect suggest that non-compliance is an important component of self-neglect. They state:

> Self-neglect and non-compliance are similar concepts in that both refer to the clients' lack of participation in a prescribed or necessary health care regimen (Reed & Leonard, 1989, p. 42).

Nevertheless it remains the case that there are many people with self-neglect who did not have either of these nursing diagnoses.

Findings indicate that a significant minority of the study group and the comparison group were independent in all areas of functioning. This suggests that dependency and self-neglect, whilst in some ways linked, are essentially different concepts. People can be regarded as self-neglecting but may be fully independent in ADL functioning. The reverse is also true in that people who are self-neglecting may also be fully dependent in ADL functioning.

The relationship between functional ability and self-neglect is further complicated by the finding that there were differences in the type of functional ability impaired in each group. Continence and feeding problems were more commonly reported in the study group.

In Orem's theory of Self-Care the concept of SCA is the ability to engage in the appropriate actions designed to maintain self-care. Therefore the finding that patients who were described as self-neglecting had lower levels of SCA suggests that the concept of SCA may play an important explanatory role in a theoretical framework of self-neglect.

In the comparison group there was a moderate negative relationship between age and SCA. This finding lends some support to Orem's proposed relationship between age and SCA. On the other hand this relationship was not apparent in the study group. It may be that self-neglect, disease or some other related variable disrupts the usual relationship between age and SCA. This is again consistent with Orem's theoretical proposition on the influence of basic conditioning factors on self-care agency.

LIMITATIONS

The method of selecting patients for inclusion in the study can be criticised for introducing selector bias into the process. Nevertheless with this limitation in mind there is support in the literature for using pragmatic methods when there is no clear conceptualization and operational measure of self-neglect available to researchers (Fabian & Rathbone-MacCuan, 1992). The small number of males in the comparison group and the fact that the group was matched for age only means that comparisons should be treated with some degree of caution.

The study and comparison groups were significantly different in terms of marital status, and this was not controlled for. It must also be acknowledged that data should be treated with caution on the basis that nurses are not in a position to give medical diagnoses, although the diagnoses were likely to have been made by medical practitioners and nurses were simply reporting these from case-notes. It is also possible that some diagnoses are under-reported, for example the numbers of patients reported as having a mood disorder is less than one might have expected. The re-categorization of nursing problems into nursing diagnoses was undertaken by a single researcher and the reliability of this procedure was not demonstrated.

Conclusions

The capacity to engage in self-care activities is dependent on the level of operable self-care agency that people

possess. A failure to engage in self-care is conceptually linked to self-neglect and therefore one would expect that self-care agency levels are lower in patients with self-neglect. This hypothesis was supported and thus Orem's notion of self-care agency may provide an important contribution to understanding why some people self-neglect.

There is no single medical diagnosis or nursing diagnosis which, on its own, provides a causal link to self-neglect. Patients with self-neglect may be more likely to experience psychiatric disorders and have compliance, ineffective management of therapy and self-care deficit related nursing diagnoses.

The levels of dependence/independence in patients who are self-neglecting are similar to those in other patients cared for by district nurses. Self-neglecting patients are more likely to have problems related to continence/toileting and feeding. Patients with functional impairments in these areas of functioning may comprise a subgroup of self-neglect.

The finding that self-neglecting individuals have low levels of SCA provides a focus for nursing interventions which are aimed at increasing SCA levels. Further research being conducted by the author explores the different perspectives of self-neglect held by professionals and patients. The assumption that self-neglect is a discrete syndrome which is bounded by the positivist assumptions of the disease model and Orem's Theory of Self-Care will also be explored.

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Feature

Constructions of self-neglect: a multiple case study design

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Constructions of self-neglect: a multiple case study design

Patients who neglect personal hygiene, household cleanliness and their own health are familiar to most nurses. Despite this familiarity, self-neglect is a poorly conceptualized and little researched phenomenon. This multiple case study design uncovers the perceptions of self-neglect held by professionals, patients and relatives. The assumptions which underpin Orem's Theory of Self-Care and the medical model construction of self-neglect are explored and it will be suggested that there are limitations in understanding self-neglect using these theoretical frameworks.

Key words: causality, intentionality, medical model, Orem, self-neglect, social construct.

Self-neglect is a problem frequently described in the health-care literature. The picture portrayed of the severely self-neglecting individual is one which is instantly recognizable to all clinicians but, nevertheless, the concept of self-neglect remains poorly understood.[1,2] Rathbone-McCuan and Bricker-Jenkins[3] suggest that self-neglect is a continuum of functioning which ranges from poor grooming to self-neglect which promotes disease or leads to death. Johnson and Adams[4] argue that there is insufficient evidence to support or reject the existence of a discrete self-neglect syndrome.

BACKGROUND

Self-neglect as a medical syndrome

The literature on self-neglect has largely developed within medicine and thus self-neglect has generally been conceptualized within the parameters of the medical model.[4] Severe self-neglect, the focus of much of the existing literature, has a number of synonyms including Social Breakdown syndrome[5] and Diogenes syndrome.[6]

Explicit in the medicalization of self-neglect are the assumptions that self-neglect is a manifestation of an underlying medical disorder and that this requires medical intervention. Cooney and Hamid[7] claim that there is a consensus that 'at least' 50% of all severe self-neglect cases have a psychiatric illness. Wrigley and Cooney[8] found that in a sample of 29 patients who self-neglect, 13 had senile dementia, three had schizophrenia, three were alcohol-dependent, and 10 had no psychiatric diagnoses. This may indicate that the basis for self-neglect in these patients is very different and that self-neglect is a heterogeneous phenomenon. The causal link between mental illness and self-neglect has been questioned, because many patients described as self-neglecting do not have a mental illness.[4]

There is a widespread recognition of the difficulties faced when caring for this client group.[7] Such a view may stem from the belief that individuals who are self-neglecting are reluctant to seek help and are resistant to offers of help when these are forthcoming.[7,9,10]

Treatment for severe self-neglect is frequently seen in terms of the use of statutory instruments which can compel individuals, who would otherwise be unwilling, to accept treatment in a place of safety.[4,7,11,12] This type of intervention may be seen as a form of social control.[13] Specific treatment modalities which have been proposed include a proactive outreach approach,[7] day centre care and community-based low-tech services,[14] drug and

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behavioural therapy.[10] Reyes-Ortiz and Mulligan[15] are sceptical about the efficacy of medical treatments of self-neglect.

One assumption implicit in both Orem's[16] work and the medical model is that disease impairs the individual's capacity to make rational choices and thus to act intentionally. The point at issue here being whether people who self-neglect have no choice in the lifestyle they lead or whether the converse is true and this is a preferred lifestyle. The extent to which people with self-neglect choose to behave in a manner which leads others to define them as self-neglecting is unclear.[4] One example of the contradictions inherent in the medical model construction of self-neglect is to be seen in the issues of responsibility, choice and freedom. Dingwall[17] suggests that the medical model exonerates individuals from responsibility for their own condition. Reed and Leonard,[18] on the other hand, believe that individuals are responsible for their own self-neglect. The notion of responsibility and choice are used in a number of ways which lead to some confusion about what is meant by these terms.[19] Foucault's[20] concept of governmentality refers to modes of action which structure the potential fields of action of others. Ideas of freedom and choice are explicit here as he suggests that institutions, in this case medicine, have the power to define, regulate and punish categories of behaviour. In this sense the individual's freedom to choose to live a particular lifestyle is limited, and those who choose to live a lifestyle can have this choice categorized as undesirable, a process which sets up possibilities of treatment-punishment. The everyday understanding of responsibility and choice is a more prosaic one and revolves around notions of blame. This notion does not distinguish between cannot do, will not do and finds it difficult to do. It is the degree of disjuncture between the various notions of responsibility and choice that is of particular interest in the current study.

CHALLENGE TO THE MEDICALIZATION OF SELF-NEGLECT

Challenges to the medicalization of self-neglect may be rooted in social constructionist,[21] and 'illness as a deviance' perspectives.[22] Social constructionism asserts that explanations of illness are social, cultural and personal products rather than universal truths.[21] Labelling perspectives suggest that a person would be labelled as self-neglecting, and thus deviant, when their behaviours do not conform to social norms with respect to hygiene and other related practices. The case of severe self-neglect presented by Reyes-Ortiz & Mulligan[15] highlights the fact that some people may be happy with this lifestyle and do not recognize this as a problem. The self-neglecting individual's perspective of their experience has not been well documented. In effect social constructionist and labelling perspectives propose that medical and nursing models of illnesses, such as self-neglect, actually create these phenomena in the first place.[23]

Medicine has increasingly colonized facets of everyday life such as hygiene and cleanliness.[13] Foucault[24] describes how in the 18th century medicine in general and matters of hygiene specifically became enmeshed in systems of social control. Thus medicine came to have power over matters of personal hygiene and was given authority to control and dominate hygiene practices. Lupton[13] argues that matters of cleanliness have become more visible and pervasive:

> The cleanliness of the body is a central discourse in contemporary notions of disease and hygiene which focus upon the maintenance of body boundaries (p. 33).

Self-neglect is inextricably bound up with matters of hygiene, cleanliness and dirt. Thus self-neglect needs to be understood within a discourse in which people who are excessively dirty are to be seen as disordered and unhealthy.

Diagnosing self-neglect may not be as scientific and objective as the medical model may suggest. The way in which diseases or syndromes are represented in visual and written texts influences the way the disease comes to be conceptualized. This process may be seen in the self-neglect literature when MacMillan and Shaw's[26] original description of 'self-neglect' came to be seen as the syndrome itself. This description has been further entrenched through visual representations of self-neglect published in the literature.[27,28] Lupton[13] suggests that the images and language used to construct disease and illness affect the way in which patients are treated by others. The professional language of self-neglect is value-laden and promotes a particular construct of self-neglect which is rooted in the medical model and the positivist assumptions on which it is premised. Thus the professional language of self-neglect may actually define and create a reality which has no a priori existence.

Theoretical framework

Nevertheless despite the possible limitations imposed on understanding self-neglect by using a theoretical framework as a starting point, a synthesis of Orem's theory of self-care and the medical model was used as the theoretical framework for the current study. This framework was used in a critical manner because the adequacy of these theories was one of the issues to be considered in the study.

Self-neglect can be regarded as the failure to engage in those self-care actions necessary for health and well-being.[29] It has been suggested that Orem's theory of self-care can be used as a theoretical framework to explain self-neglect[1,6] to provide prescriptions as to how nurses should respond to this phenomena.[30,31] Self-care agency, a key concept in Orem's theories, has been shown to be reduced in patients described as self-neglecting by district nurses.[29] Self-care agency refers to those cognitive and action-orientated capabilities which enable one to engage in self-care actions. Orem's theory of self-care focuses on why people do or do not perform operations which uncover and meet their own self-care needs.[16] In this theory Orem proposes that therapeutic self-care demand, that is the totality of all necessary self-care acts, must meet an individual's self-care requisites. Self-care requisites are essential to health and well-being, and can be classified as universal (e.g., food and water), developmental (e.g., growth) or health-deviation. The ability to meet these requisites is dependent on self-care agency. The usefulness and adequacy of this theory as a basis for understanding self-neglect will be critically evaluated in this study.

RESEARCH QUESTIONS

- Do patients, relatives and professional carers share perceptions of what constitutes self-neglect?
- Is self-neglect intentional or unintentional?
- What is the relationship between psychiatric disorders and self-neglect?
- How do professionals and patients treat self-neglect?

RESEARCH METHOD AND DESIGN

The study employed a multiple case study design.[32] Multiple case study designs involve the selection of between four and 10 cases indicative of the phenomenon under investigation. Cases are to be regarded as a series of experiments in which hypotheses are formed in one case and are then tested in a subsequent case.

Eisenhardt's[33] methodological framework for case study research (Table 1) was used to structure the current study. The case study was chosen because it allowed deeper exploration of what is a complex and heterogeneous phenomenon. The multiple case study design was chosen to provide answers to four discrete research questions, and it was not intended to develop a theory of self-neglect. In fact, the value of multiple case designs lies in the opportunity to challenge the adequacy of Orem's theory and the medical model as explanations of self-neglect. This is consistent with Popper's notion of falsification.[34] In this notion if a single instance in which a theoretical proposition is found to be untrue is discovered that is sufficient for that proposition to be rejected as untrue. Because both theories are regarded as scientific in the positivist sense, it is internally consistent to attempt to falsify their claims to truth.

Table 1 Case study methodology (adapted from Eisenhardt 1989)

Step	Activity	Rationale
Getting started	Define research question	Focus efforts
Selecting cases	Theoretical sampling	Focuses efforts on theoretically useful cases
Instrumentation	Multiple data collection methods; qualitative and quantitative data	Triangulation fosters divergent perspectives
Entering the field	Overlap data collection & analysis: flexible data collection methods	Speeds analysis and allows for adjustments to data collection
Data analysis	Within-case analysis	Gain familiarity with data and emergent theoretical formulation
	Across-case analysis	Forces researchers to contrast and compare cases
Enfolding literature	Comparison with similar, conflicting literature	Builds internal validity, sharpens construct definitions
Reaching closure	Theoretical saturation when possible	Ends process when marginal improvement is minimal

Sample

The underpinning logic of sampling in case studies is replicative.[32,33] Replication is the process of treating cases as a series of experiments with each case serving to confirm or disconfirm 'working hypotheses'.[32]

Five cases were purposely chosen from a sample of self-neglecting patients who had been identified by district nurses as being self-neglecting during an earlier study.[29] A case was to be regarded as the self-neglecting person, their professional carers and family members.

The initial case was chosen to facilitate a general entry into the field. Subsequent cases were selected to explore specific questions with a view to confirm or disconfirm findings of earlier cases. For example, on the basis of findings from the first case it was hypothesized that self-neglect was not intentional and was causally related to underlying mental illness. Subsequent cases allowed these tentative working hypotheses to be tested. This is consistent with the notion of falsification alluded to earlier.

Data collection

In case study research a variety of data collection methods are employed.[33,35] Thus data were collected by means of focused interviews, field notes recording the researcher's observation of household circumstances and conversations with participants, and other documentary evidence including casenotes and medical records. Data collection was organized around predefined questions which had been identified in the light of earlier findings[29] and the existing literature on self-neglect. Support for this approach to data collection is to be found in the literature.[33,36,37] It was recognized that such *a priori* knowledge of self-neglect which informed the research questions was tentative and provisional and may be subject to revision or rejection.[36]

Data management and analysis

Yin[32] proposes that case study analysis must take place within a general analytic strategy. The two main strategies outlined by Yin are developing a case description and using theoretical propositions. In this case study both strategies were employed. In the first instance a case description of each individual case was prepared. After the case description was completed all data were then analysed at a cross-case level using theoretical propositions in the form of research questions. Due to the considerable quantity of data collected, this paper will report only on cross-case analysis.

Cross-case analysis

Having gained an understanding of each case and having written-up the case, the next task was to move to cross-case analysis. This involves making comparisons across cases and linking data to theoretical propositions implicit in the research questions.

Data analysis was an iterative process in which data were continually compared to extant theory. Having developed working hypotheses, these were then used to select new cases. These cases provided an opportunity to confirm or refute the working hypotheses. Yin[32] supports this approach to data analysis in case studies because he believes this provides direction for data analysis and grounds data in implicit theoretical propositions, thereby increasing the validity of the study.

FINDINGS

Research question 1: Do patients, relatives and professional carers share perceptions of what constitutes self-neglect?

The degree of congruence between participants' perceptions of self-neglect varied across cases. In the case of Mrs X there was agreement between her son and the DNs that she was self-neglectful, and about the features of and reasons for this self-neglect. Mrs X's self-neglect was thought to be directly related to her dementia. In the case of Ms Y there was also agreement between all participants, including Ms Y, that she was self-neglectful in terms of her not caring adequately for her own health problems (gum infection and varicose ulcers) and that she was not self-neglectful of her personal hygiene and household cleanliness. She was in fact very fastidious in this respect. Mr V, on the other hand, neglected his personal hygiene and household cleanliness but complied with his medical regimen. This is consistent with Orem's[16] distinction between health-deviation and universal self-care requisites. Personal hygiene can be regarded as a universal requisite, whilst compliance with a medical regime is a health-deviation requisite. Nevertheless, Orem does not adequately explain why one type of self-care requisite should be met and not another.

Ms Y described how she was very aware of the consequences of her inability to attend to health self-care acts. She described how she stopped attending the local dentist:

> Never bothered after that and my teeth started falling out and I didn't bother about it ... I had not problems with them. They just seemed to fall out and they broke and I left it as it was.

The GP seemed to have a construction of self-neglect which related to the demands or lack of demands placed on him by patients in general, and Ms Y in particular. He thought patients had a right not to seek medical help even if they required it, and this was a desirable state of affairs as it prevented him being overloaded with demands from patients.

In the case of Mrs Z, both she and the CPN did not think she was self-neglectful. The CPN thought that whilst Mrs Z had a disorganized life this was no greater than many other people:

> I didn't see anything wrong with her to be honest. You know I really didn't see anything wrong with her. She maybe doesn't live the way I live but I mean I go into hundreds of houses and we all live differently.... I mean I felt that it was all a bit chaotic maybe in the sense that she was getting up in the middle of the day and that sort of thing, but then that's how things worked out for her. She's no different from an awful lot of other people.

Mrs Z thought that her condition was perfectly acceptable and understandable in the light of her many physical problems:

> I mean sometimes I'm in an awful lot of pain and as I say this tiredness I've been having lately, it's been worrying me. It only stands to reason I'm bound to worry if there's something different everyday.

The DN and the GP thought she was self-neglectful in terms of her household and lifestyle circumstances (universal self-care requisites). When asked why this lady was self-neglecting, the DN replied:

> She drinks. Sometimes she gets drunk and has accidents, like maybe scalding herself with a cigarette.... She'll lie in the chair all night and get a bit negligent.... She smokes heavily.... the house is very unkempt, she's very unkempt.

The GP described the home situation as:

> It's really full of furniture ... sorts of old bits of furniture, clothing. Sometimes you can't get up the stairs for the pile of clothing at the foot of the stairs. Well it's not tidy it's untidy. Possibly dirty and untidy ... it's the sort of situation for you to see to think she does neglect herself.... The house is filthy ... the bed is manky. I don't know whether you noticed that usually the radio, the telly upstairs, they're all on.

A similar pattern emerged in the case of Ms W who did not think she was self-neglectful but the DN and CPN thought otherwise. All participants thought that the root of her problem, however, was defined, and was directly related to the family circumstances. Participants thought that her sense of family duty meant that she cared for family members at the expense of caring for herself. There was also a sense in which the social background—both Ms W and Mrs Z were from travelling families who has been housed some years previously—played some part in both being described as self-neglecting. It is suggested that class, gender and ethnicity may influence the way self-neglect is perceived.[4] Taylor[38] and Rose[39] also suggest that cultural context influences the self-care behaviours of travelling people and the way these are perceived by others.

There was also disagreement between professional carers and Mr V as to whether he was self-neglecting or not. He thought that his way of living was a personal choice and did not present any problems for him. He was resentful at professional interference:

> That's right, they think that this business of me sleeping in the chair is not right. I want to be the way I am. Just to be left alone.

The professional carers believed him to be the worst case of self-neglect that they had come across. The DN stated that:

> There's just all the junk mail that comes through is just thrown in a heap and you go into the sitting room and there's clothes. I don't even know, it's an unbelievable house. The cobwebs, its like a film really. The cobwebs hanging down on the walls, it's just amazing. I don't even know what's lying around, but just everything accumulates over the years, it's never been moved, it's never been touched ... the kitchen is awful.

This case brings into sharp focus the different constructions of the same phenomena which are held by professionals and patients. It is not surprising then that many such 'patients' refuse treatment as they do not see any need for treatment in the first place.

Research question 2: Is self-neglect intentional or unintentional?

Self-care and self-neglect have been regarded as intentional patterns of behaviour.[16,27] In the case of Mrs X her dementia meant that she had little control over her actions and thus her self-neglect was not intentional. This case would suggest that self-neglect is not necessarily intentional and thus the positions taken by Orem[16] and Clark[27] need to be modified. In the cases of Mrs Z and Mr V it was agreed that their behaviours were a matter of personal choice and to that extent were intentional, although the GP indicated that psychological problems limited Mr V's capacity to behave intentionally. The DN on the other hand stated:

> Well I can't say he's no choice in his life. He does have a choice. I think he has chosen to live like this.... Well I think he's all right mentally. He seems to be able to make his own decisions. He's not confused. He seems to know exactly what he wants.

In the case of Ms W her choices were more difficult, in the sense that her ideas on family duty placed primacy on caring for other family members at the expense of self-care. Her self-neglect was not a preferred lifestyle choice and appeared to be a response to her brother's obsessional behaviour which meant that she and her mother had to eat, sleep, eliminate and live in the kitchen. She had very recently been allocated her own house had been able to exercise more choice and can now bathe and toilet in a way and at a time of her choosing. Johnson and Adams[4] open up the question as to whether cases such as Ms W are more appropriately regarded as neglect inflicted by others. In the case of Ms Y she chose not to contact healthcare professionals when she was ill but went to extraordinary lengths to care for herself, to the extent she self-treated two large varicose ulcers for many months.

Although he was thought by professional carers to be severely self-neglecting, Mr V was still able to actively participate in aspects of his prescribed care:

> You know at times he had a urine infection and he got antibiotics and he takes them regularly. I would say he does comply with anything like that. There was one time he had to get a dressing done and there was no problem with that.

Therefore it seems that some people who are described as self-neglecting may at the same time be able to manage their treatment regime and thus noncompliance and self-neglect may be different concepts. It was also evident in the cases of Mrs Z and Ms W that they would actively seek out healthcare and or social care resources and would manage these to what they perceived as to their advantage. Thus in this sense they were active or even proactive in managing their care.

Research question 3: What is the relationship between psychiatric disorders and self-neglect?

In the case of Mrs X there appeared to be a clear cut relationship between self-neglect and the presence of dementia. Her dementia meant that memory and capacity to function on her own was seriously impaired.

The GP claimed that Mrs Z had a number of psychiatric disorders and that her major problem was neurotic anxiety about her health status:

> (she has) a really long history, particularly the psychiatric. In 1950s she was receiving psychiatric treatment in hospital for a neurosis about cancer. She had a number of different diagnoses over the following years, such as anxiety neuroses, psychopathic disorder, alcohol abuse. Twenty years later she was diagnosed as having a paranoid schizophrenia.

The GP did not indicate how her schizophrenia was related to her self-neglect. The DN did not suggest any such link and the CPN could not find any evidence for Mrs Z having a mental illness in the first place:

> The reason for Dr X trying her on Clopixol to see if it would settle her, because if she is constantly going back and forward to the GP's surgery it's like she's seeking reassurance all the time that she's all right. Maybe he thought it would settle her.... She didn't like that but I just wondered 'What was meant to be wrong with you'. No doubt she's had problems in the past but she presented to me as being all right.

Mrs Z herself did not think she had any mental illness:

> I mean I know there's nothing like depression or anything wrong with me. If there's anything wrong with me my health that's causing it, not worry and nerves.

Therefore on close inspection participants disagreed whether a psychiatric illness was present but none suggested a clear–cut association between psychiatric illness and self-neglect. This is not consistent with Ungvari and Hantz's[10] notion of secondary self-neglect, in which there is a self-evident and causal-relationship between self-neglect and mental illness.

In the case of Ms W, who had been diagnosed as suffering from manic depression, no participant suggested there was a direct link between this psychiatric illness and self-neglect. In fact the link with mental illness was an indirect one in which the brother's severe obsession behaviours created circumstances in which Ms W found it difficult to care for herself in the way she may have wished. The DN and CPN thought she was coping well given her personal circumstances:

> She puts up with an awful lot of stuff and doesn't seem to get stressed out whereas other people I would say wouldn't be able to put up with half she has to put up with ...

Ms Y had not been formally diagnosed as having a mental illness but her pattern of not seeking professional health-related advice was labelled as the 3-D phobia (dentist, doctor and dietician). This label was first applied by a surgeon and subsequently taken up by the patient and her GP. Jones[21] refers to this process as labelling, and describes how both labeller and labelled are now committed to the deviant role. It may be that both parties gain some type of secondary benefit from this labelling process.

In the case of Mr V, who also did not have a formally diagnosed psychiatric illness, the GP offered the explanation that his self-neglect may have been caused by some deep-seated psychological problem. This explanation seemed to be a result of a circular logic. The patient presented with

a pattern of behaviour which did not conform to social norms, which in turn led to the diagnosis of personality dysfunction, the evidence for which was the presenting behaviours (which had now become symptoms). This seems to be an example of blaming the patient and the resultant reconstruction of the problem as 'personal' rather than as an artefact of the diagnosis itself.

Research question 4: How do professional carers and patients treat self-neglect?

In all cases, with the exception of Ms Y, there was a clear sense of therapeutic pessimism. Professional carers were not hopeful that any treatment would work, if in fact a treatment was available. An extreme example of therapeutic nihilism was found in the case of Mr V whose GP thought that the best solution would be for him to die peacefully. Patients themselves also expressed a sense of therapeutic pessimism. Mrs Z and Ms W had detected that their professional carers were pessimistic about treatment: 'Well as far as I can see it.... I just don't think they bother.... well there's nothing they can do really.... there's absolutely nothing the doctor can do. In the end we're just left to it ourselves ... to try and cope.' (Mrs Z) and: 'They don't bother. They just don't bother because they know there's nothing they can do' (Ms W).

In all cases there were concerns expressed about the level of co-operation between social and health services. There appeared to be some confusion in the cases of Ms W and Mrs Z about whether the CPN or DN should be responsible for nursing care. The DN commented:

> I was trying to get more involvement from psychiatric nursing to go in to do her Depixol not just as a task of doing her injections but a medium for looking at the rest of the problems in the family because we feel at a loss really as to how to deal with a lot of the problems.

and:

> Yes, it's just maintenance that we're doing, just maintenance ... One part of me wants to pull out altogether and to just say well let's just hand this right on to psychiatry and let them deal with it.

In the case of Ms Y all participants were more optimistic about her treatment and prognosis. This was the only case in which self-neglect was solely defined in terms of not caring for physical health problems. This meant that treatment had a definite focus in the sense that it was organized around observable physical events.

Professional carers were sensitive to the need to develop a relationship in which Ms Y could feel happy to stay in the treatment system and seek treatment in any future situation on her own volition. The need to develop a trusting relationship was a commonly expressed theme and the requirement to operate from the principle that compromise was an integral element in any good relationship was apparent.

In the cases of Mr V, Ms Y and Mrs Z there were informal social support systems which played an important part in their lives. These support mechanisms included the local pub, which would send a customer around to do shopping for Mrs Z, and the local chemist shop which first detected Ms Y's self-treatment of varicose ulcers and subsequently informed the DN. Ms W had a potentially large family support system. The DN identified that they were not popular with the local community:

> Yes, I feel sorry for them. I think they're in a catch 22 because of their own feeling and the family, this family. They're notorious ... and they're all very supportive. You rarely find that you have to put in home care or use facilities like day-care or meals-on-wheels or anything for this family. They all support each other greatly.

Despite this both of these women played the central role in the family network and accepted the burden of caring for other family members to the extent that their own capacity for self-care was impaired.

CONCLUSIONS

Perceptions of self-neglect varied across cases and within cases. In fact it was common to find disagreement as to whether self-neglect was actually present or not. It was clear that self-neglect is a very nebulous phenomenon which is understood differently by different social actors. This raises problems for the positivist assumptions of Orem and the medical model in terms of the existence of a 'true' objective phenomenon which can be known independently of the knower. If in fact a version of science in which truth is socially constructed is proposed, which is not the case with Orem or the medical model, then falsification is not relevant as their are no claims made about a single truth. Social constructionism for example proposes that there is no single truth; truth is plural.

Implicit in the medical model and Orem's theory is the assumption that 'patient's perspectives' can be rejected as the subjective denial of an objective reality. That reality is professionally defined in terms of a medical syndrome or nursing diagnosis. In the application of a self-neglect label these models/theories appear to operate from a circular logic. That is, when the person's behaviour and lifestyle are viewed by the professional as deviating from the norm, this

is then taken as evidence of a medical syndrome. The symptoms of this disorder are evidenced in the person's behaviour and lifestyle. Thus the professional label of self-neglect may refer not to an objective reality, but to the subjective application of normative values regarding cleanliness and dirt. Self-neglect may therefore need to be understood within the wider social discourse of cleanliness and hygiene.

Self-neglect can be described in terms of neglecting both universal and health-deviation requisites or one or other requisites. This raises some questions of the adequacy of Orem's theory of self-care as a means of understanding self-neglect. Orem does not adequately explain why one type of self-care action should be operated and not another, or in what circumstances this may occur. It may be assumed that self-care needs are hierarchically organized and self-care actions differentially employed. In effect self-care needs may be organized in a hierarchy in which some are more fundamental than others. In addition, some self-care actions may be employed by the same person in some circumstances and not others even when they are appropriate. Alternatively, the notion of a hierarchy itself can be regarded as a social construction which places differentiated values on specific forms of action. These values are culturally, historically and politico–economically located and thus Orem must be understood in the context of capitalist-individualistic societies in which the 'self' may be given priority over the 'other'. In the cases outlined in this study the hierarchy of self-care is not a satisfactory explanatory model as individuals may neglect themselves whilst at the same time caring for others.

The issues of freedom and choice are central to the medical model and to wider economic–political discourses on the place of the individual in capitalist cultures. Gerhardt[40] argues that medical constructions of disease and illness have a political dimension. Self-neglect must be seen against a backdrop of capitalist values of personal achievement and the self-neglecting individual's inability to engage in productive activities. In essence the medical model would propose that in certain circumstances, such as when an individual has a psychiatric disorder, they have a limited capacity to choose to engage in self-care actions. With respect to self-neglect and dementia it was clear that the participant did not choose to neglect themselves. In the case of the man with severe self-neglect he himself admitted that his lifestyle was intentionally chosen and yet it was assumed that this was a result of undiagnosed deep-seated psychological problems. To neglect the 'self' is to deny one of the major projects of liberal humanism, that is, care of self.

The relationship between mental illness was also not as clear-cut as some literature would suggest. Again the relationship between dementia and self-neglect was obvious to all participants. The two cases in which a psychosis had been diagnosed self-neglect appeared to be more related to lifestyle, social class and the mental health of relatives than to the patient's own mental illness. It would seem that the presence of a mental illness should not necessarily be presumed to be causally related to self-neglect. Any such link may be more complex than a simple linear cause–effect relationship, as may be implied in the disease model.

The treatment of patients with self-neglect was fragmented and professionals were unclear whose responsibility it was. There was some confusion between district nurses and CPNs about who was most competent to care for this group of patients. Professional perspectives of care were characterized by pessimism and lack of hope. The exception was Ms Y, whose care was described in terms of primarily physical treatments. It may be that conceptualizing a problem in terms of concrete physical events may be easier for professionals and may provide observable symptoms which are directly related to professional interventions. The treatment-punishment of self-neglect may be understood in terms of what Foucault[20] describes as the noso-political phenomena of a general police of healing. This policing project emerged from the 18th century concerns in capitalist societies about threats to an accumulation of men for waging war and for mass production of goods. Thus uncleanliness has come to be reconstructed as a syndrome and a harbinger of disease. In this reconstructive process the individual is to be regarded as an object; a disease category.

SUMMARY

This study describes a multiple case study of self-neglect in which a number of central propositions implicit in both the medical model and Orem's theory of self-care were critically explored. Self-neglect can be understood from a variety of perspectives, including the dominant perspective in contemporary discourse, from which explanatory frameworks such as Orem's theory of self-care and the medical model have emerged.

It is argued that there may be a number of fundamental limitations in both of these perspectives as ways of understanding self-neglect. It is not denied that participants had many significant life problems, but it is suggested that the way in which these came to be understood by different actors is influenced by personal and professional

beliefs. In turn, these beliefs are themselves rooted in a wider discourse of cleanliness and disease. Orem's theory and the medical model bring an illusion of objectivity and a reality of control by categorizing the individual and formulating a construction of uncleanliness as symptomatic of disease.

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