THE UNIVERSITY OF HULL

# PROMOTING THE QUALITY OF LIFE OF ELDERLY PEOPLE IN NURSING HOME CARE: A HERMENEUTICAL APPROACH

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by

Peter Draper, BSc (Nursing Studies), CNAA

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# DEDICATION

This work is dedicated to Janet, an uncomplaining PhD widow for six years, and to Elizabeth, Isaac, and Tamar, without whose enthusiastic help and support it would have been finished years ago.

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# INTRODUCTION

The research described in this thesis addresses two central issues. The first issue concerns the development of a series of practice standards that will promote the quality of the lives of older people who live in nursing homes<sup>1</sup>. However, before this professional issue is addressed, it is necessary to explore the meaning of the underlying concept the quality of life, and this constitutes the second issue.

The relationship between practice standards and the concept of the quality of life is informed by Bunge's discussion of the characteristics of an ideal quality of life indicator. Bunge (1975) argues that an indicator should contain three elements: i) a defensible definition of the quality of life; ii) a series of variables; and iii) a theory that links these variables to the underlying definition, and explains how a change in the quality of life is reflected in a change in the level of the indicator. The basic premise of this research is that practice standards for the quality of life should be linked to a theoretical definition of the quality of life that has sufficient power to explain the significance of the gross, and the more subtle, violations of the rights and dignity of older people that sometimes occur in institutional care.

What then is meant by the quality of life? The meaning of the concept is unclear. As McCall comments,

It should be noted at the outset that the goal of the research has changed since I was commissioned to undertake it in 1988. I was originally asked to explore the contribution that the "support worker", a new grade of nursing assistant developed as a consequence of Project 2000, might make to the quality of the lives of older people in long stay hospital accommodation. After the data had been collected, policy changes made this research question redundant. Following consultation with the commissioning agent, I therefore redefined the goals of the project, as stated above.

Not only do we not know what quality of life is, we don't even know what category of thing it is. Is quality of life a state of mind or a state of society? Does its definition vary from individual to individual, from culture to culture, from geographical area to geographical area, or is it the same for all people everywhere? Is quality of life measurable, and if so why do there continue to be profound differences of opinion over which social indicators are relevant to its determination?

## (McCall 1980:5)

The meaning of the quality of life is a matter of particular concern for professional nurses who work with older people in residential settings such as nursing homes, because the literature shows that this client group can be vulnerable to abuse and cruelty.

One of the earliest accounts of cruel nursing care was given by Barbara Robb in 1967. Robb was one of the authors of a letter which appeared in The Times (Strabolgi et al 1965) protesting about the practice, then common in general and mental hospitals, of stripping elderly patients of their spectacles, dentures, hearing aids and other civilised necessities, and of leaving them to vegetate in utter idleness. The authors of the letter invited readers who had experience of these things to write to them giving details. The resulting letters were compiled into the book, *Sans Everything*.

An extract from this book is given below. The extract is useful because it demonstrates the extent of the cruelty to which older people have, in the past, been subject, and as such, it stands as an extreme and obvious case of a situation in which the quality of life is in jeopardy. However, it is also provides a starting point from which to address the question, what is meant by the quality of life? The extract was written by a male auxiliary nurse and describes practices in two large hospital wards in the north of England. The time period is from November 1964 to August 1965.

The patients feared the staff- especially the older, fully qualified charge nurses. Their fears were justified, as anyone present at 6.55 am could vouch for, as they watched the charge nurse go into the assault armed with, for example, a short handled sweeping brush, and lay about him indiscriminately and with great ferocity. Bruises were commonplace, split eyebrows quite frequent. If the wound had to be stitched, it was always blamed on the assault of one patient on another.

The cruelty could be more refined than anything I have as yet described. Suppose for instance at meal-time a hungry patient brought his plate back for a second helping. Quite often it would then be deliberately heaped up in a revolting way with all the available scraps, until the food was piled to a height of perhaps 16 to 18 inches. The poor wretch was then "stood over" until he had eaten so much it was a wonder the poor wretch didn't burst. And this took place not in Belsen, but in the north of England.

A patient complained to the visiting psychiatrist that the charge nurse had attempted to throttle him as he lay in bed. I had the story from the patient himself as he lay in bed, forced to remain there about a fortnight as a punishment. It appeared that the charge nurse, once the psychiatrist was safely out of the way, had merely repeated the process.

(Robb 1967:43-47)

At an intuitive level, it seems reasonable to suggest that cruel treatment of this kind will undermine the quality of the lives of those who receive it. However, the concept of the quality of life is so vaguely defined in the greater part of the literature that it lacks the theoretical strength to substantiate or to refute this intuitive response (this argument is defended below); and it therefore constitutes an inadequate basis for the development of practice standards.

The purpose of this research is therefore to develop a concept of the quality of life that can adequately support a series of practice standards. The thesis is presented in five parts. Part one outlines the theoretical context of the study. It contains two chapters. The first discusses philosophical hermeneutics, which forms the conceptual and methodological framework of the research; and the second reviews aspects of the literature of the quality of life and evaluates it in terms of the purposes of the research. Part two of the thesis describes the empirical phase of the research, including the approach to data collection and the analytical strategy that was used. In part three the findings are presented, and in part four their implications are discussed for the organisation of care, and practice standards are derived. Part five evaluates the research, paying particular attention to the usefulness of philosophical hermeneutics, and suggestions are made for further research.

# PART I

# THE THEORETICAL CONTEXT

Part one contains two chapters. The first chapter describes philosophical hermeneutics and gives an account of its development; the second reviews aspects of the literature of the quality of life, and evaluates it in terms of the purposes of the research.

# CHAPTER 1

## PHILOSOPHICAL HERMENEUTICS

Philosophical hermeneutics forms the conceptual framework of this research. This chapter gives an account of the development of hermeneutics in both its early and modern phases. The chapter begins with a discussion of the etymology of the word "hermeneutics". This is followed by an outline of the discipline in its early phase. Next, the development of modern hermeneutics is traced through a review of the work of four major thinkers: Schleiermacher, Dilthey, Heidegger, and Gadamer. Following Bleicher (1980), it is shown that contemporary hermeneutics is represented by three schools: for Gadamer, hermeneutics is a philosophical discipline which is concerned with the phenomenon of understanding; for Betti and Hirsch, it is a set of techniques for the proper interpretation of texts; whilst for Habermas, hermeneutics is a critical discipline.

## The Early Phase of the Development of Hermeneutics

Hermeneutics has been defined as the theory or philosophy of the interpretation of meaning (Bleicher 1980). One of its roots can be traced back to Greek mythology: the Greek words "hermeneuein" (to interpret), and "hermeneia" (interpretation) are etymologically related to the name of Hermes, the god whose function was to transmit messages from the gods to mortals, expressing them in such a way that they could be understood by human beings. Thus, traced back to its earliest roots, hermeneutics suggests a process of bringing to understanding (Palmer 1969).

A second ancient root of hermeneutics can be found in the Hebraic and Biblical tradition. The Biblical tradition is a tradition of "word" - of word made flesh in the incarnation, but also of the Bible as the Word of God expressed in the form of a text. As Ihde (1980) comments, the meaning of the Bible has never been regarded as self-evident, but has attracted interpretive, and therefore hermeneutical, effort. One of the earliest examples of Judaeo-Christian hermeneutics is seen in St. Paul's practice of interpreting Old Testament passages in order to inform the spiritual situation of members of the early church (Riceour 1977).

The transformation of the theory and practice of interpretation into the self-conscious discipline of hermeneutics is linked to the history of the Church. The interpretation of Scripture was an issue of particular significance to Protestant theologians such as Matthias Flacius Illyricus, who challenged the right of the Catholic Church to define the meaning of the Bible, argued against the Tridentine emphasis upon tradition, and proposed that the Bible was an integrated and coherent document which could be understood without reference to external authority by those who followed the correct exegetical procedures (Bleicher 1980).

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Wilson (1989) recognises two movements within the early phase of the development of hermeneutics: the allegorical and the literal. The older allegorical approach to interpretation contended that at least some texts ought to be regarded as having a variety of senses in addition to the literal historical one; that some of these senses represented a greater depth of understanding than others; and that they ought therefore to be sought in texts under interpretation. An example of the allegorical approach can be seen in the work of Origen (185-254), who argued that

There are certain passages of scripture which, as we shall see in what follows, have no bodily sense at all (so) there are occasions when we must seek only for the soul and the spirit, as it were, of the passage.

(Book IV of Origen, On First Principles, cited by Wilson 1989:52)

The allegorical approach is also seen in the writing of Augustine (354-430), who

argued that

The whole of Old Testament Scripture, to those who diligently desire to know it, is handed down in a four-fold sense - historical, aetiological, analogical, allegorical.

(Wilson 1989:78)

The allegorical approach to the interpretation of Scripture was rejected by theologians

of the Reformation such as Calvin, Luther and Tyndale, who argued instead for a strictly

literal approach.

Thou shalt understand, therefore, that the Scripture hath but one sense which is the literal sense. And that literal sense is the root and ground of all...

(Tyndale 1492-1536, from Wilson 1989:106)

Although these early writers were clearly divided in their view as to what constituted a legitimate interpretation of scripture and how it was to be derived, they were united in so far as their attention was focused upon the interpretation of textual material. The work of Friedrich August Wolf (1759-1824) epitomises this early phase. Wolf saw hermeneutics as a body of practical wisdom for meeting specific problems of interpretation, holding that different techniques were appropriate for historical, poetic and religious texts, and by extension for sub-varieties within each of these classifications (Palmer 1969).

## Friedrich Schleiermacher: Hermeneutics as a General Art of Understanding

With the work of Friedrich Schleiermacher (1768-1834), the early hermeneutics, conceived as a set of techniques whose application would clarify the meaning of difficult texts of all kinds, gave way to a preoccupation with the nature of understanding itself, and the modern discipline of hermeneutics began to emerge (Riceour 1977).

Schleiermacher held the chair in Protestant theology at the University of Berlin between 1810 and 1834. He opened his lecture programme with the comment that

At present there is no general hermeneutics as the art of understanding, but only a variety of specialised hermeneutics.

(Mueller-Volmer 1985:72)

This statement serves as an enunciation of Schleiermacher's fundamental aim: to frame a general hermeneutics as the art of understanding (Palmer 1969).

Schleiermacher took as his starting point the process of understanding as it occurs in the case of the written word. He argued that each text contains two elements. First, there is a psychological element. The psychological element consists of all those parts of a text which

represent the imprint of its author. Consequently, it constitutes a source of evidence from which inferences about the author might subsequently be drawn. Second, the text contains a grammatical element, which is related to the language used by the author to express his thoughts and ideas. These two textual elements are complemented by two interpretive strategies: there is a comparative method, whose purpose is to enable the interpreter to understand a work in terms of its relationship to language (Mueller-Volmer 1986). The comparative method is used in order to "wring the last drop of meaning from the words and phrases which constitute the outward appearance of the work" (Hodges 1952:12). It involves analysis of the grammatical structure and stylistic properties of the work, and the ideas which prevailed at the time of its composition. The comparative method is complemented by a divinatory strategy, through which the interpreter attempts to penetrate intuitively into the mind of the author of the work. Its goal is to assist the interpreter to understand the writer "to the point that one transforms oneself into the other" (Wilson 1989:157). The use of both strategies was deemed to be necessary in the interpretation of each part of the work, although the divinatory method was of greater use in understanding the psychological element, whilst the comparative strategy was most useful in the case of the grammatical element. For Schleiermacher, then, the process of understanding was not simply a matter of grasping the meaning of a sequence of words, although it included this; it was essentially a reconstructive process through which the interpreter entered into the psychic life of an author by way of the shared medium of language in order to re-experience his creative act.

One of Schleiermacher's most important contributions to hermeneutics is seen in his statement that

Complete knowledge always involves an apparent circle... each part can be understood only out of the whole to which it belongs, and vice versa.

(Mueller-Volmer 1985:84)

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This statement shows that Schleiermacher had identified a concept that has remained at the centre of hermeneutical theory. The concept is that of the hermeneutical circle. The hermeneutical circle is a metaphorical device which shows that understanding is essentially a referential operation. As Palmer explains,

We understand something by comparing it to something we already know. What we understand forms itself into systematic unities, or circles made up of parts. The circle as a whole defines the individual part, and the parts together form the circle. A whole sentence, for instance, is a unity. We understand the meaning of an individual word by seeing it in reference to the whole of the sentence; and reciprocally, the sentence's meaning as a whole is dependent on the meaning of individual words... By dialectical interaction between the whole and the part, each gives the other meaning; understanding is circular, then. Because within this "circle" the meaning comes to stand, we call this the "hermeneutical circle".

## (Palmer 1969:67)

Palmer (1969) considers that Schleiermacher's contribution to hermeneutics marks a turning point in the development of the discipline. His goal of a general hermeneutics as the art of understanding, and his early account of the hermeneutical circle, are of particular importance.

Following the death of Schleiermacher, the project of developing a general hermeneutics fell into abeyance as consideration of the problems of interpretation tended to lapse back into the confines of specific disciplines such as history, philology and law. The next development in hermeneutics which is to be considered here came in the latter half of the nineteenth century with the work of Wilhelm Dilthey (1833-1911).

#### Wilhelm Dilthey: Hermeneutics as the Method of the Human Sciences

The significance of Dilthey's contribution to hermeneutics can best be understood if his work is placed in the context of the market-place of ideas which characterised the Europe of the late eighteenth and early nineteenth centuries. Dilthey worked in the shadow of Kant, who in his three "critiques" had examined the nature of knowledge in the mathematical and natural sciences, and the role played by the human mind in the construction of that knowledge. Dilthey's particular sphere of interest was not the natural sciences, but a group disciplines which he called the "geisteswissenschaften". Literally, the geisteswissenschaften are the "sciences of the human spirit" (Quinton 1988), although the term is more often rendered as the "human" or "cultural" sciences, or simply "the humanities". The geisteswissenschaften encompass history, psychology, and the social sciences of sociology and anthropology. Dilthey's goal was to write a "Critique of Historical Knowledge" which would extend the Kantian programme to include the cultural sciences, and in which he would clarify the grounds for their claim to valid knowledge, and identify the methods through which that knowledge could be derived.

Several authors have noted that the theme of "life" arches over Dilthey's philosophy. Life, in Dilthey's sense, does not refer to the biological characteristics which every human being shares with other animals, but is used in a technical sense to refer to

The inner conscious processes of all men, to the totality of all consciousness which is the "stuff" of history, and to the meaningful relationships that our own inner lives have to the life of other men.

(Tuttle 1969:10)

Young comments that for Dilthey,

Life... is a self-forming system always in process, and inseparable from the process of human life are the episodes whereby life constantly interprets and reinterprets itself: (it is) what unifies the various disciplines of the geisteswissenschaften...

(Young 1983:139)

In the early part of the nineteenth century, the debate about the nature of the social world, and the methods which could appropriately be used to understand that world, was dominated by the positivism of August Comte.

Comte had been influenced by the causal-mechanistic framework of Cartesian empiricism and he was impressed by the spectacular advances of the natural sciences and technologies of the eighteenth century (Giddens 1976). He regarded the extension of science into the study of human life as a direct outcome of the march of human understanding towards man himself.

Human knowledge first breaks through the shroud of mysticism in those areas of nature furthest from man's involvement and control, in which he appears to play no role as subject: first mathematics and then astronomy. The development of science subsequently edges closer and closer to human life, moving through physics, chemistry and biology to the creation of sociology, the science of human conduct in society.

(Giddens 1976:12)

As Howard (1982) explains, Comte argued that just as laws had been found to explain the interaction of elements in nature, so they could be found for the interaction of people in society, and the physics of mechanical movement complemented by a social physics of human beings. Von Wright (1971) has identified three central tenets of positivism. The first is methodological monism, or the idea of the unity of scientific method amid the diversity of subject matter of scientific investigation; the second is the view that the exact natural sciences, in particular mathematical physics, set a standard against which the degree of development of all other forms of knowledge can be judged; and the third is that explanation consists of the discovery of cause and effect relationships which, when expressed as laws, can be used to explain individual cases. Dilthey was dissatisfied with positivism as an approach to understanding life. The source of his dissatisfaction lay in his perception of fundamental differences between the subject matter and goals of the natural and social sciences. To Dilthey, it was apparent that the natural sciences take as their subject matter the many phenomena which constitute the physical world, and that their goals are to describe these phenomena, and then to formulate laws which will account for the relationships between them. The natural sciences were *explanatory* sciences, and they could be justified through reference to Kantian categories such as number, substance, cause, and effect.

Dilthey argued that the type of knowledge afforded by the cultural sciences was qualitatively different from that of the natural sciences. Our knowledge of human history and culture could never be direct, but was always derived from the study of a group of phenomena which Dilthey called "objectifications of life". Wilson refers to these phenomena as "cultural achievements", and includes in their number

Such human productions as works of art, social movements, political ideologies, texts, dances, constitutions, and laws, political forms (e.g. socialism, democracy, fascism etc.), languages, religions, customs and traditions. In sum, cultural achievements include all the human conditions and expressions that comprise the humanities.

## (Wilson 1989:169)

Dilthey believed that the explanatory procedures of the natural sciences are of little use in helping one to grasp the individuality and meaning of cultural expressions; the proper goal of the cultural sciences is to *understand* these cultural expressions, and the forms of life which lie behind them, and this goal demands a rather different approach from that of natural science.

As he attempted to clarify the nature of this process of understanding, Dilthey drew upon the hermeneutical theories of Schleiermacher, and he was also influenced by an intellectual movement which stood in opposition to the rationalism of the positivists: romanticism (Hodges 1974).

Romanticism was a movement in the arts and philosophy which swept across Western Europe and Russia at the end of the eighteenth and the beginning of the nineteenth century. Hodges (1974) finds a clear expression of Romantic ideas in the work of Goethe. Goethe argued that the universe should be regarded as a living being, whose life develops stage by stage, through inorganic nature, through plant life and animal forms, until it attains its end in man, where it becomes an object of consciousness to itself. For Goethe, man's unity with nature meant that the detailed workings of nature were accessible, through intuition, by those whose minds had been freed from the fetters of rationalism.

Dilthey was unable to accept this argument. For him, direct and unmediated insight into nature could only be possible for God, of whose will and intent it is the expression. But although "the romantic hope of grasping intuitively into the hidden meaning of nature is philosophically preposterous and methodologically absurd" (Bauman 1978:33), it need not automatically follow that intuitive understanding has no role to play in the methods of the human sciences. Indeed, it was Dilthey's argument that we can understand human culture and history precisely because, like nature for God, they are expressions of life. As Rickman comments, "this understanding is not an obscure, unanalysable intuition, a mysterious flash of lightning, or a gimmick which replaces disciplined intellectual work and makes it superfluous" (Rickman 1961:40), but it is

That which opens up to us the world of individual persons, and thereby also possibilities in our own nature. Understanding is not a mere act of thought but a transposition and re-experiencing of the world as another person meets it in lived experience... an operation of silent thought which accomplishes a pre-reflexive transposition of oneself into another person.

(Palmer 1969:115)

In summary, Dilthey's goal was to establish grounds for valid knowledge in the human sciences as Kant had done for the natural and mathematical sciences, and to clarify the methods through which that knowledge was obtained. The methods of natural science could not be applied directly to the human sciences because of differences in their subject matter: whereas the physical sciences were concerned with developing universal laws in order to *explain* the interaction of elements, the human sciences sought to *understand* expressions of culture in terms of categories drawn from life itself. Understanding was essentially an intuitive phenomenon, and was possible because each cultural achievement, having been created by human beings, could in principle be understood by human beings.

#### Martin Heidegger: the Hermeneutical Dimension of Being

Our attention now turns to the first substantial development in hermeneutical theory of the twentieth century, which came in 1926 with the publication of Heidegger's *Being and Time*. Heidegger's statements about understanding and interpretation are best considered in the context of the larger purpose of this book. Dreyfus suggests that

What Martin Heidegger is after... is nothing less than deepening our understanding of what it means for something (things, people, abstractions, languages, etc.) to be,

# and that

As a first step in his project he attempts to work out a fresh analysis of what it is to be human.

# (Dreyfus 1991:1)

(It should be noted that throughout *Being and Time*, Heidegger uses the word "Dasein", which is retained in the English translation. Literally, Dasein means "being there", but Dreyfus (1991:13), and Cooper (1990:67) consider that the term can legitimately be rendered "human being", and that is the sense in which it will be taken in this thesis).

In *Being and Time*, Heidegger was deeply critical of a traditional concept of understanding which has its origins in Cartesian philosophy. Descartes (1986) had based the notion of understanding upon the premise that a distinction could be made between the mind (res cogitans), which existed in the dimension of time, and the body (res extensa), which was physical in nature and occupied three dimensional space. Because the mind had no direct access to the external world, its understanding of that world had to be built up from impressions it received by way of the sensory mechanism of the body; and the possibility that these impressions might be wrong was always present. Within this framework, true knowledge could be defined as correspondence "between the propositional content of either mental states or assertions, and facts in the world" (Dreyfus 1991:265).

Heidegger's critique of the Cartesian tradition rejects the conventional dichotomy between temporal mind and material world and, through the notion of "being-in-the-world", asserts that the relationship between human being and world is one of necessary interdependence. The concept of being-in-the-world has two aspects, which are expressed in Sartre's comment that "without the world there is no self-hood, no person; without self-hood, without the person, there is no world" (Macquarrie 1972:81).

Heidegger's suggestion that the world is dependent upon human being does not imply a form of subjective idealism, or represent the view that the material universe depends for its existence upon the minds that perceive it; but rather that human concern and involvement serve to integrate diverse phenomena, organising and imposing a framework of coherence upon them, and thereby constituting them as world. Macquarrie comments that Heidegger's use of "world" is related to the sense of the Greek word "Kosmos", which means "order", and implies the organisation and unity brought about by personal involvement (Macquarrie 1972:79).

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Being-in-the-world also expresses Heidegger's argument that "world" is essential for human being. The material objects which are present within the world are not neutral artefacts. As they are put to everyday use by the human beings who participate in the shared social practices of a particular culture, they come to carry a burden of meaning, and form a part of the "symbolically structured environment" (Bourdieu 1977:87) within which daily life is lived. This inter-relationship of material artefacts, social practices and cultural values can be illustrated by taking a key as an example. A key represents a social practice of locking doors, and makes sense within a culture in which limited access to personal space is valued and the concept of private property is legally enforced. Generally speaking, these values are not passed on to children through verbal instruction, but as they observe social practices such as locking the door when leaving the house.

Having discussed Heidegger's concept of being-in-the-world, it is now possible to explore his development of the hermeneutical concepts of understanding and interpretation.

Understanding in Descartes and Heidegger: a comparison

The Cartesian tradition is an objectivist tradition which conforms to

The basic conviction that there is or must be some permanent, a-historical matrix or framework to which we can ultimately appeal in determining the nature of rationality, knowledge, truth, reality, goodness, or rightness.

(Bernstein 1983:8)

Like Archimedes, Descartes:

Used to demand just one firm and immovable point in order to shift the entire earth.

(Descartes 1986:16)

Generations of philosophers and methodologists have followed Descartes in assuming that if they could find a method of freeing themselves from the distorting influences of history and society, they could perceive the world in its pristine reality, and thereby claim certainty in knowledge. For Husserl, for instance, Descartes' Archimedean point could be achieved through the method of phenomenological reduction.

The method of phenomenological reduction... required that consciousness cuts itself off from its historical and social entanglements, and constitutes itself as an absolute... Then, and only then, consciousness liberated from the world will be capable of grasping the true meaning; not the contingent meaning, meaning as it happens to be seen, but meaning in its true, necessary essence.

#### (Bauman 1978:111)

At the other end of the methodolological spectrum the experimental psychologist Kerlinger (1973) considers that truth can most nearly be approximated if the scientific method is rigorously applied.

Heidegger's account of the nature of understanding is radically different from that of Descartes. Heidegger rejects the view that understanding involves extracting ourselves from the world, arguing on the contrary that understanding is only possible because we have our being-in-the-world. Heidegger asserts that there are three non-cognitive preconditions of understanding, which he calls the "fore-structure". The three elements of the fore-structure are summarised by Dreyfus (1980:10; 1991:198) in the following way.

1. Vorhabe (fore-having). The vorhabe is the totality of cultural practices which constitute the taken-for-granted background which circumscribes our possibilities for understanding and determines possible ways of questioning. The importance of the vorhabe in understanding is illustrated by a passage in which Descartes demonstrates the difficulty of understanding the nature of a piece of wax. He notices that the wax

has something of the odour of flowers, that it has a particular colour, shape and size,

and that it is both hard and cold.

But even as I speak, I put the wax by the fire, and look: the residual taste is eliminated, the smell goes away, the colour changes, the shape is lost, the size increases; it becomes liquid and hot; you can hardly touch it, and if you strike it it no longer makes a sound.

(Descartes 1986:20)

But, as Bauman comments, it is a philosopher's illusion that we do not know anything about wax until we try to attribute to it qualities which it allegedly has all by itself. Descartes' attempt to understand wax in this way presupposed a lifetime of familiarity with wax as a medium for making candles, sealing letters, and polishing tables.

All this we did without ever needing an answer to the question, "what are the attributes of wax?" - the question which we continually answered in our handling of wax and therefore had no need to ask as a question.

(Bauman 1978:158)

- 2. Vorsicht (foresight). Vorsicht implies that our understanding is mediated by the vocabulary or conceptual scheme which we bring to bear on a problem.
- Vorgriff (fore-conception). Vorgriff relates to the fact that in each act of understanding the investigator has an expectation of what will be discovered.

In the practice of science, the Vorhabe is what Kuhn (1970) would call the "disciplinary matrix", or the skills and concepts which a student acquires in becoming a scientist which enable her to determine what are the scientifically relevant facts; the Vorsicht relates to the theoretical framework within which an investigation is framed; and the Vorgriff is the particular hypothesis.

#### Understanding and Interpretation as Characteristics of Being

There is a second sense which Heidegger gives to "understanding", but before it can be discussed it is necessary to outline his development of another concept which is central to his hermeneutical theory: the concept of interpretation. Heidegger's use of "interpretation" is related to the special sense which he gives to the concept of "existence". He does not use this word in its colloquial sense: the comment that "the essence of Dasein lies in its existence" (Heidegger 1962:42) is not to be taken as indicating the obvious fact that each human being is real, and that he or she occupies a point in space. As Cooper explains, Heidegger's technical use of the word "exist" draws upon its derivation from Greek and Latin words which mean "to stand out from", and refers to the belief that a person is always already "beyond" or "ahead of" whatever properties characterise him at a given time.

No complete account can be given of a human being without reference... to what he is in the process of becoming - without reference, that is, to the projects and intentions which he is on the way to realising, and in terms of which sense is made of his present condition. As Heidegger puts it, the human being is always "ahead of himself", always "unterwegs", (on the way).

(Cooper 1990:4)

The notion of existence is closely related to the role of interpretation in the process of

human being.

Cultures and cultural institutions have existence as their way of being, and so does each of us. To exist is to take a stand on what is essential about one's being and to be defined by that stand. Thus Dasein is what, in its social activity, it interprets itself to be. Human beings do not already have some specific nature. It makes no sense to ask whether we are essentially rational animals, creatures of God, organisms with built-in needs, sexual beings, or complex computers. Human beings can interpret themselves in any of these ways and many more, and they can, in varying degrees, become any of these things, but to be human is not to be essentially any of them. Human being is essentially simply self-interpreting.

(Dreyfus 1991:23)

Logically, the mode of being which Heidegger calls existence, and the related activity of interpretation, are possible because the human being is at all times faced with a range of possible courses of action; by a "space of possibilities" that closes off certain courses of action whilst maintaining others as "live options". This space of possibilities is dependent upon the physical, social and historical situation of the individual - upon his or her "being-inthe-world" - but it never serves to commit a person's actions in a deterministic way. As Guignon explains,

Our agency is always situated in a cultural context that provides the pool of possibilities from which we draw our concrete identities as agents of particular types.

## (Guignon 1992:23)

Benner and Wrubel's discussion of the nature of caring provides a useful illustration of this process (Benner and Wrubel 1989). They point out that people may be quite heroic in caring for a loved one with a serious illness, and comment that although this kind of caregiving often appears courageous to someone who is not involved in the situation, the caregiver does not feel courageous because the option of not caring does not present itself.

There is no other option compatible with being who this person is, that is, a person who cares for a loved one. When people are praised for their courage or devotion in caring for a seriously ill loved one, they typically respond "I just did what I had to do". Walking away and not caring simply does not occur to the person.

## (Benner and Wrubel 1989:3)

The foregoing discussion has indicated how Heidegger developed the hermeneutical concepts of understanding and interpretation. It has been shown that understanding has two related senses in Heidegger's work. The first sense refers to the individual's practical familiarity with the objects which fill his or her world. The second sense refers to his or her apprehension of the "situation": of the range of possibilities which he or she faces at a given

time. It is this second sense of understanding which enables the individual to engage in the interpretive activity human being: of selecting from the possible range of courses of action which are opened up by his or her situation. As Palmer comments,

The essence of understanding lies not simply in grasping ones situation but in the disclosure of concrete potentialities for being within the horizon of ones placement in the world.

## Palmer (1969:121)

In summary, Heidegger moved hermeneutics beyond Dilthey's concern with the methodological concerns of the geisteswissenschaften by showing that understanding and interpretation are characteristics of human being.

The movement of interpretation....most basically is not an encounter between interpreter and author or with a text, but "between" human existence and the unique historical situation in which it is already involved....Both the "text" and the "author" of earlier hermeneutical theories are drawn into (this) larger context".

(Kisiel 1969)

# Hans-Georg Gadamer: Understanding as the Fusion of Horizons

This discussion of the content and historical development of hermeneutics will now consider the work of Heidegger's friend and pupil, Hans-Georg Gadamer. Gadamer's work represents a recapitulation of elements of the work of Schleiermacher, Dilthey and others, but he was particularly influenced by Heidegger. In *Truth and Method*, which is Gadamer's most important work, elements and themes from each of these writers are gathered up and synthesised into a new whole, as the writer works out his intention to "discover what is common to all modes of understanding" (Gadamer 1975:xix).

Gadamer's task is reminiscent of Schleiermacher's aim of developing a general hermeneutics; but although Gadamer shares with Schleiermacher the view that hermeneutics is, or ought to be, a general discipline, he differs from that author in that he does not make it his purpose to inform the methodology of the human sciences, or to develop an art or technique for the interpretation of texts. This is because Gadamer is concerned with a more fundamental question: how is understanding possible, not only in the humanities but in the whole of the human's experience of the world? (Palmer 1969). As Hoy comments,

The purpose of Gadamer's hermeneutical philosophy... is to describe the activity of understanding in general and not to provide an epistemological philosophy of science or a logic of scientific explanation.

## (Hoy 1978:51)

Murray (1985) considers *Truth and Method* to be a rich and difficult book. The source of the difficulty may be that Gadamer's account of the relation which truth bears to method does not consist of a systematic demonstration of specifiable theses. This causes Bernstein (1983) to observe that although the concept of truth is basic to Gadamer's entire project of philosophical hermeneutics, it turns out to be one of the most elusive concepts in his work. However, Weinsheimer defends Gadamer's approach, arguing that *Truth and Method* 

Aims to make sense of and legitimate certain ideas, but not to prove them. They cannot be proved, not because of their intrinsic irrationality, still less because they are false, but rather, precisely because they call into question the belief that proof is our sole access to truth.

## (Weinsheimer 1985:2)

This quotation is important because it draws attention to a central aspect of Gadamer's work: his rejection of the view, held since the Enlightenment, that truth is to be exclusively identified with the products of the scientific method. As Page comments,

The title (Truth and Method) announces Gadamer's intention to undermine the orthodoxy that the positive sciences are the ultimate paradigm of cognitive success, that method is wholly adequate to all of the truth.

## (Page 1991:171)

Gadamer's critique of the Cartesian tradition extends that which Heidegger had begun in *Being and Time*. According to the tradition, the scholar who espouses objective truth must recognise that he or she holds certain presuppositions and prejudices; that these presuppositions and prejudices have the power to distort his or her understanding; and that their effect can be minimised through the use of a method. The method may be Husserl's method of phenomenological reduction, which enables the scholar to put his or her presuppositions in brackets; it may be the scientific method, or some other. Method is necessary because as Peters (1974) comments, presuppositions for the natural scientist are like "lice in the hair": they are something to be eliminated.

In his work, the ideal scientific thinker believes he must become an innocent "tabula rasa", a purely open mind onto which the data of his research can inscribe unbiased knowledge.

# (Peters 1974:209)

Gadamer rejects these arguments. It is his view that the prejudices which a person holds are derived from that person's historical situation; and he argues that far from being the enemy of understanding, prejudice constitutes its necessary precondition (Gadamer 1975). (It should be noted that where Gadamer uses the word "prejudice", some of his commentators substitute "presupposition". The two terms will be used interchangeably here).

Gadamer seeks to rehabilitate the concept of prejudice from negative connotations which he traces back to the Enlightenment. The word was originally derived from two Latin words: "pre" (before); and "judex" (a judge); and therefore simply refers to a judgement which has already been made. For Gadamer, our prejudices are indivisible from the historicality of

our being: from the fact that each of us is historically as well as socially situated.

History does not belong to us, but we belong to it. Long before we understand ourselves through the process of self-examination, we understand ourselves in a self-evident way in the family, society and state in which we live. The focus of subjectivity is a distorting mirror. The self-awareness of the individual is only a flickering in the closed circuits of historical life. That is why the prejudices of the individual, far more than his judgements, constitute the historical reality of his being.

## (Gadamer 1975:245)

Gadamer's analysis of the role played by prejudice in understanding draws upon Heidegger's theory of the fore-structure of understanding. Gadamer argues that the prejudices which tradition hands down to a person constitutes his or her "situation".

We define the concept of situation by saying that it represents a stand-point that limits the possibility of vision. Hence an essential part of the concept of situation is the concept of horizon. The horizon is the range of vision that includes everything that can be seen from a particular vantage point... the prejudices that we bring with us... constitute, then, the horizon of a particular present, for they constitute that beyond which it is impossible to see.

(Gadamer 1975:272)

The concept of horizon provides Gadamer with a powerful metaphor which he uses to explain the process of understanding. For Gadamer, both the scholar, and the text which is the object of study, exist within horizons whose boundaries are determined by their historical situation. Gadamer is critical of earlier hermeneutical theorists (Schleiermacher and Dilthey) for underestimating the role which the historicality of the interpreter plays in the process of understanding (Linge 1976). Understanding does not occur as the scholar steps out of his or her own horizon and into that of the text, for that would not be possible; but neither does it involve the relentless superimposition of the prejudices of the scholar upon the text. Rather, understanding is the result of the formation of a comprehensive horizon in which the limited horizons of text and interpreter are fused together into a common view of the subject matter with which both are concerned - the meaning (Linge 1975:xix). Thus, understanding can be defined as the fusion of the horizons of scholar and text.

Conversation can be regarded as a model of the way in which understanding occurs. Palmer (1987) considers that in a true conversation, one person does not simply ask questions of the other in order to discover what they think, for this would not be conversation but interrogation. Equally however, we do not say that two people are in dialogue when one is haranguing the other without listening to their response. True conversation demands a quality of openness from both participants: an attempt by each to discover what the other is saying; and a preparedness from each to place their own prejudices at risk through openness to what the other has to say.

If this model is applied to historical understanding, it shows that truth in history is not discovered by attempting to recreate the mental processes of those whose texts, words and deeds we have received; and it invalidates attempts to make definitive pronouncements about the meaning of historical events. But,

Just as in a conversation, when we have discovered the stand-point and horizon of the other person, his ideas become intelligible to us without our necessarily having to agree with him, the person who thinks historically comes to understand what has been handed down, without necessarily agreeing with it, or seeing himself in it.

## (Gadamer 1975:270)

Two important aspects of Gadamer's hermeneutics deserve final emphasis. The first is that Gadamer's argument that prejudice plays a necessary role in understanding does not infer that the range of a person's prejudice is fixed, that their prejudices are all equal in validity, or even that they are all defensible. However, the person who seeks to understand the past will find that his or her understanding of the present is also enhanced, and that the prejudices which constitute his or her own horizon will come more clearly into view. Gadamer

suggests that we should test all our prejudices, and considers that

An important part of this testing is the encounter with the past and the understanding of the traditions from which we come.

(Gadamer 1975:273)

He asserts that

The historical movement of human life consists in the fact that it is never utterly bound to one stand-point, and hence can never have a truly closed horizon. Horizons change for the person who is moving.

(Gadamer 1975:271)

The second point to be made is that Gadamer's approach obviates the possibility of arriving at a definitive or canonical interpretation of a given text. Particular interpretations cannot claim objectivity because each is the product of the interaction of the horizon of the text with that of the interpreter. Consequently the meaning of a text will vary in different historical periods (Hekman 1984). This does not mean that the process of interpretation is an arbitrary one, or that competing interpretations are of equal validity; but that judgements of the validity of a particular interpretation of a text will, like the interpretation itself, be influenced by the horizon within which they occur (Bernstein 1983).

Emilio Betti and Jurgen Habermas: Gadamer's critics

The philosophical hermeneutics of Hans-Georg Gadamer has been criticised on two principal fronts.

The source of the conflict between Gadamer and his critic Emilio Betti seems to relate to their differing perceptions of the possibility of identifying the objective meaning of a text. Betti argues that Gadamer's work is flawed because the method he proposes will not enable the correct meaning of a text to be exposed. In his own work, Betti defines the correct meaning of a text in terms of the original intention of the author, and he offers a canon of methodological principles which will enable it to be brought to light (Bleicher 1980).

It is difficult to avoid agreeing with Gadamer's conclusion that Betti has substantially misinterpreted the purpose of *Truth and Method* (Gadamer 1975), because Gadamer is explicit in his statement that his project of philosophical hermeneutics does not constitute a methodology but an attempt "to discover what is common to all modes of understanding" (Gadamer 1975:xix).

The work of Jurgen Habermas offers the second major critique of Gadamer's hermeneutics. It has been shown that hermeneutics, as developed by Heidegger and Gadamer, is a philosophy with both ontological and epistemological implications. Heidegger and Gadamer have used the hermeneutical concepts of understanding and interpretation to explain the nature of human being as being which is rooted in an historical situation which creates possibilities for human existence without defining it in a deterministic way. History also constitutes the source of the prejudices which make understanding possible. Language occupies a central place in philosophical hermeneutics because it is the medium for the transmission of tradition, and because it constitutes the necessary condition for the dialogue between text and interpreter which arises from the fusion of horizons.

Habermas, like Betti, criticises Gadamer for the relativism of his approach. Although he agrees with Gadamer that prejudice constitutes the precondition of understanding, he criticises Gadamer for appearing to celebrate the necessary impossibility of discovering independent and objective standpoints. He implies that Gadamer is essentially a conservative force because his approach does not offer a convincing way of discriminating between the merits of various clusters of prejudices, with the consequence that their ideological bases can go unchallenged. He advocates a form of "depth hermeneutics" which is modelled on psychoanalysis, and which he claims will break through the distortions of language and enable us to identify in an objective way the forces which shape our existence (Hekman 1986:131; Bleicher 1980:3). The debate between Gadamer and his critics is not sufficiently central to the purposes of this study to merit further attention here.

#### Conclusion

This chapter has described important features of hermeneutics and given an overview of the historical development of the discipline. As the thesis develops, it will be seen that hermeneutics offers a critical perspective on the literature of the quality of life; justifies the methodological decisions that were taken during the empirical phase of the study; and informs the development of the findings. These various functions are evaluated in chapter eight.

#### **CHAPTER 2**

#### THE QUALITY OF LIFE: A REVIEW OF THE LITERATURE

This chapter examines parts of the literature of health and related disciplines that address the concept the quality of life.

Although the quality of life is currently regarded as a significant issue in fields as diverse as medical ethics (euthanasia and abortion), environmental ethics (resource use and allocation), moral issues in law (punishment), and social justice (welfare rights and future generations), its meaning is far from clear. As we have seen, McCall has suggested that

Not only do we not know what quality of life is, we don't even know what category of thing it is. Is quality of life a state of mind or a state of society? Does its definition vary from individual to individual, from culture to culture, from geographical area to geographical area, or is it the same for all people everywhere? Is quality of life measurable, and if so why do there continue to be profound differences of opinion over which social indicators are relevant to its determination?

(McCall 1980:5)

Many of these questions are still being debated in the contemporary literature.

In an earlier paper, McCall (1975) suggested that there are two basic approaches to the quality of life: the eudaemonistic, and the social scientific. The eudaemonistic approach draws upon Aristotle's concept of "eudaimonia", or human flourishing (Den Uyl and Machan 1983). It is concerned with the nature of human being, and seeks to identify conditions in which human beings can flourish. It is concerned with the social environment as an enabler of human beings to reach their potential (Aiken 1982). This approach to the quality of life is discussed later in the thesis. The social scientific approach regards the quality of life as a phenomenon that can be operationalised and measured, and which can be used in the evaluation of policies and programmes of various kinds. This chapter is primarily concerned with the literature that uses the quality of life in this way. Although this literature is so extensive as to be almost without limit, a number of important themes and debates recur. In order to give a reasonable account of these themes and debates, it has been necessary to approach the literature in a way that is at once systematic and selective. For this reason, the chapter focuses on three distinct bodies of literature: social indicators research; quality of life as an outcome measure in medical research; and the "Quality Adjusted Life Year", or QALY.

The social indicators literature is discussed because it probably represents the earliest systematic exploration of the problems inherent in the measurement of the quality of life, and many of the debates and issues that it explores can be found in other parts of the literature.

There is a substantial body of literature that relates the quality of life to health. A single aspect of that literature is explored here: the use of the quality of life as an outcome measure in the evaluation of medical interventions. This section illustrates some of the practical problems associated with the measurement of the quality of life in the context of empirical research, and complements the more theoretical discussion of the first section.

Finally, there is a critical discussion of the suggestion that decisions about the allocation of resources within the health service should be made on quality of life grounds.

In the first instance, each of these bodies of literature is discussed independently, and the critique is principally concerned with matters of conceptualisation and measurement. The critique becomes broader in the last section of the chapter, where there is a discussion of issues that are common to each of the three approaches. Finally, the chapter draws upon hermeneutical theory to criticise the notion that the quality of life can be measured, and the implications of the social scientific literature for the research question are assessed.

#### **The Social Indicators Movement**

The History of Social Indicators Research

Social indicators research attempts to quantify the impact of economic and social policy upon the quality of life.

The notion that social topics might be analysed in a quantitative way can be traced to the "political arithmeticians", a group of chemists, naturalists and scientists whose work made possible the pioneering surveys of poverty in nineteenth century England (Lazarsfeld 1961).

Modern attempts to quantify the quality of life can be traced to the work of the philosopher Otto Neurath, a prominent member of the Vienna Circle who sympathised with Marxist thought. Writing in 1937, Neurath rejected the utilitarian philosophy underlying mainstream economics and its use of terms such as "the standard of living", "the general welfare", or "the good of the people" when evaluating the impact of economic policy. He proposed instead to

Co-ordinate the totality of a person's feeling, or that of a group, with his or its entire living condition,

and

To investigate the extent to which changes in the state of felicity in a positive or negative direction depend upon changes in these conditions.

(Neurath 1937 cited by Callebaut 1978:162)

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Neurath's ideas had no impact at the time of their expression, and the notion that it might be possible to measure the impact of economic and public policy upon the quality of life remained unexamined until the 1960s.

In the 1960s, commentators in the Unites States began to argue that there was an over-emphasis on conventional indicators of economic performance such as the Gross National Product (GNP). For instance, Gross (1966) criticised the emphasis that (US) policy makers were placing upon cost-benefit analysis, and for operating on the premise that any meaningful benefits from Government programs can be expressed in dollars and cents. He proposed a shift in emphasis from economy to society, suggesting that, for many of the important topics on which social critics pass judgement, there are no yardsticks to know whether things are getting better or worse.

President Johnson, who was sympathetic to this argument, established a "Panel on Social Indicators" to explore new approaches to social accounting (Moberg and Brusek 1978). In its first report, this panel defined a social indicator as

A statistic of direct normative interest which facilitates concise, comprehensive and balanced judgements about the condition of major aspects of a society. It is in all cases a direct measure of welfare and is subject to the interpretation that, if it changes in the "right" direction, while other things remain equal, things have gotten better, or people are "better off"

(US Department of Health, Education and Welfare 1969)

#### **Objective Social Indicators**

The early literature of the social indicators movement can be divided into two categories: objective and subjective (Andrews 1974). The objectivists assumed there to be a causal relationship between the quality of life and the consumption of public and market goods and aspects of the physical environment, and advocated that crime rates, population

density figures and the level of public service provision should be collated to give an "objective" index of the quality of life in a given population (Gillingham and Reece 1980).

The work of Liu (1975) illustrates this approach. Liu defined the quality of life in terms of a number of physical inputs, which consisted of social factors (individual status, individual equality, and living conditions); economic inputs (economic status, technological development and agricultural production); and political inputs (health and welfare provision, educational development and government). In principle, Liu accepted that the quality of life was also influenced by psychological, sociological and anthropological factors such as community belongingness, esteem, self-actualisation, and love, but he omitted these from his work because they were unquantifiable, thereby reducing the measurement of quality of life to the assessment of material circumstances (Huxley 1986).

Gehrmann (1978) has also suggested that quality of life studies should concentrate on those parts of the social domain that are measurable in an objective way. The list of social phenomena which Gehrmann considers to be so measurable includes crime, safety, social participation, social disintegration and unemployment. The view that data on these phenomena are objective is clearly naive: the definition and measurement of unemployment, for instance, are not matters of objective fact but of political debate informed by ideological perspective.

Critics have identified a tenuous link between global objective indicators, and people's evaluation of their own life situation. Rescher (1972) noted that although the material circumstances of Americans, as measured by indicators such as life expectancy, income, and social welfare expenditure had increased, their level of happiness had declined; and Campbell, Converse and Rogers (1976) noted that a nation which had been known and criticised for its materialistic values was now asking itself whether in fact the good life can be measured in terms of consumer goods.

A number of studies conducted in the mid-seventies empirically demonstrated that the objective conditions of life are only marginally related to the subjective experience of a better quality of life. For instance, Campbell and co-workers (1976) found that the correlation between income and a person's satisfaction with their standard of living was 0.23; whilst Schneider (1975) found a low degree of correlation between a range of objective indicators and individual's satisfaction with various aspects of their lives. Various explanations of this observation will be considered below. Huxley (1986) suggests that these factors contributed to a sense of dissatisfaction with objective indicators and led to the development of subjective indicators of the quality of life.

#### Subjective Social Indicators

Subjective indicators assume that each person is the most legitimate judge of their own life's quality, and provide a mechanism through which such self-assessments can be made. Andrews (1974) has offered four reasons for developing subjective indicators of the quality of life: first, because they provide direct measures of individuals' evaluations of their own well-being; second, because they enable the relationships between life concerns to be explored; third, because they provide a check on the adequacy of a range of a set of objective measures; and fourth, because they lead to knowledge which is useful in designing programmes whose aim is the enhancement of individual well-being.

Research in the subjective indicator field has its roots in the work of Cantril (1965), who interviewed a cross-section of people from various countries to determine what aspects of life they considered to be important from positive and negative points of view, and where they scaled their personal standing in the present and the future.

One of the largest studies of this type was conducted by Andrews and Withy (1976), whose research involved interviews with over five thousand Americans and provided baseline data on the distribution of perceptions of well-being across society. The basic concepts in their model concerned well-being at several levels of specificity. At the most general level were global indicators referring to life as a whole; the next level addressed concerns, consisting of aspects of life about which people have feelings. These were divided into domains (such as job, family life and neighbourhood) which could be evaluated in terms of criteria (such as privacy, comfort and security).

Similar work was conducted in the UK by Abrams (1976). Having defined the quality of life as a function of the satisfaction felt by individuals, Abrams invited respondents to give an overall assessment of their life situation in terms of twelve domains including housing, health, neighbourhood, job, family life, financial situation and others.

One of the most striking features of this part of the literature is the lack of consensus on the nature and definition of the underlying construct "well-being". A range of terms such as satisfaction, morale and happiness are often used in an interchangeable way (Zautra and Hempel 1984). Following Peschar (1977), this discussion will first evaluate the idea that selfreports of happiness give a useful index of the quality of life, and will then focus on the measurement of well-being.

#### Quality of Life as Happiness

Inevitably, there is disagreement in the literature about the nature of happiness and about its relationship to the quality of life. The historical development of the concept is discussed by Tatarkiewicz.

In early times "happiness" means simply success. Then for long centuries, covering much of antiquity and the middle ages, it signifies a man's perfect condition or the possession by him of the highest virtues and goods. Modern times reduced happiness to pleasure. This evolution has tended to swing between two extremes: the idea of happiness as perfection and as pleasure.

(Tatarkiewicz 1976:36)

The modern literature continues to reflect these approaches to happiness. Malcolm-Gill (1984), for instance, reduces happiness to an internal psychological state akin to pleasure or euphoria; whilst Bradburn (1969) relates it to well-being, a much broader concept in the tradition of Aristotle's "eudaemonia" (human flourishing).

The problem with using self reports of happiness as indices of the quality of life is that happiness appears to be a consequence of the gap between expectation and achievement (Shin and Johnson 1978, Mason and Faulkenberry 1978). This results in the paradox that conditions that are objectively identical can elicit very different responses from different individuals, whilst subjectively similar responses can result from widely differing objective situations (Callebaut 1980). As Kennedy (1978) comments, different individuals can be satisfied or dissatisfied with the same objective conditions.

McCall's explanation of this phenomenon is that human needs are specific and limited, whereas wants are potentially boundless (McCall 1980). He argues that the satisfaction of human needs is a necessary but not sufficient condition for happiness\satisfaction. A person will be satisfied or unsatisfied to the extent to which basic needs and major wants are filled. It is because wants vary from individual to individual that the correlation between objective conditions, and the subjective evaluation of those conditions, is relatively weak.

Seashore (1974) offers another explanation. He refers to human adaptability, arguing that being satisfied is a common coping response which offers a means of defining ones situation in an acceptable light and thereby coming to terms with it. It is quite possible, of course, that these two mechanisms operate simultaneously.

Although Veenhoven (1991) rejects the assumptions upon which this paradox is based, most other authors consider that it throws into doubt the validity and usefulness of self

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reports of happiness as an index of the quality of life (Shin and Johnson 1978, Mason and Faulkenberry 1978, Callebaut 1980).

#### Quality of Life as Well Being

The discussion now turns to the subjective assessment of well-being. Having reviewed thirty years of research into the life satisfaction and morale of older Americans, Larson (1978) considered there to be sufficient evidence to regard subjective well-being as a single summary construct. Like Zautra and Hempel (1984), Larson found the well-being of people over sixty to be most strongly related to health. It is also associated with socio-economic factors and the degree of social interaction (Najman and Levine 1981). Lehman (1983) has also found health and social relationships to be closely associated with global assessments of the quality of life.

Neugarten's "Life Satisfaction Index" (Neugarten 1961) offers one example of a scale to measure subjective well-being. Neugarten and his co-workers considered life satisfaction to be made up of the following factors: zest vs. apathy, resolution and fortitude (for example, accepting responsibility for one's life), congruence between desired and achieved goals, self concept (satisfaction with one's psychological, social and physical attributes), and mood tone (for example, optimism and happiness).

Carley (1981) has identified a number of problems associated with subjective social indicators. One relates to the difficulty of establishing the significance of the results and findings. He suggests that while few things may be simpler that dreaming up evaluation scales and then finding a few hundred obliging people to tick the boxes, it is not easy to interpret or judge the significance of their responses. This is partly because, as we have seen, people may respond differently to the same set of circumstances. Campbell (1976) has also noted a "happiness barrier", or a tendency for people to respond in an overly positive

manner at a global level whilst being critical of their life situation at the level of specific issues.

A related problem concerns the difficulty of separating out the effects of demographic and other variables on subjective responses. For instance, Huxley (1986) reports that young people return high scores on happiness but low scores on life satisfaction, while older people score more highly on life satisfaction and have lower scores on happiness.

The final issue related to subjective social indicators concerns their relevance for policy. Although Andrews (1974) argued that subjective social indicators would be useful in policy planning, Carley (1981) considers that global measures of the quality of life remain vague and general, and finds it is difficult to imagine their value to policy beyond that of the average Gallup poll.

#### The Quality of Life as an Outcome Measure in Medical Research

There is a body of literature that explores aspects of the relationship between health and the quality of life. Some parts of this literature define the quality of life in terms of health status (for a review see Bowling 1991); whist others bring the quality of life to bear on the resource allocation debate (see later in this chapter). The present discussion focuses on medical literature which uses the quality of life as an outcome measure in clinical trials. It shows that problems of conceptualisation and measurement identified in the social indicators literature are also present here, and illustrates the difficulties that they can cause in empirical research.

The quality of life has become popular as an outcome measure in clinical trials. Between 1956 and 1976 only five percent of clinical trials in the cancer field included quality of life outcomes (Bardelli and Saracci 1978). In 1983, over two hundred papers which included the term in their title were published (Fayers and Jones 1983), and the field has continued to expand since then.

Najman and Levine (1981) justify this increase by arguing that if technologically based medical care were to be judged on the purely quantitative criteria of increasing longevity then only a small fraction of the care delivered would meet the required standard. They suggest that most health care must ultimately be evaluated in terms of the impact that it has on the quality of life, and that those activities and procedures that produce the largest improvement should receive the most support.

van Dam (1981) also argues for the quality of life to be used as an outcome in medical research.

Most disease is not dramatically fatal, but chips away at comfort and happiness. At the same time, treatments for life-threatening diseases often have different impacts on patient comfort. To the extent that we are unable to measure and compare the effects of treatment on the quality of the patient's life, we are unable to document advantages of treatments as well as their defects. The lack of such documentation is a major problem in studies evaluating medical and surgical treatment and in developing information useful to both the patient and physician in selecting therapy.

#### (Van Dam 1981:166)

The purpose of this section of the chapter is to evaluate medical research that uses the quality of life as an outcome measure. Because of the great volume of literature in this area, a selective approach has been taken. Papers listed under "quality of life" in the Index Medicus for the latter half of 1991 were examined, and a series of twenty outcome studies obtained<sup>2</sup>. Review articles are not included. This analysis of that literature is concerned with four issues: the extent to which quality of life criteria are used to assess the benefits of health care; the nature of the quality of life indicators used; the adequacy of research designs; and the findings. This approach is adapted from Najman and Levine (1981). The outcome studies reviewed are listed as table one.

Table one confirms that the quality of life has become a popular outcome measure in medical research, with twenty studies being cited by Index Medicus in a six month period. This is a considerable increase since 1977 when six outcome studies were published, and 1978 when eight were published (Najman and Levine 1981). The procedures discussed include anti-hypertensive medication (mentioned four times), chemotherapy regimes for cancer (mentioned twice), transplant surgery of the heart, liver, kidney and pancreas, interventions into the urinary system (mentioned three times), cardiac therapies (mentioned three times), as well as interventions in bowel disease, epilepsy, diabetes mellitus, and osteo-arthritis. Many of the interventions assessed in these studies are expensive and life-threatening, and their continuation would be threatened if it was consistently found that they have no beneficial impact on the quality of life of patients receiving them.

<sup>2</sup> When this part of the literature review was conducted, this research was the most recent available.

# Table 1.The research questions addressed by a series of twenty outcomestudies

NUMBER	AUTHORS	QUESTION ADDRESSED		
1	Ali Oto et al (1991)	Difference in qol when pacemaker is fixed rate or responsive		
2	Applegate et al (1991)	Comparison of effect of three anti-hypertensive agents on qol of older women.		
3	Bunzel et al (1991)	Effect of heart transplant on qol.		
4	Cassileth et al (1991)	Comparison of effect of conventional and unconventional therapy for cancer.		
5	Dimenas et al (1991)	Effect of Felodipine on the qol of hypertensives.		
6	vanHolten Verzant-voort (1991)	Effect of Pamidronate on gol in breast cancer.		
7	Hunter Group (1991)	Comparison of effect of two anti-hypertensive drugs or qol.		
8	Keown (1991)	Effect of recombinant human erythropoeitin on gol in end stage renal disease.		
9	Kober et al (1990)	Effect of liver transplant on qol.		
10	Kohler et al (1991)	Comparison of effect of three surgical procedures for proctocolectomy on qol.		
11	Kriel et al (1991)	Effect of rectal diazepam on qol in children with prolonged fits.		
12	Mays et al (1990)	Comparison of effect of two forms of treatment for renal calculi.		

13	Nathan et al (1991)	Effect of renal\pancreatic transplant on qol in patients with IDDM.		
14	Nissinen et al (1991)	Comparison of effect of two angina therapies on qol.		
15	Oldridge et al (1991)	Effect of rehabilitation after myocardial infarction on qol.		
16	Rossignol et al (1991)	Effect of radical retropubic prostatectomy on qol.		
17	Sundar et al (1991)	Comparison of effect of four anti-hypertensive drugs on qol of Indian hypertensives.		
18	Tarter et al (1991)	Effect of liver transplant on qol.		
19	de Weerdt et al (1991)	Effect of education on qol in IDDM.		
20	Wiklund et al (1991)	Qol before and after hip arthroplasty.		

Reliability, Validity and Other Characteristics of Scales Used

The studies reviewed here use an enormous variety of questionnaires, interviews, psychometric tests, visual analogues and standardised tests to measure the quality of life. These include the Haceteppe Quality of Life Questionnaire (used in study number 1), the Psychological General Well Being Schedule (study 2), the Center for Epidemiologic Studies Depression Inventory (2), the Digit Symbol Substitution Test (2), the Rey Auditory Verbal Learning Test (2), the Rey-Osterreith and Taylor Complex Figure Test (2), the Functional Living Index (4), the Complaint Scale (5), the Subjective Symptoms Assessment Profile (5), the General Health Questionnaire (7), STAIX Anxiety Questionnaire (9), the Nottingham Health Profile (12 and 20), the DCCT Quality of Life Questionnaire (13), the Psychological General Well-Being Index (14), the Angina Pectoris Quality of Life Questionnaire (14), the Spielberger State Anxiety Inventory (15), the Sickness Impact Profile (18), the Social

Behavioural Adjustment Scale (18), and the Bradburn Affect Balance Scale (19). Scales used in some of the studies were specifically designed for the project reported (3, 6, 10, 11, 16, 17).

Collectively, these scales employ more than fifty different variables as indicators of the quality of life, as shown in table two.

There is a close relationship between the reliability and validity of psychometric and sociometric scales. An instrument is valid to the extent that it reflects the construct of interest to the researcher, and reliable if it does so in a consistent way (Reaves 1992). It is possible for an instrument to be reliable without being valid, but validity always presupposes reliability (Waltz, Strickland and Lenz 1991).

Bunge (1975) suggests that a valid quality of life scale will possess three characteristics: an adequate definition of the quality of life; a range of indicators that are sensitive to and reflect variations in the quality of life; and a theory that explains how changes in the quality of life produce changes in the indicator.

Very few of the researchers discuss the validity of their instruments. Most appear to assume that their instruments have face validity, and some could claim content validity. (For instance, the scale used by Ali Oto and his colleagues (1991) was "carefully designed by a team of cardiologists and statisticians"). None of the papers satisfy Bunge's criteria.

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# Table 2.Variables used to express the quality of life in a series of twenty<br/>outcome studies

1	general well being, physical symptoms and activity, sleep dysfunction, appetite, sexual dysfunction, cognitive function, social participation, work performance.		
2	sense of well being, physical symptoms, emotional status, cognitive function, physical performance, social participation.		
3	physical, emotional, mental, vocational, and sexual status, financial situation, leisure activities, partnership and overall life quality.		
4	physical well being, psychological state, sociability, effect on family members, nausea.		
5	self reported health problems, reports of problems related to depression, tension, head, heart and lungs, metabolism, musculo-skeletal, gastrointestinal and urinary tracts, emotional stress, sex life and dizziness.		
6	mobility, bone pain, fatigue, gastrointestinal toxicity.		
7	criteria not discussed.		
8	physical, fatigue, relationships, depression, frustration, psychosocial, six minute walk.		
9	functional status, ability to work, general symptoms, symptoms specific to the liver, anxiety, depression, social integration, pain, treatment strain, overall physical condition, overall quality of life.		
10	social activities, sports, housework, recreation, sexual activity, family relationships, travel.		
11	frequency of fits, number of emergency room visits, parents assessment of drug efficacy, adverse reactions psychosocial impact of drug.		
12	physical mobility, pain, sleep, energy, social isolation, emotional reaction, job, social life, home life, sex life, interests, holidays.		
13	criteria not discussed.		

14	general health, depressed mood, vitality, positive well-being, anxiety, self control, somatic, psychological, leisure time activities, physical limitations, sleep disorders.	
15	limitations, emotions, time trade-off, problems related to mobility, physical activity and social activity.	
16	urinary continence and sexual function.	
17	sense of well-being, physical state, emotional state, intellectual function, social roles, sexual function.	
18	behavioural disturbance, social role performance, impact on family, disease impact	
19	sense of well-being, physical state, emotional state, intellectual function, social roles, sexual function.	
20	pain, energy, sleep, social isolation, housework, holidays, hobbies, social life, sexual function, family life.	

Although the medical literature contains theoretical papers that acknowledge the difficulty of defining the quality of life (indeed, Hollenberg and his co-workers (1991) suggest that a satisfactory definition does not exist), the empirical literature tends to use the term in an unproblematic way. For instance, Nissinen et al (1991) confidently state that

Quality of life measurements quantify information about how patients perceive the impact of disease and how they respond to treatment.

Nissinen et al (1991:989)

Although this definition enables the researchers to make certain measurements, it completely ignores the fact that other researchers define the quality of life in quite different ways and measure it with a different range of indicators. The consequence of this approach is the profusion of indicators that has been described. Fayers and Jones (1983) argue that this diversity is defensible because diseases will vary in terms of their impact upon the quality of life. They suggest that mastectomy for breast cancer produces different psychosocial problems from cytotoxic chemotherapy for lung cancer, and that different measures must therefore be used.

Although this argument may carry some weight, it is difficult to accept that it justifies the use of approximately twenty five different scales within a group of twenty studies. It also fails to explain why studies concerned with the same substantive issue - such as the evaluation of liver transplant (studies 9 and 18), or anti-hypertensive medication, (studies 2, 5, 7, and 17), - should use different measurement instruments.

In summary, this body of research is largely dependent on face and content validity. This is associated with a lack of clarity about the nature of the quality of life. In consequence, it is impossible to compare the findings of one study with those of another, although Najman and Levine (1981) have argued that this is one of the most important reasons for conducting research of this kind.

The low level of validity has implications for reliability. A few of the variables used as indicators and presented as table two can clearly be measured quite simply: the distance walked in six minutes, for instance, or the number of visits made to the emergency room. Even in these cases, a high level of apparent reliability is undercut by dubious validity, as discussed above.

The validity and reliability of other variables is in double jeopardy. Several of the studies employ criteria such as housework, sex life, holidays, and home life. These terms are not precisely defined by the researchers, and their significance for the quality of life is assumed without being demonstrated. It is difficult to know how people's experience of these phenomena could be adequately represented by numbers.

#### Research Design

The studies employed a variety of different research designs, which are described here according to the categories developed by Campbell and Stanley (1966).

In studies 3 and 11, the quality of the subject's life was measured after an intervention, and they were asked to retrospectively compare their post-intervention with their pre-intervention state. This approach can be considered a variant of the one shot case study. This approach invalidates the findings of the research (which in both cases was that the intervention enhanced the quality of life) because the subjects might be giving responses to please the researcher, who was also the clinician responsible for care. This danger is heightened because the quality of life measures used involved patient self-assessment.

Studies 18 and 20 used the one group pre-test post-test design. This research design enables the comparison of pre and post-intervention measures, but its drawbacks are history (other events may explain observed differences), maturation (natural changes over time), testing (learning to answer the questions in a certain way), and instrumentation (changes in the instrument over time).

The non-equivalent control group design also involves measurement before and after the intervention. Its principal weakness is that there is no way of knowing whether the groups are equivalent. This approach was taken in studies 4, 10, 12, 13, and part of 9.

The time-series design involves an intervention being made in the middle of a series of measurements. Campbell and Stanley consider that its biggest weakness is its failure to control history, and to this must be added the possibility that subjects might attempt to please the researcher. This risk is particularly present when self-assessment instruments are employed. This approach was taken in study 17 and part of study 9. Researchers were considered to have conducted a randomised clinical trial if they had randomly allocated their subjects to control and experimental groups, and measured before and after the intervention. In addition, some studies involved a degree of blindness. This approach, which is clearly the strongest, was adopted in studies 1, 2, 5, 6, 7, 8, 14, 15, and 19.

#### The Findings

It is interesting to consider the claims made by researchers in the light of the research design employed.

The researchers who used the variant of the one-shot case study, and the pre-test post-test designs were all attempting to evaluate a single type of intervention in terms of its effect on the quality of life. In each case it was claimed that the intervention was successful. The validity of these claims is substantially threatened by the weakness of the research designs.

Not all of the researchers who used the stronger designs of the non-equivalent control group and the time-series went on to claim that the interventions they were assessing had a beneficial effect on the quality of life. Studies number 4 and 12 both compared two types of therapy: number 4 assessed conventional and unconventional approaches to cancer care, and number 12 compared two treatments for renal calculi. Neither of these studies was able to demonstrate a difference in outcome for the treatment modalities.

Three of the studies classified as randomised clinical trials also discovered that the assessed intervention did not have a beneficial effect upon the quality of life. Study 2 demonstrated there to be no difference in the effect which each of three anti-hypertensive medications had upon the quality of the lives of elderly women; study 5 demonstrated that an

anti-hypertensive drug did not adversely the quality of life; and study 19 demonstrated that an education programme for diabetics had no effect on their quality of life.

These findings support the observation that the results of poorly designed research are likely to support the preconceptions of the researcher, whilst more rigorous designs may well not.

#### Summary

In his discussion of the assessment of the impact of anti-hypertensive treatment on the quality of life, Dahlof (1991) says that

It is naturally extremely important that this type of study is methodologically faultless. This means, for example, that it is performed with randomised, double-blind technique.

#### (Dahlof 1991:99)

Although it would not be possible for all medical interventions to be assessed in this way, this review of twenty outcome studies has shown that methodological weakness undermines the claims made by some researchers. For instance, Bunzell's research design (a comparison of the patients' assessment of their post operative quality of life with their recollection of life's quality before surgery) invalidates his claim to have found an absolute increase in life quality after heart transplantation. The change which he claims to have detected could equally be explained as the patients' desire to please the surgeon, or in a number of other ways. However, the overall quality of research design does seem to have improved since Najman and Levine's survey of the literature in 1981: they found that only one study from a series of twenty three could be classified as a randomised clinical trial, whereas the figure in this review is nine from a series of twenty.

In other aspects of the research, such as the definition of the quality of life which the researchers are attempting to measure, and the justification of indicators chosen, little advance seems to have been made. It has been argued that the great range of indicators chosen cannot be justified by the argument that different diseases impact upon the quality of life in different ways, but that it is more likely to reflect an underlying inability to determine the nature of the quality of life. As Najman and Levine (1983) argue, there has been a failure to derive an adequate conceptual understanding of what it means to have a better or worse quality of life. The argument made by Bunge in the context of social indicators research seems equally to apply here:

A better understanding of the quality of life calls for more intense theoretical and methodological work rather than an increase in the amount of statistics. Here as elsewhere, data without ideas are sterile when not misleading.

#### (Bunge 1975)

## The Quality Adjusted Life Year (QALY)

There is a contemporary debate about the allocation of resources within the health service. The debate begins with the premise that the financial resources available to pay for health services are limited, whilst the demand for those services is potentially infinite. If this premise is accepted, then it becomes necessary to choose which health services to buy, and to decide how much money to spend on each of them. As Gudex says,

With limited resources, decisions have to be made to determine priorities in the health care system.

#### (Gudex 1986:1)

In the commercial world, funding decisions are resolved in the market place; but the influence of market forces upon British health care was effectively suspended when the National Health Service was created (Culyer 1984). The only formal mechanism for resource allocation with statutory power has been RAWP, the formula of the Resource Allocation Working Party, which was responsible for diverting money from London to the Regions (Carr-Hill 1991). It has been argued that strategies for funding at the local level often lacked coherence, and that "allocation by shroud-waving" or "allocation by decibel" has been all too prevalent (Crisp 1989).

According to Lockwood (1988), a natural response to the resource allocation problem is simply to say that one should put one's resources where they will do the most good. This raises two questions: what does one mean by the "most good", and how can one discriminate between alternative programmes in terms of the "good" which they achieve? Health economists have responded to these questions by attempting to develop measures of the output of health care programmes.

One kind of good that health care may achieve is the saving of lives. An appropriate measure of this good would be the overall extension of life expectancy generated by a particular therapy, expressed as years of life gained. Gould (1975) strongly advocates this approach, arguing that we should give a very high priority to the aim of maximising aggregate years of life gained.

In the name of justice, as well as efficiency, we have got to adopt new methods of medical accounting. One such assesses the relative importance of threats to health in terms of the loss of life-years they cause... (On this basis) a large proportion of the "health" budget ought to be spent on preventing accidents and suicides and a lesser but still substantial amount on attempting to prevent and cure heart and lung disease. Much less would be spent on cancer, which is predominantly a disease of the latter half of life, and which therefore contributes relatively little to the sum total of life-years lost. Little would go towards providing kidney machines, and even less towards treating haemophiliacs. No money at all would be available for trying to prolong the life of a sick old man of 82.

(Gould 1975:633)

If, as Gould suggests, the single goal of health care policy is to extend the length of life, then years of life gained constitutes a fair criterion of success. As we have seen, however, a good deal of health care activity claims to be concerned with enhancing the quality of life, and so analyses that focus exclusively on life years gained are of limited value. For this reason, health economists have attempted to develop measures of outcome which balance the life extending and the life enhancing aspects of care: "quality and quantity of life have somehow to be rendered mutually commensurable" (Lockwood 1988:35).

The notion of the "Quality Adjusted Life Year", or "QALY", represents an attempt to provide a basis for resource allocation decisions which values both quantitative and qualitative outcomes. In Britain, the QALY has been advocated by Alan Williams of the Centre for Health Economics at the University of York. The approach is fully described in discussion papers produced by that centre (Gudex 1986, Gudex and Kind 1989).

Williams describes the QALY in the following way:

(We) need a simple, versatile, measure of success which incorporates both life expectancy and quality of life, and which reflects the values and ethics of the community served. The... QALY... measure fulfils such a role. The essence of a QALY is that it takes one year of healthy life expectancy to be worth 1, but regards a year of unhealthy life expectancy as worth less than 1. Its precise value is lower the worse the quality of life of the unhealthy person (which is what the "quality adjusted" bit is all about). If being dead is worth zero, it is, in principle, possible for a QALY to be negative, i.e. for the quality of someone's life to be judged as worse than being dead. The general idea is that a beneficial health care activity is one that generates a positive amount of QALYs, and an efficient health care activity is one where the cost-per-QALY is as low as it can be.

#### (Williams 1985:3)

Crisp (1989) offers an hypothetical example of the QALY at work. He considers a patient who is expected to live in perfect health for ten years after having a heart transplant. In such a case, the gain in QALYs is  $10 \times 1 = 10$ . In a parallel case, a patient undergoing treatment for leukaemia may also live for 10 years, but with a quality of life which is

diminished by the illness. If it is assumed that her quality of life is only half as good as it would be if she were in full health, then the QALYs produced by treating her work out at 10 x 0.5 = 5. It is now possible to work out costs-per-QALY. If heart transplant costs £100,000, the cost-per-QALY is £100,000/10 = £10,000; whereas the cost-per-QALY for a course of chemotherapy costing £20,000 is £20,000/5 = £4,000. In this case, treating leukaemia would be deemed a more efficient use of resources than transplanting hearts.

The Quality Adjusted Life Year has had an impact on health policy and the management of health services both in this country (Gudex 1986) and in the United States of America (Haddorn 1991). It has also been the focus of vigorous debate between health economists, ethical philosophers, and health professionals. Criticisms that have been made can be placed into two groups. Internal criticisms concern the technical procedures used to generate QALYs and the assumptions upon which these procedures rest. External criticisms concern the broader social and economic context in which QALYs are used, the purposes to which they are put, and the possible consequences of their use.

# Internal Criticisms of the QALY

Internal criticisms of the QALY focus on the mechanism used to attach values to various health states, and the validity and usefulness of the evaluations so made. Williams (1985) employed the "Rosser Classification of Illness States", which combines various categories of distress and disability (see table three).

Seventy respondents were asked to classify various combinations of disability and distress according to their undesirability, using a score where 1 = healthy and 0 = dead. The resulting scores are reproduced as "Rosser's Valuation Matrix" (see table four). The mean score for each combination of disability and distress is represented by the figure in the cell.

The Rosser Valuation Matrix, which lies at the heart of the QALY procedure, can be criticised for the assumptions that it embodies. The first of these is the assumption of correspondence: i.e. that the scores generated will correspond with people's everyday judgements. This assumption has two parts: that when people are asked to make hypothetical decisions about resource allocation they will employ the quality of life as a criterion: and that they will define the quality of life in terms of disability and distress.

# Table 3. Rosser's classification of illness states

Levels of disability

1	No disability.
2	Slight social disability.
3	Severe social disability and/or slight impairment of performance at work. Able to do all housework except very heavy tasks.
4	Choice of work or performance at work very severely limited. Housewives and old people able to do light housework only but able to go out shopping.
5	Unable to undertake any paid employment. Unable to continue any education. Old people confined to home except for escorted outings and short walks and unable to do shopping. Housewives able only to perform a few simple tasks.
6	Confined to chair or to wheelchair or able to move around in the house only with support from an assistant.
7	Confined to bed.
8	Unconscious.

# Levels of distress

A	No distress
В	Mild distress
с	Moderate distress
D	Severe distress

#### Table 4.Rosser's valuation matrix

DISABILITY ↓ DISTRESS →				
	A	В	С	D
1	1.000	0.995	0.990	0.967
11	0.990	0.986	0.973	0.932
111	0.980	0.972	0.956	0.912
IV	0.964	0.956	0.942	0.870
v	0.946	0.935	0.900	0.700
VI	0.875	0.845	0.680	0.000
VII	0.677	0.564	0.000	-1.486
VIII	-1.028	Not appl-	iccable	

Fixed points: Healthy = 1 Dead = 0

The validity of the assumption of correspondence is challenged by a recent empirical study from Norway. Nord (1993) asked subjects how they felt a hospital should prioritise between two patients admitted within a few hours of each other. Both were described as being in a life-threatening condition. One could regain full health if treated, and the other could be given a life of moderate pain and dependency on crutches for walking. The hospital might not manage to operate on both in time. In the subject's opinion, how should the hospital prioritise between the two?

48 of the subjects in Nord's study (79 per cent) felt that the two patients should be treated in the order in which they were admitted to the hospital. Only 9 subjects (15 per cent) were in favour of giving priority to the patient with the better expected outcome. In commenting on their responses, 31 subjects in the majority group of 48 explicitly argued in terms of equality in value of life and/or entitlement to treatment.

Nord accepts that the sample used is too small to support broad generalisations, but argues that health economists should determine people's ethical preferences in matters of prioritising, rather than taking it for granted that their own values are shared by the general public.

The second part of the assumption of correspondence is that the quality of life can be expressed as a function of disability and distress. Although Williams accepts that this definition is crude and in need of refinement (Williams 1985), he defends its use on the grounds that physical mobility and freedom from distress are fundamental aspects of the life experience and that without them, we are unable to perform the activities of daily living and to engage in normal social interaction. This may be true, but for Rawles (1989) it is not the point. Rawles argues that to equate the value of human life with the absence of disability and distress is to undervalue human existence very greatly. He claims that life is valued for infinitely more reasons than the absence of suffering.

The assumption of correspondence is also challenged by Loomes and McKenzie (1989), who note the conditions that Williams imposed upon his respondents as they evaluated various combinations of distress and disability. The respondents were instructed to think of each health state as existing for the same length of time; to judge each state on the basis of its intrinsic "enjoyability"; to evaluate all states as if the respondent were "in them now"; and to be uninfluenced by the likely prognosis of the sufferer (Williams 1981). Loomes and MacKenzie argue that the value attached to a health state ought not to be considered

independent either of the time spent in it, or of the health states preceding or expected to follow it. For example, the grading of a particular combination of disability and distress may well differ if experienced for a long or short time; and an acute, self-limiting illness will have a different meaning from one whose expected outcome is death. Loomes and McKenzie also argue that people's evaluation of health states will vary with their attitude to risk, which should therefore be held constant when comparisons are made between subjects.

The assumption of stability is that people have a set of internal preferences or evaluations which are relatively stable, and that these preferences are accurately represented by the numbers they assign to various health states. However, Mulkay, Ashmore and Pinch (1987) argue that the values given by respondents must be seen within the context of the highly structured social situation produced by the researcher: a context in which the respondents are required to answer a very specific question in a format which is predetermined by the researcher. They can find no reason to suppose that the responses given in these circumstances will represent the responses to situations encountered in real life.

The assumption of quantification, which is fundamental to the procedure for constructing QALYs, concerns the requirement for respondents to make precise numerical assessments of situations described by the analyst. The method of analysis assumes that the numbers assigned by respondents have some real meaning for them in ordinary situations and that these numbers express quantifications that are already implicit in individual respondents' scales of preference. Carr-Hill (1991) rejects this assumption, arguing that index numbers are not neutral observations upon the world, but that they are the product of a highly specific set of technical procedures, and that they serve the interests of particular groups. (This line of criticism will be developed further in the conclusion of the chapter).

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Haddorn's criticism of the assumption of quantification questions the meaning of the numbers generated by the QALY procedure.

What does it mean to speak of someone having a "one-tenth normal" quality of life? How could we come up with such an overall numerical estimate? Anyway, how can we quantify a quality, especially one so amorphous and ill defined as quality of life?

(Haddorn 1991:14)

Haddorn, who reports the use of the QALY as part of the Oregon Priority Setting Exercise, also points out that some of the quantifications generated are quite at odds with common sense. On one occasion, for example, respondents awarded the same numerical values to an upset stomach, and burns over large areas of the body.

Carr-Hill (1991) expresses his doubts about the assumption of quantification through

the words of Cartwright, who declared himself

Particularly suspicious of factor analyses in which responses to a series of questions are combined in elaborate exercises with dubious statistical validity and then given pretentious labels. Such techniques may be particularly tempting to researchers dealing with responses to questions of little interest and concern to the people being interviewed.

(Cartwright 1983:170)

External Criticisms of the QALY

External criticisms of the Quality Adjusted Life Year focus on the economic and political environment in which the system is used, the purposes to which it is put, and the potential consequences of its use.

The QALY was developed in response to the political argument that demand for health care is potentially infinite, whilst the financial resources available to meet that demand are strictly limited. Rawles (1989) and Rawles and Rawles (1990) argue that infinite demand is no more true for the National Health Service than it is for a free public lavatory. Rawles (1989) says that at each stage of life, from birth to death, the incidence of disease, the nature and cost of its treatment, the requirements for preventive measures, and the loss of life from various causes are all known with a high degree of precision. Harris (1987) argues that the limits on health care expenditure are much more stringent than they need or ought to be, and suggests that health has a stronger moral claim upon the nation's financial resources than does, for example, defence. Rawles (1989) argues that additional funding of 2.0 per cent per year would enable the National Health Service to keep pace with demographic, technological and policy changes. Whilst acknowledging that this is a substantial increase, Rawles claims that it is "a long way short of infinity" (Rawles 1989:144).

Harris argues that the QALY is logically defective. He suggests that the plausibility of QALYs depends upon our accepting the generalisation of the "truth" that given the choice, a person would prefer a shorter healthier life to a longer period of survival in a state of discomfort. Harris argues that, although this assumption enables one to claim that the best treatment for an individual is the one that supplies the most QALYs, it does not follow that treatments yielding more QALYs are preferable to treatments yielding fewer where *different* people are involved.

It does not follow that where the choice is between three years of discomfort for *me* or immediate death on the one hand, and one year of health for *you*, or immediate death on the other, that I am somehow committed to the judgement that you ought to be saved rather than me.

(Harris 1988:118)

Harris's criticism of the QALY rests on the belief that the value of one life cannot be traded off against the value of another.

The value of someone's life is, primarily and overwhelmingly, its value to him or her; the wrong done when an individual's life is cut short is a wrong to that individual.

#### (Harris 1987:119)

Harris (1987, 1988) also objects to the QALY because he believes that it will bias the distribution of health care resources away from some groups in society, whilst placing others at a relative advantage. He argues, for instance, that elderly people will be disadvantaged because money spent on their health care will not generate as many QALYs as money spent on younger people. Donaldson, Atkinson and Bond (1988) suggest that the QALY will be less sensitive to changes in the health status of elderly people than will programme-specific measure such as the Crichton Royal Behavioural Rating Scale.

Lockwood (1988) accepts that the QALY will disadvantage elderly people but does not agree that this is be unjust. He argues that, all else being equal, it is preferable to give a scarce resource to a younger person rather than an older one because the older one has had a "fair innings". Lockwood argues that the QALY is unsatisfactory because it is not sensitive to situational factors such as the number of a person's dependants.

What one must ask, then, is whether the death or continued ill health of the patient compromises the capacity of these dependants to flourish as human beings. If it does, then the health care needs of the patients are, in an extended sense, their needs too, and should be taken into account as such.

(Lockwood 1988:51)

Finally, it is noted that the QALY uses the concept of the quality of life in a manner that is radically different from its historical use. Aiken (1982) shows that within the liberal tradition, the quality of life has been used in a normative sense

To describe the necessary material and social goods which persons must have if they are to achieve that minimal level of well-being which enables them to live a human quality of life as moral entities and thus to pursue the "good life".

# (Aiken 1982:28)

This liberal tradition has its roots in the nineteenth century, whose reformers

Stressed the need for basic material amenities to satisfy physical needs. Contra Malthus, the plight of the masses was not doomed to subhuman levels of existence... Not only were all humans entitled to liberty but they were also entitled to a minimal level of physical well-being and the institutions which could guarantee this.

# (Aiken 1982:28)

The social indicators movement and the medical outcome literature both represent aspects of this tradition because their declared purpose is to promote the quality of life. Aiken (1982) contrasts this equalitarian use of the concept with an exclusionary use that he associates with the QALY.

Unlike the traditional prescriptive uses of "quality of life" which *promote* this value, the "exclusionary" use cites "quality of life" as providing a criterion for exclusion of some from the moral community and concomitantly from normal standards of moral treatment. The judgement is made that because a person's quality of life is below the desirable level, that person's life is not worth living and we are justified in treating them accordingly.

(Aiken 1982:30)

The Quality Adjusted Life Year uses the quality of life as a criterion for including or excluding individuals and groups from access to health care resources. It therefore is exclusionary in Aiken's sense.

#### A Critique of the Social Scientific Literature of the Quality of Life

The initial impression that the reviewed literature of the quality of life gives to the casual reader is one of confusion and disorder. The most fundamental problem is that there is very little consensus about the nature of the quality of life. This lack of clarity expresses itself in an endless profusion of scales and instruments that claim to be able to measure the concept, and in the persistent debate between those who argue that the quality of life is an objective phenomenon, and those who suggest that it is subjective in nature.

The subjective-objective dichotomy is a particular expression of an historical conflict between two schools of thought whose adherents differ with respect to their ontology, epistemology and methodology - Bernstein's "objectivists" and "relativists" (Bernstein 1983). The tension between these two schools can be traced back to the writing of Descartes.

In his *Meditations on First Philosophy*, Descartes attempted to discover grounds which would justify a claim to certainty in knowledge. He wanted a point of reference as firm as the place Archimedes had sought (but never found) in order to shift the world, and to which appeals could be made in all cases of doubt. His enquiry took the form of a thought experiment in which he adopted an approach of radical scepticism, pretending to believe that "some malicious demon of the utmost power and cunning has employed all his energies in order to deceive me", and that "the sky, the air, the earth, colours, shapes ,sounds and all external things are merely the delusions of dreams which he has devised to ensnare my judgement" (Descartes 1986:15). Descartes even suspended belief in his own body as the only evidence he had for its existence came through the senses and experience had taught

him that the senses could mislead. Ultimately, Descartes found firm evidence for his own existence in his ability to think, expressing this conclusion in the famous *cogito* - I think, therefore I am. For Descartes, thinking was the ground and ultimate proof of being.

This is the basis upon which Cartesian philosophy rests, and from it flow a number of consequences. The first is ontological: the assumption that the person ultimately exists as mind. The second is epistemological: that the mind, being fundamentally distinct from a world of which it can have no direct knowledge, might be misled by the information transmitted to it by the sensory apparatus of the body. The third is methodological: that true knowledge will exist when the contents of the mind correspond precisely with external reality, a state which is most likely to be attained if subjective sources of error are controlled through procedures like those of natural science.

The literature is divided by the persistence of the subject-object dichotomy, but there are also a number of features that unite it. The first of these is the assumption that the quality of life can be measured, at least in principle.

The measurement of social phenomena is a central part of the positivist approach to social science, and the goal of measurement is one of several features linking the literature reviewed with the positivist tradition. The goal of measurement is also associated with the positivist assumption that the social world and its structures have an independent existence that can be discovered and described. Burrell and Morgan describe this assumptions as an ontology of "realism".

Realism postulates that the social world external to individual cognition is a real world made up of hard, tangible and relatively immutable structures... For the realist, the social world exists independently of an individuals apperception of it... it is not something which the individual creates, it exists "out there"; ontologically, it is prior to the existence and consciousness of any single human being. For the realist, the social world has an existence which is as hard and concrete as the natural world.

(Burrell and Morgan 1979:4)

I argue that each of the three bodies of literature reviewed in this chapter shares an assumption of realism: a belief that the quality of life is a "social fact" that can be uncovered if the appropriate methodology is employed (McCarthy 1992). Other factors that demonstrate the positivism of the reviewed research are the "scientific" pretensions of the medical outcomes literature, the claim to objectivity of parts of the social indicators movement, and the belief of the health economist that numbers represent people's evaluations of health states. It is also significant that Otto Neurath, who laid the foundations of the social indicators movement, was a member of the positivist Vienna Circle.

The hermeneutical philosophers have criticised the positivist tradition at the level of its most basic assumptions. Gadamer rejects the Enlightenment view that truth can only be perceived if the distorting effects of culture and history are negated, arguing that it is our historical situation - our placement in culture, in time and in society - that creates the possibility of understanding. When the reviewed literature is approached from the perspective of philosophical hermeneutics, it becomes evident that quality of life researchers are not uncovering and measuring "social facts". As Mulkay, Ashmore and Pinch (1987) argue, the "facts" generated by any group of cognitive experts should be treated as the cultural products of the respective group and not as representations of phenomena which exist independently of that group. The description of these influences is congruent with contemporary approaches to the history of science that relate scientific knowledge to its social context, demonstrated by Latour (1987), Desmond (1989) and others.

The influence of cultural, social and historical factors is evident throughout the quality of life literature, influencing measurement strategies and affecting research outcomes. A clear example is offered by the objective school of the social indicators movement, where Gehrmann (1978) suggests that statistics on crime, safety, social participation, social disintegration, and unemployment should be taken as indices of the quality of life. I have already argued that it is naive to claim that these data are neutral, as the definition and measurement of unemployment, for instance, are not matters of objective fact but of political debate informed by ideological perspective. Callebaut (1980) acknowledges that social indicators are "politically explosive", but his suggestion that their ideological bias might be offset if quality of life research were to be conducted in a theoretically neutral environment begs the question, where is such an environment to be found? Callebaut's statement reveals the positivist struggling at the limits of his paradigm.

Paradoxically, the influence of Enlightenment thinking can also be seen in the subjective school of the social indicators movement. It appears that the subjectivist's case does not rest upon a fundamental critique of the possibility of objective measurement, but upon a simple belief that it is not appropriate in this case. The subjectivist's argument is reminiscent of certain critiques of positivism, rejected by Gadamer, that argue that the knowledge base of the social sciences can never approach the degree of objectivity of the natural sciences.

Without questioning that truth is the exclusive product of the scientific method or that the natural sciences have an exclusive claim on this truth, the antipositivist argues that the social sciences are simply excluded from this realm. But when anti-positivists attempt to identify the kind of knowledge that *is* appropriate to the social sciences, they define it as "subjective" knowledge that is culturally and socially determined.

#### (Hekman 1986:8)

The influence of social factors upon the measurement of the quality of life can also be seen in the QALYs literature. Mulkay, Ashmore and Pinch (1987) suggest that when health economists measure the quality of life of patients undergoing different forms of medical treatment they are not directly identifying what Williams (1985:329) has called the "benefits to patients". Rather, they are offering quantitative indicators of benefits that only exist through the interpretive actions of health economists, whose meaning is relative to a number of assumptions held by those economists about the way that patients and people in general experience the world. Many of these assumptions have already been identified and discussed. They include the assumptions of correspondence, stability and quantification.

Mulkay (1987) and his colleagues argue that if the background assumptions are changed, then entirely different, but equally valid conclusions, can be drawn from the same body of data. For instance, in his 1985 paper, Williams noted that respondents who were doctors tended to give a lower quality of life rating to particular combinations of disability and distress than did other people. He inferred from this that doctors "appeared to have a much greater aversion to disability and distress than the population at large" and that they therefore overvalued "reductions in disability and distress compared with the rest of the population" (Williams 1985:327). Mulkay and his colleagues suggest that the differences between the scores of doctors and others could equally be attributed to the fact that the doctors had received a scientific education and were therefore better able to understand the rather stringent requirements of the procedure used to generate scores.

But if we make this assumption, we will be led to conclude that the average scores for a sample as a whole are inaccurate and that the scores furnished by the sub-sample of doctors may be a more valid indicator of quality of life valuations for the population at large.

(Mulkay Ashmore and Pinch 1987:554)

The use of the Quality Adjusted Life Year is advocated on the grounds that the numbers it produces reflect underlying social preferences This case is weakened by the demonstration that QALYs are not simple "facts", but that they rest upon certain assumptions, and represent an interpretation of the data.

The point is that index numbers are not an observation upon the world: they are *generated* and *produced* by a specific set of technical procedures, and the QALY is no exception. In turn, technical procedures are not neutral: they serve different interests, and this should be made explicit.

(Carr-Hill 1991:361)

#### The Significance of the Reviewed Literature for the Research Task

In the introduction to the thesis, I explained that the purpose of the research is to develop a series of practice standards that are based on a concept of the quality of life that has sufficient power to explain the significance of the gross, and the more subtle, violations of the rights and dignity of older people that sometimes occur in institutional nursing care. In this chapter, various aspects of the social scientific literature of the quality of life have been reviewed. The significance of this literature for the research task will now be evaluated.

I argue that the various social scientific approaches to the quality of life discussed above generally lack significance in terms of the research task. In part, this lack of significance can be attributed to the recurrent subject-object dichotomy, and the persistent assumption of realism. Another problem relates to the high degree of specificity of many of the scales used. This tendency is clearly apparent in the medical literature, where implicit definitions of the quality of life often relate to particular diseases (see for instance the Arthritis Impact Measurement Scale of Meenan et al 1980), or types of functional impairment (such as the Barthel Index of Mahoney and Barthel 1965); and it can also be seen within the QALYs literature, where the quality of life is defined in terms of disability and distress. This high degree of specificity combines with a general failure to explain the theoretical link between individual variables and some overarching definition of the quality of life to limit the relevance of this literature for the present study.

The argument that has been pursued to this point can be summarised as follows.

- The social scientific literature of the quality of life lacks the power to explain the significance of the violations of the rights and dignity of older people that sometimes occur in nursing care.
- This lack of power can partially be attributed to researchers' failure to relate indicating variables to some overarching definition of the quality of life in order to establish their validity.

It can also be attributed to the Cartesian ontology that underpins the social scientific literature, which is evidenced by a preoccupation with measuring the quality of life, and a tendency for the literature to fall into subjective and objective approaches.

Having reviewed the social scientific literature of the quality of life, I reached the conclusion that it was generally unable to inform the development of practice standards, for the reasons discussed above. I therefore decided to discover what the quality of life means to a group of older people, and to nurses and members of various other occupational groups, and to gather their views as to how the quality of life might be promoted. This phase of the study coincided with my growing interest in philosophical hermeneutics. Hermeneutics offers a useful perspective from which to criticise the social scientific literature of the quality of life, but it also suggests a new approach to the quality of life, and it contains certain principles that can be used to guide methodological decisions. These issues are discussed in the next phase of the study.

# PART II

CREATING AND INTERPRETING THE TEXT

### **CHAPTER 3**

#### DATA COLLECTION AND ANALYSIS

This chapter gives an account of the next phase of the research and explains and justifies the approach taken. This phase of the study involved a series of interviews with a small number of older people, and with nurses and other professionals who care for them<sup>3</sup>.

The goals of this research are to develop a concept of the quality of life that has the power to explain the significance of the violations of the rights and dignity of older people that sometimes occur in institutional care, and to identify and illustrate aspects of current nursing practice that will promote the well-being of older people who require care in a setting other than their own home.

The previous chapter approached the social-scientific literature of the quality of life from the perspective of philosophical hermeneutics. It identified a fundamental dichotomy between the subjective and objective approaches, and explained this dichotomy with reference to Cartesian ontology. The chapter concluded that the subject - object dichotomy combines with other features of the literature to limit the literature's significance for the research task.

This chapter contains four parts, and develops in the following way.

i) It is argued that hermeneutics provides the promise of a new approach to the quality of life that transcends the subjective - objective dichotomy that characterises the conventional literature.

<sup>&</sup>lt;sup>3</sup> Please bear in mind the footnote on page eight.

ii) It is shown that hermeneutics, whilst not being a research method in itself, does have implications for the conduct of social research. Some of these implications are discussed, and concrete examples are provided from the published literature.

iii) The methodological decisions that were taken are explained and justified.

iv) The principles underlying the analytical approach are discussed.

It can thus be seen that the chapter moves from the general to the specific. At every point, the decisions taken and the strategy adopted are justified through reference to the primary and applied literature of hermeneutics.

#### Hermeneutics and the Quality of Life

The hermeneutical tradition shows that the subjective - objective split which characterises the literature of the quality of life is an expression of the Cartesian approach, and that the quality of life cannot be regarded as a "social fact" that can be isolated, measured, described and manipulated. However, not only does hermeneutics provide a useful perspective from which to criticise the conventional or social scientific literature, but it also has a positive contribution to make to the debate about the nature of the quality of life. This contribution is possible because Heidegger offers an alternative to Cartesian ontology. As Benner suggests, Heidegger's work

Offers a critique and an alternative to a strictly cost-benefit approach to the quality of life where benefit is primarily defined in economic or mastery terms. Quality of life can be approached from the perspective of quality of being, and does not need to be approached from the perspective of doing and achieving.

(Benner 1985:5)

Benner develops this argument elsewhere (Benner 1990:6), outlining an approach that transcends "subjectivism" and "objectivism" by critiquing the Cartesian view of the person as a private, disconnected subject standing apart from an objective world, and suggesting that common language, habits, skills, practices, situations, meanings and embodiment make it possible to understand others as participants and members of a common humanity, language, and culture group. This approach is fully congruent with the present study's intention to describe and discuss the habits, skills, practices, and meanings that a group of older people and their professional carers associate with the concept the quality of life.

#### **Hermeneutics and Social Research**

This section of the discussion shows that a great many practical and theoretical disciplines have explored the implications of hermeneutical philosophy for their research methods. The range of these disciplines is described in order to show that this project is located within an established and growing tradition of hermeneutical research, and that the research strategy employed reflects the consensus of that tradition.

Before the 1970s, discussions of hermeneutics were most commonly found in such disciplines as continental philosophy, theology, and literary criticism (Thompson 1990). Since that date however, there has been increasing reference to hermeneutics in the methodological literature of the social sciences. This literature discusses hermeneutics as a philosophy that redefines the scope and nature of the social sciences (see for instance Bauman 1978, Giddens 1976). In this literature, hermeneutics is recognised as a philosophy that supports an approach to social research which focuses on meaning and understanding in context, and which is therefore appropriate for this study. Thompson (1990) suggests that this methodological literature is part of a movement among practitioners and scholars in applied disciplines and the social sciences who are becoming dissatisfied with positivism as

an adequate philosophical grounding, and notes that as a consequence of the steady growth of interest that occurred in the 1980s, hermeneutics has emerged as a philosophy whose relevance extends beyond the humanities to the social sciences, practice disciplines, and even to the natural sciences themselves. Bernstein equally recognises the relevance of hermeneutics for many fields of inquiry:

In contemporary re-examination of the social disciplines, there has been a recovery of the hermeneutical dimension, with its thematic emphasis on understanding and interpretation. This is also what has been happening in the post empiricist philosophy and history of science... There is, however, a much stronger and much more consequential sense in which the hermeneutic dimension of science has been recovered. In the critique of naive and even sophisticated forms of logical positivism and empiricism; in the questioning of the sharp dichotomy that has been made between observation and theory (or observational and theoretical language); in the insistence on the underdetermination of theory by fact; and in the exploration of the ways in which all description and observation are theory-impregnated, we find claims and arguments that are consonant with those that have been at the very heart of hermeneutics.

(Bernstein 1983:301)

The range of disciplines whose scholars have explored the implications of hermeneutics for practice and research includes anthropology (Maranhao 1986); education (Olson 1986); psychology (Honey 1987, Packer 1986); clinical psychology (Silvern 1990); psychoanalysis (Harney 1978); psycho-biology (Fischer 1987); medicine (Schwarz 1986, Daniel 1986, Lock 1990, Churchill 1990, Leder 1990, Baron 1990); social science (Gadamer 1975, Kockelmans 1975, Cooper 1981, Palmer 1987, Hekman 1986); the philosophy of natural science (Heelan 1983, Bender 1984, Kelly 1987, Rickman 1990); and nursing (Leonard 1989, Stevens 1989, Brykczynski 1989, Allen and Jensen 1990, Skodol Wilson and Hutchinson 1991, Rather 1992, Diekelmann 1992). Several of these authors specifically discuss the implications of hermeneutics for social research (Maranhao 1986, Honey 1987, Hekman 1986), whist others take hermeneutics as the conceptual framework for social

research projects. (Packer 1985, Leonard 1989, Brykczynski 1989, Allen and Jensen 1990, Rather 1992, Diekelmann 1992).

The research project that is reported in the forthcoming chapters consists of a programme of qualitative social research that is based on a hermeneutical foundation. It is possible to justify the conjunction of hermeneutics and social research by citing precedent, and by establishing a theoretical case. Both of these approaches are taken here.

#### Hermeneutics and Social Research: Establishing the Precedent

A considerable precedent exists for the conjunction of hermeneutics and social research. Database searching of dissertation abstracts published within the last two years shows that PhD theses in the following disciplines have taken this approach: business studies (Thompson 1992, Pelfini 1993); cinema (Fowkes 1993); education (Aylin 1993, Bethanis 1993, Cota 1993, Dortch 1993, Forte 1993, Friesen 1993, Gonzalez 1991, Jones 1993, Kanu 1993, Keebler 1993, Lundgren 1992, Malinowitz 1994, Nelson 1993, Nixon 1993, Prior 1993, Roscoe 1993, Ruata 1993, Sparks 1993, Volkmann 1993, Whorton 1993); psychology (Hunt 1992, Linesch 1992, Deraney-Reilly 1993, Washburn 1992); philosophy (Beringer 1993); and sociology (Brewer 1993). Hermeneutics has also been used as the framework for research in a substantial number of PhD theses published in the disciplines of health sciences and nursing. These are listed in table 5, which shows the author's name, the research question or area of inquiry, and the principal source of information.

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# Table 5: PhD theses employing a hermeneutical approach to social research

Researcher's name	Research question/area of inquiry	Source of information
Abate 1993	Pregnant daughter/mother relationships	Interview
Appleton 1993	Client's experience of nursing	Interview
Barleben 1993	The experience of homelessness for women with children	Interview
Bernat 1994	Contraceptive decision making	Interview
Bryant 1993	The care giving experience of mothers and daughters	Interview
Burns 1993	The meaning of engagement	Interview and journals
Chao 1993	The meaning of good dying for Chinese Americans	Interview and observation
Eberhart 1992	The clinical thinking of expert nurses	
Ekman 1993	Communication between nurses and demented people	Videotape of interaction
Faxel 1993	Collective bargaining	Interview
Hagedorn 1993	Living with chronic childhood illness	Interview
Madayag 1993	Aids: a phenomenological perspective	Interview
McGehee 1993	The experiences of radical women in academia	Interview
Nelson 1993	The meaning of breast cancer	Interviews and photographs
Pieranunzi 1992	Power and powerlessness in psychiatric nursing	Interview
Pitts 1993	Ambulatory training	Interview
Plowfield 1994	Family waiting following neurological crisis	Interview and observation
Rowan 1992	The experience of mandated reporting of perinatal substance abuse	Interview
Scharbo-Dehaan 1993	The experience of menopause	Group interview
Smith 1993	Survival of difficult situations	Interview
Steeves 1993	The interaction between women experiencing surgery and their care-givers	Interview and observation
Thomas 1993	The lived experience of liver transplant	Interview

Hermeneutics and Social Research: the Theoretical Case

The previous section shows that researchers from many disciplines claim to have conducted research that reflects the insights of the hermeneutical tradition. However, it is important to note that the primary literature of hermeneutics does not discuss method (Barrett and Sloan 1988). Neither Heidegger nor Gadamer were social scientists, and in the introduction to *Truth and Method*, Gadamer explicitly states that his purpose is not to describe a method of interpretation, but to discover what is common to all modes of understanding. The point is clearly made by Palmer:

Gadamer is not directly concerned with the practical problems of formulating right principles for interpretation; he wishes rather to bring the phenomenon of understanding itself to light. This does not mean that he denies the importance of formulating such principles: on the contrary, such principles are necessary in interpretive disciplines. What it means is that Gadamer is working on a preliminary and more fundamental problem: how is understanding possible, not only in the humanities, but in the whole of man's experience of the world.

(Palmer 1969:163)

Many scholars misunderstand this point, and describe a "hermeneutic method" in such a way that one would imagine them to be following the methodological prescriptions of Heidegger and Gadamer themselves (see for instance Skodol Wilson and Hutchinson 1991). However, although hermeneutics does not offer methodological tools on a par with, for example, statistical analysis, it clearly does have implications for research method (Hekman 1986) and by extension for nursing research. These implications are now explored.

It was shown in the previous chapter that the division of the quality of life literature into subjective and objective approaches is not an idiosyncratic or accidental feature of that literature but a function of its Cartesian underpinnings. Hekman (1984, 1986) recognises that a similar dichotomy exists within the methodological literature of the social sciences, and traces it to the same source. The objectivist or positivist pole of this dichotomy received early expression by Mill, who argued that the behaviour of human beings in the social context does not differ methodologically from the movement of physical objects. Hekman contends that the positivist's research programme entails the substitution of the social actor's own understanding of his or her actions with the social scientist's precise, unambiguous concepts, and the analysis of data according to the universal rules of logic and scientific method, with a particular focus on causality. This approach is deemed to avoid the subjectivism entailed by reference to social actors' understanding of their actions. (See Bunge 1993 for a contemporary exposition of this approach).

Hekman distinguishes the positivist approach from an "interpretive" school whose position, although less easy to define, is characterised by agreement on two points: that the methodology of the social sciences must be regarded as different from that of the natural sciences because social action can only be defined by reference to the subjective meanings of social actors; and that the purpose of the social sciences is to understand social action rather than to subsume it under a universal law of causality. Hekman suggests that the methodological debate between these two schools has reached deadlock.

The principal difficulty of the positivist approach has been frequently... stated by its... critics. They argue that since the actor's meanings are constitutive of the category of social action the analysis of social action must begin with the actor's concepts. Thus positivist social scientists, by substituting their own concepts for the concepts of the social actors are, quite literally, missing the point of social scientific analysis. But the problem attendant upon the interpretive approach to social action has emerged just as clearly in these discussions. The critics of interpretive social science have argued that if the actor's meanings constitute social action, then the social sciences would appear to be limited to the "mere" description of social action.

(Hekman 1984:335)

Hekman suggests that Gadamer's philosophical hermeneutics offers a way of transcending this problem. As a preliminary step she draws upon the work of Riceour to show that there are sufficient similarities between the texts that constitute the traditional focus of hermeneutics, and the accounts of social action with which social scientists are concerned, for hermeneutical insights to be brought to bear within the social sciences.

Riceour (1981) argues that textual material and accounts of social action can be considered equivalent because they differ from conversational discourse in similar ways. Riceour refers to these modes of differentiation as "distanciation". The first expression of distanciation between discourse and text is that discourse has the character of a fleeting event, whereas the content of textual material is fixed in its written from.

The second form of distanciation pertains to the relation between meaning, and the subjective intention of the author or speaker. In the case of discourse, the subjective intention of the speaker and the meaning of the discourse overlap, so that "it is the same thing to understand what the speaker means and what his discourse means" (Riceour 1981:200). The meaning of a text, however, may no longer converge with its authors' subjective intention. "The text's career escapes the finite horizon lived by its author. What the text says now matters more that what the author meant to say" (Riceour 1981:201).

The third form of distanciation refers to the freeing of the text from the world of the original audience, as opposed to spoken discourse where the act of speaking presupposes a shared world. The consequence of this is that

When the dialogue is inscribed in writing, it is freed from this specific reference. That is, the text opens itself up to unlimited readings and is no longer bound to the particular time and place in which the dialogue occurred.

(Allen and Jensen 1990:243)

Fourth, distanciation refers to the relationship between discourse and its audience. Riceour states that in the case of a text, The narrowness of the dialogical relation explodes. Instead of being addressed to you, this second person, what is written is now addressed to all readers.

(Riceour 1981:202)

Hekman argues that each of these forms of distanciation applies to accounts of social action, thereby justifying the application of hermeneutical insights to the field of social research. The features of hermeneutics that Hekman relates to social research include the notion of understanding as the fusion of horizons; the idea that understanding is a dialectical process; and the Gadamerian emphasis on understanding as social, historical and contextual.

Hekman (1984) suggests that Gadamer's notion of understanding as the fusion of horizons, when applied to social research, avoids the problems inherent in both the subjectivist and objectivist approaches. For Gadamer, meaning is neither located in the subjective intention of the author or actor, nor produced by the interpretive methods of the scholar. Rather, understanding occurs as the horizon of the scholar intersects or fuses with that of the text. In practical terms, Hekman contends that the notion of understanding as the fusion of horizons permits the scholar to respect and retain the perspective of the research participant whilst simultaneously approaching the text or focus of enquiry from the perspective that is offered by a nominated theoretical position.

Gadamer's approach legitimises the imposition of the observer's conceptual scheme without denying the constitutive role of the social actors' concepts

(Hekman 1984:333)

In describing the manner of the interaction between the horizons of interpreter and text, Hekman draws upon Gadamer's metaphor of understanding as a dialogical process. The way in which this dialogue (or dialectic, in Dey's terms) was conducted in the present study is discussed towards the end of this chapter.

This section ends by identifying the characteristics and limitations of the knowledge that might be produced during a programme of hermeneutical research.

Thompson (1990) suggests that hermeneutic philosophy emphasises the social and historical nature of inquiry, and shows that understanding cannot be separated from the social interests and standpoints that we assume as the result of our being cultural agents. Hermeneutics, she argues, shows us that human understanding is limited and conditioned by our social interests, values, language, concepts, time and history, and helps us to understand that the decisions made in the process of doing research are value laden and interest bound. As Wachterhauser argues,

Hermeneutical thinkers can be characterised quite generally by their concern to resist the idea of the human intellect as a wordless and timeless source of insight... hermeneutical theories of understanding argue that all human understanding is never "without words" and never "outside of time". On the contrary, what is distinctive about human understanding is that it is always in terms of some evolving linguistic framework that has been worked out over time in terms of some historically conditioned set of concerns and practices. In short, hermeneutical thinkers argue that language and history are always both conditions and limits of understanding.

#### (Wachterhauser 1986:5-6)

I have argued that there is close correspondence between the positivist-interpretive debate that Hekman identifies within the methodological literature, and the tension between the objective and subjective approaches that exists within the quality of life literature. Philosophical hermeneutics offers an approach that transcends both of these conflicts by critiquing the Cartesian assumptions upon which they are based, and offering positive alternatives.

The hermeneutical emphasis on the social, historical and contextual nature of understanding is reflected in the present study in the assumption that the research will not and cannot discover certain a-historical features of the quality of life that can be isolated, described, measured and manipulated. However, the hermeneutical view of understanding as social, historical, and contextual also warns against a form of radical subjectivism bordering upon solipsism that suggests that the quality of life is a completely private and idiosyncratic affair. Consequently, while the hermeneutical basis of this research suggests that care must be taken when extrapolating the findings to some wider population, it also implies that there is no reason in principle why the findings might not inform the situation of other older people, particularly if these findings can be supported by evidence drawn from the broader philosophical, theoretical and empirical literature.

#### **Methodological Decisions**

The goals of this research are to develop a concept of the quality of life that has the power to explain the significance of the violations of the rights and dignity of older people that sometimes occur in institutional care, and to identify and illustrate aspects of current nursing practice that will promote their well being. These goals are advanced by using hermeneutically grounded methods to get beyond the subjective - objective dichotomy that characterises the conventional literature in order to describe and discuss the meanings and practices that a group of older people and their professional carers associate with the concept of the quality of life. This section discusses the methods that were used and relates them to the theoretical underpinnings of the study.

Although there is a growing tradition of hermeneutical research, the implications of hermeneutics for the practice of nursing research are still being explored. For this reason, it is important that the approach used should be explained and justified as fully as possible. In seeking to do this, the researcher is confronted by two problems: how to structure the report, and what vocabulary to use.

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Research reports conventionally use a structure in which the method of data collection is described, the approach to analysis is discussed, and presentation of the findings is followed by an account of their implications. Commonly, these reports employ a conventional vocabulary of social research which contains words such as sampling, data, analysis, and findings.

The problem facing the hermeneutical researcher is that whilst this structure and these words have the advantage of familiarity they may have become associated with a tradition of empirical research that does not reflect the insights of the contemporary hermeneutical literature. Despite these potential disadvantages, this chapter adopts the traditional structure and vocabulary, whilst rejecting their customary associations.

It should therefore be understood that the use of the conventional vocabulary of research does not imply an occult belief that the researcher's role is to discover pre-existent social facts. I have clearly rejected the view that the quality of life is a social fact, and espoused the belief that knowledge is contextual, historical and perspectival. The conventional vocabulary is used despite its empiricist connotations because its familiarity helps to give a clear account of the research. The words are intended and should be taken in the context of the range of meanings specified in column two of table 6, labelled "hermeneutics". The researcher also retains the right to employ the vocabulary of hermeneutics, and will use "text" and "data", "interpretation" and "analysis" interchangeably. This practice follows the convention of the published literature discussed above, and is appropriate in a project that occupies the cusp between philosophy and social science.

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	1. Empiricism	2. Hermeneutics
Domain of inquiry	Independent entities with absolute properties	Action in context: text and text analogues
Ground of knowledge	Foundation provided by interpretation-free facts: brute data	Starting place provided by practical understanding, articulated
Character of explanation	Statements of regularities among data: causal laws	Narrative accounts: a reading of the text
Method: relationship to researched	Objective, value neutral stance	Familiarity with practices: participation in shared culture
Method: justification of explanation	Assess correspondence with reality	Consider whether interpretation uncovers an answer to its motivating concern

# Table 6:Comparing Empiricist and hermeneutic perspectives (adapted from<br/>Packer and Addison 1989)

For the sake of clarity, the following discussion follows the conventional stages of the research process, except in the section where analysis is discussed. Here, the principles that guided analysis are discussed, but the process approach is rejected for reasons that are discussed below.

#### Ethics

A research protocol was examined and approved by the Ethics Committee of the Health Authority. The research is generally free of ethical problems. However, two specific issues are addressed. The first is beneficence, the ethical principle that exhorts the researcher not to cause harm. My research assistant and I felt that there was no real prospect that the research participants would be harmed by the interview method that was used, although it was possible that some older people might be distressed by discussion of certain aspects of their lives. We decided that if such distress became apparent we would ask the participant if they wished to terminate the interview, offer support, and inform the nursing staff before leaving the ward. In fact, this situation did not arise.

The second ethical principle is that of informed consent. Consent was obtained from participants before interview. In a small number of cases, it became apparent during the preamble to the interview that the selected person was severely confused. Such people were not interviewed, both because they were incapable of giving informed consent, and because the content of their conversation was unusable as data.

Mrs B. was in a moderate confusional state. She appeared to understand simple instructions and happily participated in the interview, thereby implying her continuing consent. Although her early brain failure made her unable to participate in discussion at a conceptual level, it was felt appropriate not to exclude her simply because she found it difficult to order her thoughts. The judgement was made that muddled people have a right to be heard in research. A single quotation from this interview is given (see page 118).

#### Sampling

Sampling decisions reflected the need to identify research participants for interview who could discuss the meaning of the quality of life for older people, and describe practices and situations which both enhanced and impaired their well being. Accordingly, two major groups of research participants were chosen: older people who were currently in receipt of nursing care, and members of occupational groups responsible for the organisation and delivery of that care. Sampling decisions were modified by the decision to include participants from each of the many types of hospital facility that was available within the Health Authority in which the research was conducted. The size of the sample was also shaped by two factors: the need to include participants from each facility, as discussed above; and redundancy of data, which occurred when the pool of ideas and practices described by the research participants appeared to be exhausted.

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Seven hospitals within the Health Authority had long-stay facilities for elderly people. Hospital A had a number of wards classified as "psycho-geriatric"; hospitals B, C, D, E, and F had a mixture of rehabilitation wards and long stay facilities; and hospital G was a busy District General Hospital with a number of acute "geriatric" wards, and some long stay places. The selection of hospitals A, C, E, F, and G provided a mixture of acute, long stay and "psycho-geriatric" facilities.

A staged form of quota sampling (Cohen and Manion 1989) was used to select individuals for interview, with the hospital ward being taken as the basic sampling unit.

#### Selecting older people

One ward was selected from each of the hospitals chosen. The selection of wards was made with the assistance of the hospital nursing managers, who gave us access to the weekly meetings of the ward sisters. At these meetings, we explained the purpose and nature of the research project, and invited those who were interested in participating to volunteer. In this way, five wards were chosen, one from each hospital. An element of self-selection was inescapable, because it would not have been possible to involve wards without the permission and goodwill of the sister.

A number of older people was then selected from each of the five wards chosen. It was felt to be inappropriate to delegate the selection of patients to ward staff who may have been reluctant to choose patients whom they considered to be confused or difficult. In principle, any patient was considered to be eligible for the study whose name appeared on the ward list. Patients were selected from the list according to certain categories: we interviewed patients of both sexes; patients who had, in the opinion of the staff, a reasonable prospect of discharge home in the near future and those for whom this prospect was remote; and some classified by the staff as confused and some not. The final criterion was the willingness of the

person to be interviewed for the study. In total, fourteen elderly patients were selected in this way and agreed to participate in the study.

#### Selecting Staff

The staff who manage and deliver hospital care have the potential to influence the quality of the lives of elderly patients. As the ward sisters probably have the greatest potential influence, we interviewed more of them than any other staff group. We invited the ward sister/charge nurse from each of the wards from which patients had been selected to participate in the study, and eleven accepted. We also included two district nursing sisters, one social worker, one occupational therapist, one physiotherapist, one nurse manager, one staff nurse, and one physician.

# Data Collection

Kvale (1985) suggests that the qualitative interview is a particularly suitable method of data collection for hermeneutical research, because it implies a hermeneutical mode of understanding in which people are able to describe their world, their opinions and their acts, in their own words, and subjects can organise their own description, emphasising what they themselves find important.

The method used also corresponds with the ethnographic interview as described by Martin, Hammersley and Atkinson (1984). This type of interview is not a free conversation, but neither does it follow a highly structured list of pre-determined questions. The interviewer's task it to structure the encounter in such a way that the informant can give a full and clear account of his or her ideas. Benner acknowledges that

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The interviewer cannot avoid influencing the conversation, therefore the goal is to make the communicative discourse mutual, comfortable, and focused on understanding the participant's meanings. Questions of clarification and participation are phrased so that the participant can disconfirm as well as confirm the participant's meanings. The researcher seeks engagement in the participant's world, and through participant observation and interview sets up a friendly dialogue where understanding can occur.

(Benner 1990:7-8)

Interview Technique

The work of interviewing was shared between myself and a research assistant. Interviews were recorded on a small portable tape recorder for later transcription. On the few occasions that the tape recorder failed, the interviewer took brief notes during the interview and subsequently reconstructed the exchange.

The quality of the interview may be impaired if insufficient attention is paid to the possibility of reactivity. Reactivity occurs when the interviewer imposes his or her own perceptions on the informant through the form and content of his or her questions. This possibility clearly existed in the present case as both researcher and research assistant were experienced in the clinical care of elderly people and held certain views. The following aspects of the interpersonal relationship between interviewer and informant also add to the danger of reactivity: i) the role of the interviewer is often more clearly defined than that of the informant. Informants may have very little idea of what is expected of them, and may lack the necessary skills to express complex ideas in a verbal form. Informants who are unfamiliar with their role may adopt a subordinate attitude in the face of interviewer "expertise", and express what they imagine to be a socially acceptable response, taking cues from the interviewer if these are available. ii) Research has shown that many people enjoy the experience of being interviewed (Cannell and Axelrod 1956), and may try to reward the interviewer, once again by giving acceptable answers (Goudy and Potter 1976). iii) The exchange of information might be influenced by the respective social status of interviewer

and informant (Benny and Hughes 1967). In the present case, it was possible that the responses given by staff might be influenced by their knowledge that the research project had been instigated by the Chief Nurse of the Authority. It was also possible that the elderly people, knowing that we were nurses, might avoid criticising the care that they had received. With the danger of reactivity in mind, the goal of the interview was to lead the interviewee towards the themes of the research (i.e. the quality of life) but to avoid leading him or her in the direction of expressing specific meanings about these themes (Kvale 1985).

Staff members who had expressed an interest in participating in the study were sent a letter outlining the nature of the project and explaining the contribution that we wanted them to make. In a subsequent telephone call, a date was fixed for the interview, and the informant was asked suggest a place where the interview could be conducted without interruption. Most interviews took place in an office off the main ward area. Each interview began with another explanation of the research. Informants were reminded that the project concerned the quality of life of elderly people in hospital, that we were interested in their views of the meaning of the quality of life, and that we would also like to explore aspects of good practice.

The interview was not structured according to a fixed list of questions, but certain "stem questions" were held in mind.

- What do you understand by the phrase "the quality of life"?
- Can you suggest other terms for the quality of life?
- (To staff) What do you do in order to promote the quality of the lives of the patients on this ward?
- (To older people) How do the staff help to promote your quality of life?
- (To staff) If you could do one thing to improve the quality of the lives of the patients on this ward, what would it be?
- (To older people) If one thing could be done to promote the quality of your life, what would it be?

These questions were used to get the interview started, whilst retaining the focus on the quality of life. The subsequent strategy was to respond to the issues contained within the participant's answer to these opening questions, and to explore them at greater depth. The following example of an opening question is taken from the interview with Sister A:

Researcher: So... the topic is the quality of life. Can you tell me what the phrase means to you... in connection with elderly people? There is no such thing as a wrong answer... I just want to know what you think.

Honey (1987) argues that there is an intrinsic relationship between hermeneutics and the research interview. She argues that both hermeneutics and the interview are driven by the interplay between "belief" and "scepticism".

On the one hand, hermeneutics aims at the restoration of meaning, which is "animated by faith, by a willingness to listen, and is characterised by a respect for the symbol" (Thompson 1981:6). On the other hand, hermeneutics attempts to uncover or decipher meanings that are presented in the form of a disguise. Here, hermeneutics is "animated by suspicion, by scepticism towards the given, and is characterised by a distrust of the symbol as a dissimulation of the real".

(Honey 1987:7)

This tension between the "hermeneutics of faith and the hermeneutics of suspicion" (Thompson 1981) is apparent during the interview process, where the researcher's willingness to let the participants speak is complemented by strategies whose goal is to expose contradictions and uncover deeper levels of meaning; and it is also apparent during the analytical process, where the intention to present a clear account of the informant's views is matched by an attempt to discover the assumptions upon which those views rest, and to highlight the conflict that sometimes exists between the rhetoric and the reality of nursing practice.

As each interview developed, we employed the techniques of focusing, clarifying, reflecting and summarising that are described in the context of the helping interview by Egan (1986) and Connor, Dexter and Walsh (1984).

#### Focusing and Clarifying

After the informant had made an initial statement, we focused on the issues that they had raised and ask them to clarify what they had said. Clarification might involve asking the informant to define a term that they had used, or give an explanation for what they had said. The following example of this process is taken from the interview with ward Sister B:

Researcher: Yes... Right... you've mentioned a lot of words there, said a lot of things. If I can go back and perhaps explore some of them in more depth. Why is it that choice is so important?

#### <u>Reflecting</u>

Minimal responses were used to encourage the informant to continue, and we reflected back the content of what had been said. The following example is taken from the interview with Sister A.

Researcher: So is it something about just being in hospital that takes away this kind of control?

Sister A: I think the minute you walk through the hospital doors...

Researcher: Yes...

Sister A: That responsibility and control is taken away from you. Simply by taking off your clothes and putting you in pyjamas, or a a white gown in casualty. You strip somebody of everything. You strip somebody of their identity in a way, by putting a white gown on.

Researcher: So there is more in taking somebody's clothes away from them than just taking off what they're wearing?

Sister A: Yes.

#### Summarising

Benner (1990:7-8) argues that the interviewer cannot avoid influencing the conversation, and suggests that his or her goal should be to make the communicative discourse mutual, comfortable, and focused on understanding the participant's meanings. To this end, questions of clarification and participation should be phrased so that the participant can disconfirm as well as confirm the participant's meanings.

Kvale (1985) recognises that the process of interpretation begins during the interview itself, as the interviewer interprets the meaning of what the research participant says, and "sends" this interpreted meaning back to check its validity. The interviewee then has the option of saying "I did not mean that", or "that was precisely what I meant". Consequently, we summarised what the informant had said and ask them to check the accuracy of our understanding. Here, the informant (Sister B) was talking about fulfilment;

Researcher: To summarise that, there's a phrase I've heard that I like the sound of... the "stream of life"... and it sounds as if you're suggesting fulfilment in some way comes with being able to, from your particular point in that stream of life, look back into the things you've done in the past, and reflect on them with some satisfaction or regret or whatever...and also to project yourself forward and make plans for the future.

Sister B: Yes. Yes its both, isn't it? And it doesn't matter that you've also got some things in your past that you don't like, as long as you feel you've somehow grown from the experience.

Interviews with Elderly Patients

At interview, some elderly informants had difficulty in answering questions about the quality of life. Part of this difficulty appeared to be related to their relative unfamiliarity with the role of informant: they simply did not understand what they were being asked to do. Our response to this problem was to drop the rather formal term "interview" and to ask the informants if we could have a chat with them. We also took care to structure the interaction

as a social encounter. We would sit next to the person, making sure that good eye contact and occasional physical contact were possible. Sometimes we had a cup of tea with them.

Some of the elderly people also appeared to be unfamiliar with the term the quality of life. In these cases, we used the term "happiness" as a substitute. We felt that this solution was reasonable because there is a body of literature that defines the quality of life in terms of happiness.

Many of the interviews with elderly people included lengthy diversions into areas only tangentially related to the research question. We did not interrupt these, believing that they reinforced the social nature of the interview and brought a useful sense of informality to the encounter. The strategies of focusing, clarifying and summarising that were used for staff interviews were also used here.

#### The Guiding Principles of Analysis

It is common for hermeneutical researchers to describe analysis as a sequential process consisting of several stages. Thus, Benner, Tanner and Chesla (1992) describe a five stage analytical process, and Rather (1992) and Diekelman (1992) both describe seven stage processes.

This discussion of analysis rejects the process approach because it comes too close to reducing hermeneutics to a method, and would therefore be in contravention of Gadamer's work. Also, a sequential account would not reflect the complex dialogical interplay between the horizons of the text and interpreter which is central to hermeneutical analysis.

Despite these problems, it is clearly important to explain the relationship between the raw data and the findings that constitute the next three chapters of the dissertation. The

following account reflects the work of Miles and Huberman (1994), who suggest that qualitative analysis is a non-linear activity consisting of three concurrent activities: data reduction, data display, and conclusion drawing/verification. Data reduction is the process of "selecting, focusing, simplifying, abstracting and transforming the data as it appears in transcriptions or field notes"; data display consists of organising and presenting the data in such a way that conclusions can be drawn and the process by which those conclusions are drawn can be made transparent; and verification consists of confirming the validity of the conclusions through argument, replication of the findings in another data set, placing the conclusions in the context of theory, or in various other ways. The following account discusses the *principles* that guided analysis, but does not reduce that analytical activity to a linear process.

#### Principle one: transcribed interviews can be regarded as text for analysis

Interviews were transcribed verbatim. Transcriptions were interleaved with plain paper and bound. Transcribed and bound interviews were then regarded as text for the purpose of hermeneutical analysis. The social scientific and practical disciplines that draw upon hermeneutics commonly regard documents and artefacts of various kinds as texts or text analogues in precisely this way. For instance, Kurz (1994) describes the archaeological remains of an ancient city as a text analogue for the purposes of hermeneutical analysis.

Justification for treating interview transcriptions as text is that they display the modes of distanciation that are definitive of text for Riceour (see above). Text is characterised by its fixedness in written form, and the interviewee speaks in the knowledge that his or her words will be recorded and transcribed. The meaning of a text may no longer converge with its author's subjective intention, and in the same way the meaning that a researcher ascribes to a research interview may not correspond with the speaker's original intention. Finally, a transcribed interview, like a conventional text, is open to an unlimited number of interpretations, and is similarly addressed to an audience of unknown size and composition.

Honey (1987) argues that a transcription is like a conventional text because it is a work: that is to say, it consists of a structured whole that cannot be reduced to its individual components; it is produced according to a series of rules that define its literary genre (research interview); and it is characterised by the style resulting from the interaction of interviewer and interviewee.

Kvale (1985) notes that the text is not pre-given in qualitative research, but is created by the joint efforts of researcher and participants. The text bears the mark of the researcher's theoretical framework, sampling decisions, choice of questions, interviewing strategy, and guiding research question. Consequently, the interviewer is co-author of the text. (In this respect, the research text varies in kind from the texts that are the traditional focus of the hermeneutical approach).

Principle two: although competing interpretations of a given text may be equally valid, interpretation is not an arbitrary activity

It is recognised within hermeneutics that a single text is open to many different interpretations, each of which may in principle be valid. This is because the meaning of a text is not simply defined in terms of the subjective intentions of its author, but is the outcome of the fusion of the horizons of text and interpreter. Consequently, interpretations that proceed from different perspectives may be equally acceptable. As Eagleton comments,

The meaning of a literary work is never exhausted by the intentions of its author. As the work passes from one cultural or historical context to another, new meanings may be culled from it which were perhaps never anticipated by its author or contemporary audience.

(Eagleton 1983:71)

This feature of hermeneutics means that the validity of a particular interpretation is not a function of its reproducibility, which is a canon of validity in natural science and positivist social science. Kvale (1985) supports this point, arguing that if the principle of the legitimate plurality of interpretations is accepted, it becomes meaningless to impose conventional standards of validity.

Although the principle of understanding as the fusion of horizons may cause the researcher to reject the idea that there is a single correct interpretation of a text, it does not follow that all interpretations are equally valid. Hekman (1984) suggests that horizons are *particular* vantage points which, although they encompass a range, are also exclusive. Hekman does not reject the notion of validity *per se:* her point is that interpretations are not arbitrary, and that criteria must exist by which they can be evaluated. Two such criteria are suggested.

First, it is argued that a valid interpretation will be defensible. As Kvale (1985) comments, what matters is to formulate as explicitly as possible the evidence and arguments which have been applied in an interpretation in order that the interpretation be testable by other readers. Giorgi (1975) suggests that it is necessary to show "whether a reader adopting the same viewpoint as articulated by the researcher can also see what the researcher saw, whether or not he agrees with it". Riceour agrees. He suggests that

It is always possible to arbitrate for or against various interpretations, to confront them, arbitrate them, and seek agreement. The task... is to show that (the) interpretation is more probable than the other limited number of constructions

# (Riceour 1981)

Second, Hekman (1984) suggests that interpretations may be evaluated in terms of the common understandings of the linguistic community and in our critical examination of and openness to tradition, and specifically by their conformity to the horizon from within which the interpretation was conducted.

The validity of my interpretation of the research text is defended on the following grounds.

1. The interpretation is the result of a systematic approach. Kvale (1985) points to the danger of reading a complex text "like the devil reads the Bible"; in other words, of selecting passages that support the interpreters preferred view, and neglecting those that suggest a contrary opinion. The interpretation presented below draws upon every part of the text. The approach used was one of categorisation, and is discussed fully below.

 The researchers' understanding of the research participants was validated during the interview process by the use of techniques such a focusing and clarifying (see above).
 Kvale (1985) suggests that the process of interpretation is concurrent with rather that distinct from the process of data collection.

3. The validity of the interpretation is supported in that it corresponds with the findings of empirical literature from a number of different disciplines. This literature is summarised and integrated into the findings.

4. The interpretation is congruent with insights of the hermeneutical tradition that partially defines the interpreter's horizon.

5. The interpretation is supported by multiple extracts from the text.

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#### Principle three: interpretation involves description of the text

For the sake of clarity, the next sections discuss interpretation as if containing two elements: a descriptive phase that proceeds from within the horizon of meaning of the text; and a later phase in which the text is approached from the interpreter's horizon of meaning. In reality, the practice of interpretation involves continuous dialectical movement between the two horizons. Consequently, the effect of the interpreter's horizon is apparent during description of the text; and conversely, the nature of the text modifies the researcher's understanding of his own theoretical perspective.

There is a degree of consensus that hermeneutical analysis involves a descriptive element. Hekman (1984) suggests that an interpretation should clarify the horizon of the text: that is to say, it should give an account of the research participants' view of the phenomenon under study, and should clarify the assumptions, beliefs and views that constitute their perspective. Benner (1985) and Brykczynski (1985) support this view.

Kvale (1985) notes that transcribed interviews are often vague and repetitious with many digressions, and that they generally contain a lot of "noise". He suggests that identification of the essential meanings of a text may require an extended process of condensation, although he recognises that what originally appears as noise may eventually yield important information. It is for this reason that early attempts to "clean up" the text should be avoided, and the interview transcribed in its entirety.

The descriptive component of this interpretation is based upon a systematic process of categorisation. The process of categorisation may begin with line-by-line analysis of the data in the manner described by Strauss (1987); or with an initial comprehension of the whole text, as described by Jones (1985). The principle of the hermeneutical circle asserts that both the parts and the whole are important in understanding. Analysis must therefore function at both levels, giving an adequate account of the entire text, and building this account through the identification of discreet units of meaning. The first analytical task was therefore to develop a sense of the whole of the text. This was done by reading through it several times. It was then necessary to move from the whole to the parts. This phase of analysis involved the development and definition of basic units of meaning known as "categories". A category can be defined as "A bit of data that presents and intelligible and coherent point which is in some sense self-sufficient" (Dey 1993). Categorisation of the data involves two interrelated processes: identification of the categories within the text (also known as constructing a category list); and collating every instance of each category in the text.

There is a view in qualitative research that the process of categorisation is an inductive activity in which categories "emerge" from the data (Glaser and Strauss 1967). Dey is implicitly critical of this approach, arguing that there is never a single set of categories "waiting" to be discovered, but that there are many different ways of "seeing" the data (Dey 1993:110), each of which will reflect the researcher's perspective or horizon of meaning.

The process of categorisation was rather fluid in nature. When the text was first read, an initial and rather tentative set of category titles was affixed to the data. When the whole text had been categorised in this way, it became apparent that some of the category titles represented the idiosyncratic view of a single informant, that others were rather trivial in nature, and that a third group represented issues that were discussed by many of the informants and were conceptually significant. The category list was then adjusted as certain provisional category names were deleted, whilst the portion of text to which they referred was subsumed under a more appropriate title. The final category list contained thirty-one category titles which were thought to represent the best compromise between the need to account for the diversity of the views expressed by the informants, whilst reducing the text to a manageable number of conceptually important generalisations. The final category list is presented as Appendix C. Here, the category titles are given, the major aspects of each category are discussed, and each category's instanciation within the text is indicated.

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Although every part of the text was scrutinised during categorisation, certain portions were not subsumed within a category. The most common reason for excluding a part of the text was that is represented "noise". Other portions of the text that might have been classified in principle were excluded because their content was irrelevant in terms of the research question.

The number of interviews within which a particular category was represented varied from one to ten, with most categories receiving reference within five, six, or seven different interviews. Conversely, every interview conducted with an older person gave rise to at least one analytical category. (The range was one to six with a mode of three). In the case of interviews with staff members the figures range from two to eighteen with a mode of ten. In part, this difference can be ascribed to the relative unfamiliarity of older people with the role of interviewee, as a consequence of which their interviews tended to contain a high proportion of noise, or material that did not directly relate to the research question. The relatively small number of categories derived from some interviews might also be a function of the fact that many of the analytical categories are rather broad in nature, with the effect that several paragraphs of text might be subsumed within a single analytical category. It should also be noted that categories initially derived from interviews with older people were often of considerable conceptual importance, whilst those derived from interviews with staff members tended to be of practical importance, in that they were related to the organisation of care.

After the category list had been developed, the entire text was re-read, and each instance of every category was collated. Subsequent analysis drew upon the data as reorganised into categories. Categories were explored for major themes, structures and processes, and areas of agreement, disagreement, contradiction and tension were discovered.

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Principle four: interpretation involves the fusion of the horizons of the interpreter and the text

Hermeneutical interpretation involves but is not limited to systematic description of the text within the terms of its own horizon. One of the strengths of the hermeneutical approach is that it permits the scholar to respect and retain the perspective of the research participants, whilst simultaneously approaching the text from a different horizon of meaning.

Hekman (1986) identifies two elements within the researcher's horizon of meaning.

The Gadamerian (should) be aware that in the course of interpretation a different horizon of meaning (is) necessarily... imposed on the actor's horizon, that of the interpreter. The horizon of the interpreter is defined jointly.. by the historical perspective of the interpreter and a specific ideological perspective.

(Hekman 1986:151)

The effect of the historical perspective upon the course of this study is apparent in various issues such as the background to the project, the research question, methodological decisions, and the approach to data collection, all of which have had their impact upon the final shape of the text. Hekman's suggestion that the interpreter's horizon is also constituted by a specific ideological perspective is taken up by Thompson (1990). Thompson argues that hermeneutical researchers must deal explicitly with their own interpretive theories and should understand that the use of these theories provides them with a specific ideological perspective. She discusses as an example the work of Melosh (1982) who used the theory of professionalisation as an interpretive background that provided a specific orientation to "the facts" in her historical study of professionalisation in nursing. Thus, Hekman (1986) and Thompson (1990) broadly support Dey's suggestion that analysis involves a dialectic between ideas, and the data (Dey 1993).

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In the present case, philosophical hermeneutics provided the ideological orientation. It has been shown that the ontological component of hermeneutics offers a contribution to the debate about the nature of the quality of life. Benner (1985) draws upon this tradition as she suggests that the quality of life might be conceptualised as the quality of being. Benner's approach is congruent with a well established philosophical tradition that defines the quality of life in terms of *eudaemonia*, a term which has variously been described as happiness, and human flourishing. The roots of the eudaemonistic approach lie in the work of Aristotle (Aiken 1982, Graham 1990). Aiken explains that philosophers in this tradition have typically sought to determine human essence, and then to work out what is required for happiness, fulfilment and a life of quality. Typically, this approach has been

Concerned with the upper limits of quality of a human life. It seeks to define the "good life" and to provide knowledge of both necessary and sufficient conditions for its attainment. It is concerned with the social environment.....as an enabler of individuals in reaching this fulfilment level. It has a noble tradition (from Plato and Aristotle through Hegel and Marx) and is alive today in much of the literature of the holistic humanists.

(Aiken 1982:27)

The ideological perspective that I have adopted during this study, which forms part of my interpretive horizon, draws broadly upon the hermeneutical tradition, and more specifically upon the contribution that Heidegger's ontology makes to that tradition. The outcome of this study is intended as a contribution to the eudaemonistic approach to the quality of life.

During the descriptive phase of interpretation, this ideological perspective acted as a "lens" that enabled me to "see" certain categories within the text. For instance, Heidegger's notion of Being-in-the-world", which was discussed in chapter one, represents the idea that the physical world is saturated with meaning. This idea sensitised me to numerous instances within the text where physical artefacts such as personal possessions are valued more for

their meaning than for their usefulness. In other cases, the process of categorisation was less self-consciously informed by the researcher's perspective, and category titles were derived from the vocabulary used by the informant.

# Presenting the findings

The findings are presented in the form of an extended text (Miles and Huberman 1994) in which the boundaries between individual categories become once more become indistinct. Aspects of the findings are presented in each of the next three chapters. Chapters four and five each contain a central organising theme: the theme of chapter four is the importance of places and personal possessions and their relation to the quality of life; and the organising theme of chapter five is the principle of individuality. Chapter six explores the implications of these findings for the organisation of care in nursing homes, and forms a basis for the development of practice standards in chapter seven.

# PART III

# THE FINDINGS

The major findings of the research are presented in the next two chapters of the thesis. Chapter four discusses the importance of places, personal possessions and clothing; and chapter five discusses the meaning of being an individual. Each of these chapters draws upon the data, the hermeneutical literature, and empirical literature. In chapter four, the analytical process is explained in a series of methodological notes, presented in boxes.

### **CHAPTER 4**

# BEING AT HOME: THE RELATIONSHIP OF PLACES AND PERSONAL POSSESSIONS TO THE QUALITY OF LIFE

This chapter shows that places, personal possessions and clothing are not only important to older people because of their functional attributes, but because they have meaning. The chapter's context is provided by Heidegger's notions of being-in-the-world, and interpretation. Various references to the meanings of places, personal possessions and clothing are drawn from the text, and the discussion also incorporates material from the empirical literature. Each section of the chapter is headed according to its function.

## **The Theoretical Perspective**

Many nurse theorists, particularly those in the American tradition, claim that the environment is one of the central concerns of the theory and practice of nursing (Fawcett 1989). Typically, their view of the relationship between person and environment is informed by the scientific disciplines of physiology and psychology. For instance, King claims that

The internal environment of human beings transforms energy to enable them to adjust to continuous external environmental changes.

(King 1981:5)

whilst Roy argues that the environment is made up of

All conditions, circumstances and influences surrounding and affecting the development and behaviour of persons or groups.

(Roy 1984:39)

The British literature also demonstrates a preoccupation with the objective characteristics of the environment. For instance, Cormack (1990:3) praises nurse managers

"who are sufficiently enlightened and flexible to provide equipment, furniture, decoration, or wall covering that is varied, domestic, and otherwise non-clinical and non-institutional" in order to "present the illusion of home rather than hospital". The importance that Cormack attaches to the physical characteristics of the environment is not justified by research evidence that the level of satisfaction that people express with their dwellings is only weakly correlated with objective characteristics such as the number of rooms and the state of structural repair (Campbell, Converse and Rogers 1976, O'Bryant 1982).

Although it is clear that the scientific conceptualisation of the person as existing in an environment is useful in some circumstances, Heidegger would argue that it is a highly specialised approach that does not correspond with or inform the human being's normal experience of the physical world. Where science expresses direction in terms that are relative to the fixed points of the compass, the human being understands direction as it relates to the disposition of his or her own body (left and right, up and down, before and behind); and where the scientist expresses distance in standard units of length the everyday experience is of a spatial world whose meaning is expressed in terms relating to human concerns and activities. This experience of space presupposes the ownership of a human body and is frequently expressive of values and meanings. In several cultures, that which is above is both morally and physically superior to that which is below; to be seated at the right hand is a special sign of favour; and regrettable episodes in life are "put behind one" (Tuan 1977, Dovey 1978).

Scholars from various disciplines have been critical of a tendency to examine the environment in purely "objective" or scientific terms. Some of these writers have been selfconsciously influenced by Heidegger's writing, whilst the work of others is broadly congruent with his approach. For instance, Ley (1977:500) criticises social geography for becoming overly concerned with the categorisation of "landscape facts" which have been "sprung loose" from their everyday context in the human world, resulting in the transition "from a science of man in place to a science of phenomena" and preparing the way for a "scientism which ultimately abstracted place to a geometry of space and reduced man to a pallid entrepreneurial figure". Ley argues for an approach to geography that recognises the subjective as well as the objective, and the adoption of a philosophical underpinning that embraces both object and subject, fact and value. Heidegger's insights into the day-to-day experience of space have prompted scholars from fields as diverse as environmental psychology (Seamon 1982), sociology (Agnew and Duncan 1989), architecture (Lukermann 1961), gerontology (Rubenstein 1987, 1989) and anthropology (Rowles 1981, 1983a, 1983b) to explore the phenomenon of place as a locus of meaning. For instance, Relph (1976) has suggested that the identity of places is constituted by three fundamental components which, although irreducible one to the other, are inseparably interwoven into our experience of places. The first is the static physical setting, the second is the range of activities with which each place is associated, and the third is the meaning.

#### The Phenomenon of Attachment to Place

#### Focus on the Data

Rowles ethnographic study of the phenomenon of attachment to place as manifest by the elderly residents of Colton, a small American town in decline, is fully congruent with the Heideggerian approach (Rowles 1983). Rowles developed a theory of "insideness" to explain the relationship of his elderly subjects to their town. This theory offers a useful theoretical principle that enables certain aspects of my own data to be explored in a systematic way. In this section, references are found to existential insideness, physical insideness, social insideness, and autobiographical insideness. Methodological note: Gadamer's philosophical hermeneutics asserts that understanding is a dialectical process that occurs during the fusion of the horizons of interpreter and text. Dey (1993) makes essentially the same point as he describes analysis as a dialectic between ideas and the data. Dey also suggests that it is in order for the researcher to make use of existing theory during the analytical procedure. This dialectic process now begins as one aspect of the data is explained in terms of Rowles theory of "insideness".

## Existential Insideness

Every hospitalised elderly person who was interviewed during the course of this research expressed a desire to return home or regretted that this was no longer possible. This is seen in the simple response of Mrs A.

Researcher: Where would you rather be then?

Mrs. A: At home.

Later in her interview she was asked:

Researcher: What sort of things do you think about?

Mrs A: I think about am I going to stay here all the time or am I going to go home. They never mention about me going home.

Researcher: They don't say anything?

Mrs A: No

Researcher: Not at all?

Mrs A: No, nothing about going home.

Researcher: Do you talk about it?

Mrs A: Yes. I say to them, "When am I going home?", but they say "All in good time".

Indeed, the desire to return home was even expressed by a woman whose early brain-failure made much of the rest of her conversation meaningless.

Researcher: Where would you rather be then?

Mrs B: At home! (said very positively).

Researcher: Why?

Mrs B: 'Cos its too new

Researcher: Why would you rather be at home?

Mrs B: Because... I like... its just... its just...

Some of the elderly people to whom we spoke clearly felt that the desire to return home was so self-evidently "normal" that its justification was neither necessary nor possible. Others were able to explain or illustrate the reason for their attachment to home. The following extract from an interview held with Mrs C serves as a point of departure for an explanation of the meaning of home for older people that draws both upon the research text and the empirical literature.

Mrs C: Where would I rather be? There's nowhere else really. I'd rather be at home in my own home, but its impossible really because I can't see for one thing. I did manage, you know.

Researcher: Why would you rather be at home?

Mrs C: At home? Well, I'd be in the house I lived in, and I'd be satisfied.

This passage illustrates something of the complexity of the concept of home. As the word is used here, it can be interpreted in three different ways. First, Mrs C's mention of "My own home" refers to a specific place, either a house or flat, which has its own postal address;

second, her wish to be "in my own home" is expressive of her desire to return to that place; but at the third level, "to be at home in my own home" reveals the sense of attachment to place that is so characteristic of the experience of home. Relph reserves the term "existential insideness" for the experience of knowing implicitly that *this* is the place to which you belong.

(Existential insideness) is the insideness that most people experience when they are at home and in their own town or region, when they know the place and its people and are known and accepted there. Existential insideness characterises belonging to a place and the deep and complete identity with a place that is the very foundation of the place concept.

(Relph 1976:55)

Further evidence of existential insideness can be found elsewhere in the research text, where Mr Ds comment that:

What me and the wife would like to do is go back to the flat, put on the fire, and do the usual things

gives a sense of his desire to return to a place that is valued for its familiarity. In

contrast, Mrs C's remark that:

You have to be content (here in hospital even though) its another world

indicates her profound sense of displacement.

Physical Insideness

Mrs B: One thing I don't like is you have to keep asking for the commode all the time when you can't go yourself. I've been trying to find it myself this morning. I don't know where it is . I don't know my way around yet. If I can go on my own I'll be happy. I won't have to ring anybody.

This quotation demonstrates the innate sense of familiarity with place that Rowles (1983) calls "physical insideness". The elderly person's knowledge of the home environment does not simply exist in a cognitive form. In his study of the process of attachment to place, Rowles (1983) used the term "body awareness" to describe the finding that his elderly subjects had internalised a sense of the pathways they traversed during the rhythm and routine of their daily lives.

Each old person, over the years, had developed an intimate familiarity with environmental barriers, slippery places and pathways affording frequent physical supports to compensate for an unsteady gait.

### (Rowles 1983:302)

Rowles' notion of body-awareness serves as a specific instance of Heidegger's more general concept of "readiness-to-hand". Readiness-to-hand occurs where an item of equipment in use "is transparent or unnoticed, an extension of the body and the action" (Benner 1989:412). It is descriptive of skilled, habitual performance in familiar circumstances, and is characteristic of many of our unreflective dealings with the physical world, such as the use of equipment and tools. When we use a hammer, for instance, we are not interested in its properties in the detached and objective manner of the scientist; rather, our focus is on the task of hammering.

For the older person, the familiar environment of the home is ready-to-hand in this way. If an older person is removed from the place to which they are accustomed and which for them is ready-to-hand, their capacity for independence may be impaired. Rather than facilitating the processes and activities of daily life, the unfamiliar environment becomes an obstacle that gets in the way. Heidegger calls this state "un-readiness-to-hand".

In our dealings with the world of our concern, the un-ready-to-hand can be encountered not only in the sense of that which is unusable or simply missing, but as something which is *not* missing at all and *not* unusable, but which "stands in the way" of our concern. That to which our concern refuses to turn, that for which it has "no time", is something *un*-ready-to-hand in the manner of what does not belong here, of what as yet has not been attended to. Anything which is un-ready-to-hand in this way is disturbing to us, and enables us to see the *obstinacy* of that with which we must concern ourselves in the first instance before we do anything else.

(Heidegger 1962:103)

Un-readiness-to-hand is precisely descriptive of the situation of Mrs B, as described in the quotation with which this section began. She finds herself in an unfamiliar environment, and rather than facilitating her concern - which is to use the commode - the environment "stands in the way". This is disturbing to her and, to paraphrase Heidegger, the accomplishment of environmental familiarity becomes that with which she must concern herself before she does anything else.

Methodological note: The hermeneutical notion of understanding as a dialectical process brings to mind the idea of a conversation or dialogue between the text and the theoretically-informed interpreter. The first voice in this dialogue was heard as the data were explored from the perspective of Rowles theory of "insideness". We now hear the second voice as the data, represented by Mrs B's quotation at the head of this section, are given priority, and used to explain Heidegger's notion of "unreadiness-to-hand".

Social Insideness

Researcher: What are your plans from the hospital?

Mrs F: Why, to go home as soon as I can

Researcher: That's your plan?

Mrs F: Yes, and probably one of my nieces will pop in every day. And my grand-daughter with the two children, she pops in after school, you know, she fetches the children from school and pops in to see me. If I write down something I wanted, then she'll see I get it.

Rowles (1983) suggested that the intimacy of physical insideness was supplemented by a sense of social insideness stemming from integration within the social fabric of a local age peer group and constituting a supportive milieu with shared norms of behaviour and a common value system. In their study of the local sense of place as experienced in north-east England, Taylor and Townsend (1975) also identified a social aspect to the link between person and place, with the familiarity and friendliness of the local area being of particular importance.

For many older people, home is the fulcrum of the social dimension to their lives, because it is a place that provides them with the opportunities and means to socialise, entertain, be close to and maintain contact with family and friends (Rutman and Freedman 1988). For some, the home may represent a reservoir of family history and a link between past and future generations.

There is a temporal dimension to the link between person and place: it takes time to develop a network of friends. Rowles found that many of the individuals who constituted the social network of his research subjects were age peers with whom relationships had been developed over a lifetime of shared experience made possible by residential proximity. For this reason, length of residence and a history of shared social experiences tend to strengthen attachment to place, whereas a history of mobility tends to reduce it (Taylor and Townsend 1976).

#### Autobiographical Insideness

At interview, Mrs G said that her plan was to go home. Her daughter had asked her to live with her, but she said she wouldn't go because it wasn't her own home. She said she loved her home, even though it was a Corporation house and too big. She had lived there for fifty-four years. As part of his research, Rowles (1983) drove elderly people about the town so that they could show him the places that were particularly evocative of past friendships, the memories of childhood, and other important events in their lives. Autobiographical insideness describes the sense of attachment that links person to place through the memory of important events in ones personal history.

This section of the chapter has established that home is important to the older people who were interviewed. In the next, various important characteristics of home are identified. Priority is given to the data, but other research is integrated into the discussion as and when it is relevant.

#### Home as a Locus of Autonomy

## Focus on the Data

Some older people said that home was important because it was a place where they were free to make choices.

Researcher: But what do you like about being at home, though?

Mrs C: Being able to please yourself. Freedom of being able to choose what you do and what you eat. You see, you can't do that in hospital.

Similarly at interview, Mr H said that he would rather be at home than in hospital because then he could do what he wanted to do: go out, watch T.V., go to bed when he wanted, and so forth; and Mrs G, explaining why she missed her home, said it was the place where she could do what she liked: turn the lights on or off, watch the T.V., talk to her neighbours. This gave her a sense of independence. It is interesting to note the mundane

nature of the choices that were valued by these older people: they wanted to be able to turn the light on or off, go to bed at the time of their choice, and choose what to eat at mealtimes.

#### Focus on the Literature

The theme of home as a place where choice is maximally available is examined in the literature. Furby (1978) identified control as an explanatory variable for the acquisition of property; and in a study of older people who had chosen to relocate to age-segregated rentsubsidised apartments, Rutman and Freedman (1988) found that responses from fifty-seven percent of the relocated group and seventy-two percent of the waiting-list group suggested that home was valued because it gave the opportunity of personal autonomy

Some writers explain the claim that the home is valued as a locus of autonomy in terms of a theory of territoriality. Porteous (1976) suggests that homo-sapiens shares with many animal species a tendency to assert exclusive jurisdiction over physical space. The territorial boundary, which may exist in either a physical or a symbolic form, demarcates a zone to which access may be controlled by an individual or a social group. Porteous suggests that control of territory is maintained by two major means: personalisation of space, and defence of space; and that territorial ownership bestows a range of satisfactions that includes identity and security. He suggests that there is a particular link between personalisation and identity, and argues that the placement and display of personal objects within the home constitutes an important display of the self.

The security of the home allows the personality to flower... (it) becomes a vehicle for expressing identity... Jung suggests that the house is a universal, archetypal symbol of the self. The house reflects how the individual sees himself, and how he wishes others to see him.

(Porteous 1976:384)

Porteous also suggests that the defence of space through the control of territorial boundaries bestows a sense of security. Whereas animals tend to use scent or excreta to mark the extent of their ranges, human territorial boundaries are marked in culturally specific ways. Porteous notes the difference between the rigid demarcation between public and private domains expressed in the high wall surrounding the Muslim dwelling, and the much less defensible open plan of many western dwellings. He argues that the importance of territorial boundaries is illustrated by the "sanctity of the threshold", and the rituals involved in entering the home of another, such as knocking on the door.

In this section, the argument has been examined that home is important because it may offer opportunities for personal control. Two particular forms of control have been explored: control of territorial boundaries has been linked to a sense of security, and personalisation of the environment has been linked to the expression of identity.

In the next section, the role of personal objects as medium for self expression will be examined in more detail. It will be suggested that personal possessions are not only important as signs of the self, but that they also have a role to play in the constitution and maintenance of the self. Other roles for personal possessions will also be identified.

### The Meaning of Personal Possessions

## Focus on the Data

At interview, older people sometimes said that they wanted to go home because home was the place where their personal possessions were to be found. In the following discussion, the significance of personal objects for older people will be explored.

Mrs B: When I get better I want to go home. Everybody likes their own home. I miss my telly and all that.

Researcher: What do you like about your own home?

Mrs B: My telly.

Mrs I also introduced the idea that home is important because certain things are to be found there.

Researcher: What do you do at home?

*Mrs I:* We have a cassette with loads of opera, operatic and classical music on *it*, and I look at television if there's a good film on. I read a lot, lots of books. And of course I have friends come in. We can chat and that. In the summer when the flowers are out, roses and that, I can go in there among the roses. Yes, in the fresh air.

Finally, Mrs J felt that no-one could be really happy in hospital because they were not surrounded by their own things.

Focus on the Literature

Rochberg-Halton (1984) describes two theoretical traditions in which personal objects have been taken as significant. The first is environmental studies, and the second is semiology, or the study of symbols and signs.

The environmentalist tends to emphasise the physical characteristics of material artefacts. This is the position taken by Cormack who praised nurse managers for decorating their wards in a domestic style "in order to present the illusion of home rather than hospital" (Cormack 1990:3). We have already noted Cormack's failure to attend to research that demonstrates a weak correlation between the level of satisfaction that people express with their dwellings and observable characteristics such as the number of rooms and the state of structural repair. As Taylor and Townsend report, "There is not necessarily anything about the

nature of the physical or built environment which influences people's sense of belonging to it" (Taylor and Townsend 1976:104). At interview, Sister K made a related point:

Some people are happy at home, in appalling home circumstances - perhaps in back to back houses with no heating, in dirty surroundings - and they're happy. That's their life, and they're happy with that life".

The second theoretical tradition that Rochberg-Halton describes is semiology, which is rooted in Freudian psychoanalysis. An example of this tradition is found in the work of Winnicot (1958) who elaborates the concept of the transitional object to refer to external things that are not distinguished completely from the individuals own person. Transitional objects are those things that initially take the place of the breast before the individual has gained a sense of the distinctness of self and other. Winnicot also includes more subliminal versions of transitional objects that are applicable to the later stages of the development of the self, but that retain the underlying psychological meaning of the breast-substitute. The idea of the transitional object is taken up by Sherman and Newman (1977) who suggested that objects could help elderly people to move from independent to institutional living, and noted a positive correlation between the ownership of cherished personal possessions in residential care, and life satisfaction score.

In his comparative critique of the traditions of environmental studies and semiology, Rochberg-Halton (1984) says that each displays a tendency to ignore or deny what the other assumes. While environmentalists have often failed to appreciate that human behaviour, perception, consciousness, environments and objects interlock to form a web of signs, psychoanalysts and others who work in the symbolic tradition have tended not to appreciate that signs are rooted in some environment, not a mentalistic nether-world. Rochberg-Halton attempts to resolve the tension between the environmentalist and semiological traditions by drawing upon symbolic interactionist theory to develop a notion of "cultivation" or the "environmentally situated interpretive act". It is noted that the purpose of defining cultivation is to signify that "the web of meaning that is the medium for the self is not merely a noun, "culture"... but is an active process of interpretation reciprocally requiring care and enquiry, and endowing one in turn with the broader perspective of community life". He suggests that personal objects play an important role in this interpretive process because they "act as signs of the self that are essential in their own right for its cultivation, and hence the world of meaning that we create for ourselves, and that creates ourselves, extends literally into the objective surroundings" (Rochberg Halton 1984:344). To clarify this point, Rochberg-Halton is suggesting that personal objects are important mediators between self and the world. They serve as a display of personal meanings, but they also play a part in the psycho-social processes through which the self is constituted and maintained.

Rochberg-Halton's theory of cultivation is essentially a reformulation of one of the central arguments of Heidegger's *Being and Time*: that there is an interpretive dimension to human being. It was shown in chapter one that Heidegger's discussion of the role of interpretation in human life represents his distinctive contribution to hermeneutical theory.

Empirical support for the notion of cultivation is found in the work of Rubinstein (1989), who conducted a cultural-anthropological examination of the psychosocial processes linking person to place. His conclusions were developed during the course of hundreds of hours spent talking to older people in their homes. Rubinstein suggested that there is a "person-centred process" that constitutes one of the ways in which person and environment can be linked. It's four points offer a continuum upon which the relationship of person and personal object can be plotted. The base-line form of the person-centred process is "accounting".

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#### Accounting

The older person at home is intimately familiar with the configuration of the physical environment, and because of this familiarity is able to conduct everyday life with a minimum degree of difficulty. Rubinstein (1989) uses the term "accounting" to describe this kind of knowledge of the environmental features of the home. He makes two observations. The first is that objects and environmental features vary with respect to their degree of significance: some things are rarely significant, whilst others are especially so. His second observation is that there are at least two modes of significance. Some things, like tools, are significant because of what they enable their owners to do; whilst other things which are of little practical value are significant because they carry some special meaning.

While awareness of the total inventory of environmental features at any one time was rare, it was apparent that all the objects in the home environment, from the pencil hidden under a stack of newspaper to the most personally significant photograph or memorabilia, had some kind of meaning, either as something merely owned or tolerated, or as occasionally useful, or in a more intimate way... The process of accounting can be considered as subsuming all environmental features, some of which are constantly, periodically, or rarely significant.

(Rubinstein 1989:48)

Significance, then, is not so much an attribute or property of a thing in itself, as a function of the relationship between that thing and its owner. Heidegger uses the word "concern" to indicate some of the many forms in which this relationship may be expressed.

Having to do with something, attending to something and looking after it, making use of something, giving something up and letting it go, accomplishing, evincing, interrogating, considering, discussing, determining... All these ways of Being have concern as their way of Being.

(Heidegger 1962:83)

It follows that objects that are unrelated to current concerns will tend to loose their significance and fade into the background. This is the meaning of Rubinstein's statement that "accounting... incorporates the meaninglessness all environmental features have at times". Heidegger puts it this way:

Leaving undone, neglecting, renouncing, taking a rest-these too are ways of concern; but these are all deficient modes, in which the possibilities of concern are kept to a "bare minimum".

Heidegger (1962:83)

## Personalisation

The second aspect of the person-centred process is "personalisation", which is the endowment of environmental features with meanings whose referents are the distinctive events, properties or projections of one's own life. Personalisation is the most modest level of involvement with environmental features.

## Extension

"Extension" refers to an aspect of the person-centred process in which a greater degree of personal involvement with a feature occurs, and in which there is a more direct equation of the environmental feature with a part of the self. It is the process by which individuals utilise environmental features as a direct and conscious representation of some key aspect of the self. Illustration of this phenomenon is provided by Sherman and Newman's (1977) study of the meanings of cherished possessions to a sample of ninety-four older people in community centres and nursing homes. A male respondent spoke of his violin, saying "I am a musician, and the violin means everything to me". Referring to photographs of the family, a woman said "They mean I was a woman. I had children and built my life around them. Happy memories". Equally, objects could be symbolic of important relationships. One

woman said that her bracelet was her most cherished possession: "My husband gave it to me sixty years ago. My feelings for him add much meaning to the object". These quotations amply demonstrate how personal possessions can act as "signs of the self" (Rochberg-Halton 1984).

# Embodiment

Embodiment is the final and most extreme stage of the person-centred process. It describes a relationship with objects or environmental features which have become so heavily charged with meaning as to be almost indistinguishable from the self. Rubinstein suggests that embodiment can be important for older people who may feel that aspects of the environment have a greater potential for endurance than do their own bodies.

Environmental features may therefore be assigned the task, through embodiment, of carrying the load of personal meaning and thereby aid in the maintenance of the self, when it is threatened... enlisted as an ally, and environmental feature can come to function as part prosthetic self.

#### (Rubinstein 1989:50)

In summary, the four stages of the person-centred process differ with respect to the degree of interpenetration of person and environmental feature. In personalisation, the hypothetical boundary between self and environment remains intact. In the stage of extension it becomes blurred; and in the final stage of embodiment it completely disappears.

In an earlier study than the one described above, Rubinstein (1987) explored the meanings of personal objects to a sample of eighty eight older people who were asked to name and discuss the meaning of personally significant objects. Their responses were analytically sorted into a number of thematic categories, some of which add useful detail to the notion of the person-centred process.

## Connections with Others

Rubinstein found that the largest category of meanings attributed to objects valued by older people involved connections with others, including grandparents, parents, children or spouses. Several subjects valued things that had been in the family for a number of generations, and were therefore symbolic of its continuity through time. Objects which had been handed on in this way helped their owners to see themselves as occupying important care-taking and custodial roles. An eighty four year old man spoke of his prized grandfather clock. "Its been in the family for seven generations. Its gone to the eldest son in every generation". At other times the value of objects was related to their status as gifts, either given or received. Older people who were moving into less spacious accommodation would sometimes give their property away to carefully chosen recipients; items which had been received as gifts gained value through their association with the giver.

## References to the self

A second large category of meanings related to objects which were important because they represented particular aspects of the self. Rubinstein describes the case of a woman who had built up a collection of "old lady" dolls, each of which represented her at different periods in her old age; and the case of an eighty seven year old retired academic who continued to write scholarly works who listed his typewriter, because it represented his continuing desire and ability to write. Respectively, these cases show the power of objects to represent the self as it is manifest both in being and doing.

## Defences Against Negative Change

Another set of meanings for objects related to their properties as defences against change and negative events such as loss, boredom or loneliness. A seventy eight year old woman valued her rocking chair, saying "I can't sit in it any more now that I broke my neck and I'm crippled, but I used to sit there in the evenings and talk to my husband when he was alive. Later, my children dubbed it 'Granny's chair'". Objects were also valued as aids to overcoming boredom and loneliness. A seventy three year old woman listed her books: "I read a lot. You can never be bored if you read".

### Objects of care

A fourth group of meanings was related to objects which enabled their owners to express themselves through care. A woman mentioned her bird, her dog, and her plants, saying "These are things that need care, that need me. I have to be needed".

# **Objects of Mature Sensuousness**

Rubinstein found that the significance of many objects had an affective or qualitative dimension, expressed in words such as liking, taste, comfort, warmth and pride. Beyond this, some objects appeared to be especially important because they embodied deeply held personal values and acted as material representations of aspects of personal meaning systems.

Such objects are a referential and meaningful component but also possess a sensuous and vivid nature, acting as lightening rods for feeling and memory. This multifaceted, affectual complex may be considered a form of mature, summative or transcending sensuousness in which an object stands for or represents key experiences and complex emotions at the core of a person's identity.

(Rubinstein 1989:235)

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### Objects as Representations of the Past

The final group of meanings were attached to objects significant as links to important events in the past, including childhood, married life, residence in another home, or the duration of the adult life.

Another study which is relevant here is described by Kalymun (1983) who interviewed elderly women about the decisions that they made concerning the retention and disposal of personal possessions during relocation to new residential accommodation. Content analysis of interview transcriptions led to the development of a taxonomy of influencing factors. It was found that decisions were influenced both by environmental concerns such as spatial features and the occasional existence of regulations, and by personal considerations. These included issues of function and utility, but once again the self-expressive role of personal objects was noted.

# The Role of Personal Objects in the Constitution of the Home

In the light of the forgoing discussion, comments can be made about the relationship between personal objects and the home. Rochberg-Halton notes that

Household artefacts do not exist atomistically... rather they form part of a gestalt for the people who live with them - a gestalt that both communicates a sense of home and differentiates the types of activities that might be more appropriate for one part of the home than another. Hence the meanings of the things one values are not limited to the individual object itself, but also include the spatial context in which the object is placed.

#### (Rochberg Halton 1984:352)

In other words, ones personal possessions are not simply located in one's home, but they help to constitute home as home. We therefore find that the interpretive process of cultivation which Rochberg-Halton has described relates as much to the disposition and placement of artefacts as it does to the simple fact of their ownership. The work of Rubinstein provides empirical justification for this suggestion. He argues that the decisions that people make about room function, furniture placement and the use of decoration represent individual interpretations of sociocultural ideals.

Culture suggests general rules for ordering and arranging space. The act of making order in a home is a basic cultural act, as domestic order expresses some of the most basic cultural notions about personhood and social life...The individual reproduces basic ideas about cultural order through the act of ordering domestic space and also interprets ideas about the cultural order.

(Rubinstein 1989:47)

This process, which Rubinstein calls ordering, is another example of Rochberg-Halton's environmentally situated act of cultivation.

It has been noted that personal objects play many important roles in the lives of older people. Those who are faced by change may use them in a manner which is analogous to the transitional object of early childhood, and thereby find that they are better able to cope with the move from independent to institutional living (Sherman and Newman 1977). It is interesting to note that these authors found a positive correlation between the ownership of a cherished personal possession, and life satisfaction score; but beyond this, there is recurrent empirical and theoretical evidence for the proposition that personal objects support older people in their personhood. Goffman (1961) has noted that the personal possessions of an individual are an important part of the material out of which he builds a self, and Simone de Beauvoir has said that:

Thanks to his possessions, the older person assures himself of his identity against those who claim to see him as nothing but an object.

(de Beauvoir 1973:699)

The ontological significance of personal objects has been explained by Rochberg-Halton's theory of cultivation, which argues that a person is related to the physical world through an active process of interpretation. According to this theory, personal objects are not simply a passive medium through which aspects of the self can be expressed; they also constitute key elements in a web of personal meanings, occasionally representing important aspects of the self, and playing a part in the psycho-social processes through which the self is constituted and maintained. In proposing a mechanism to show how personal meanings can extend into the objective surroundings of the physical world, the notion of cultivation offers a powerful theoretical perspective which helps us to understand the importance of home for older people.

# The Importance of Clothing

## Focus on the Data

The role played by material artefacts in the interpretive processes of human being is illustrated with particular clarity by the case of clothing. The following extracts from the research text serve to illustrate the importance of clothing. The informant was talking about choice and control:

Sister K: I think the minute you walk through hospital doors that....that responsibility and control is taken away from you. Simply by taking off your clothes and putting you in pyjamas or a white gown in casualty. You strip them of their identity in a way, by putting a white gown on.

Researcher: So there is more in taking somebody's clothes away than just removing what they're wearing?

Sister K: Yes.

Later, Sister K described her personal experience of the loss of control involved in wearing a white gown.

Sister K: I think it's foul. I've only ever once had a medical examination, and it was the most embarrassing thing that I've ever been through. It was the time when I felt least in control.

Researcher: Yes.

Sister K: Because I felt not only that I was physically naked, but I felt mentally naked as well.

Researcher:	Mentally naked?
Sister K:	It was a terrible feeling.
Researcher:	What do you mean by mentally naked?
Sister K:	l felt so vulnerable.

Focus on the Literature

This informant's perception of a link between personal identity and clothing is justified by the research-based literature. Veblen (1953) was one of the earliest writers to argue that clothing did more than protect the body. Rudd (1992) argued that clothing is a rich example of a cultural sign-system which has strong communicative value and which is used by individuals, groups and cultures to negotiate meaning and interact on the basis of that meaning. Kaiser (1990) drew upon semiotics and social psychology to propose a model linking the structural analysis of appearance with the social processes engaged through appearance in constructing meaning. For Kaiser, Clothes rarely convey a single meaning; more commonly, their messages may be described as consisting of layers of meaning, with some layers being more applicable that others in a specific context.

### (Kaiser 1990:9)

The anthropologists Roach and Bubolz-Eicher (1979) argue that the human practices of personal adornment and dressing are communicative acts that serve critical functions within human societies. They claim that these practices support the individual in his or her endeavour to appear as a unique person and provide a way of expressing, reinforcing, initiating or camouflaging mood. They also identify a number of socially useful functions fulfilled by clothing. These include the identification of social worth, symbolisation of economic status, representation of political power or ideological orientation, reflection of magico-religious condition, and reinforcement of beliefs, customs and values.

Social psychologist have examined the role played by clothing in the presentation of self, and person perception (Davis 1988). Ericksen and Sirgy (1992) found that employed women were more likely to wear outfits at work that matched their actual and ideal self images; Kwon and Farber (1992) reported that the style of dress often affects the perception of the wearer's professionalism, intelligence and competence; and Rudd (1992) described the sign-value of the dress patterns of a group of homosexual men.

Schwarz (1979) offers an assessment of the role of clothing that is fully congruent with Heidegger's notion of interpretation and Rochberg-Halton's concept of cultivation:

Taking the position that what men *make* may be as important as what they say in defining a relationship with the environment (sociocultural as well as natural), the study of clothing and adornment becomes rather significant as an anthropological enterprise. It is not just the fact that only humans adorn themselves, but that *more than any other material product, clothing plays a symbolic role in mediating the relationship between nature, man, and his sociocultural environment.* In dressing up, man addresses himself, his fellows, and his world.

(Schwarz 1979:30)

The relationship of clothing to the quality of life will be discussed in more detail in the next chapter.

# Conclusion

This chapter has discussed places, personal possessions and clothing in terms of the meanings that they have for older people. The concepts of being-in-the-world and interpretation have offered a theoretical perspective from which to address the text, and evidence from the empirical literature has been introduced to enrich and corroborate the findings. The practical implications of the chapter are discussed in chapters six and seven.

## **CHAPTER 5**

## **BEING AN INDIVIDUAL**

# Introduction

When they were asked to discuss the quality of life, many people used the word individual: the quality of life was seen to be an individual thing, individuality was a property that must be respected, and the quality of life depended upon individualised care. The tendency to link individuality and the quality of life is illustrated in the following extract from the text:

Sister O: Treating people as individuals increases the quality of their lives. Not treating them as individuals and telling them what is happening is detrimental to their quality of life.

Although many members of staff identified a link between the quality of life and being treated as an individual, most were unable to go beyond simple statement to justification of their position.

(Notes from an unrecorded interview) When asked why we should treat people as individuals, Sister P said that it was because they <u>were</u> individuals.

(Notes from an unrecorded interview) Sister N suggested that people should be treated as individuals because they are individuals. She felt that it was difficult to go beyond this point.

Within the text, all references to individual infer that it is a goal to be aimed at, a state to be approved of, or a generally good thing. No informant stated that to be or to be treated as an individual was undesirable. However, when the informants were asked why being an individual was such a good thing, they were unable to say. For most informants, then, the state of being an individual was regarded as both self evidently true and self evidently desirable. As individuality is a widely held and largely unexamined assumption that underpins the thinking of many of the carers who were interviewed, it can be described as a principle or axiom.

### The Nature of Individuality: an Historical Perspective

Historically, the notion of individualism has carried widely varying connotations. One of the earliest references to the individual is found in the Bible where, in the book of Ezekiel, the prophet rejects the earlier teaching that children should pay the penalty for the sins of their fathers, and argues that people should bear responsibility for the outcome of their own actions. Elsewhere in the Bible the notion of individualism denotes that national and social categories are of little significance to God: "There is neither Greek nor Jew, circumcision nor uncircumcision, Barbarian, Scythian, bond nor free, but Christ is all and in all"(Collossians III:II).

Lukes (1974) has written a history of the development of the idea of individualism in Europe and America from 1820 to 1974. He claims that the concept expresses five basic ideas: the dignity of the individual; autonomy; privacy; self-development; and the abstract individual. The *dignity of the individual* expresses the "Ultimate moral principle of the supreme and intrinsic value, or dignity, of the individual human being" (Lukes 1974:45). This ideal received systematic expression in the work of Kant, who asserted that "man, and in general every rational being, *exists* as an end in himself, *not merely as a means* for arbitrary use by this or that will: he must in all his actions, whether they are directed towards himself or other rational beings, always be viewed *at the same time as an end.*" Kant argued that rational beings

Are called persons because their nature already marks them out as ends in themselves-that is, as something which ought not to be used merely as a means-and consequently imposes to that extent a limit on all arbitrary treatment of them (and is an objective of reverence). Persons, therefore, are not merely subjective ends whose existence as an effect of our actions has a value for us: they are objective ends-that is, things whose existence is in itself an end, and

indeed an end such that in its place we can put no other end to which they should serve *simply* as means; for unless this is so, nothing at all of absolute value would be found anywhere.

## (Kant 1991:91)

Autonomy is the idea that every person has the ability and the right to think and to make judgements and decisions for him or herself. The idea of *privacy* describes a private domain in which the individual has the right to do whatever he or she chooses. The principle of *self-development* promotes the complete realisation of an individual's unique potential. The fifth idea, that of the *abstract individual*, refers to a way of conceptualising the individual in terms of needs, interests, wants or other purposes that are assumed to be common to all people, irrespective of specific social and historical circumstances.

Lukes argues that these five basic ideas of individualism have given rise to six doctrines of individualism (summarised here as by Wilkie 1986). Economic individualism is the doctrine of laissez-faire capitalism including the principle of free trade; political individualism is the core principle of representative democracy, as expressed in the slogan "one man one vote"; religious individualism refers to the doctrines of individual salvation and conscience; ethical individualism expresses the same doctrine in a secular form; methodological individualism is the idea that all valid explanations of social phenomena can be reduced to the thoughts, feelings and motives of individuals; and epistemological individualism is the sources and criteria of valid knowledge are individual, not social.

The principle of individualism has often been invoked in political debate. In England, the philosopher John Stuart Mill, expounding the ideas of "the present socialists", wrote of their belief that

The very foundation of human life as at present constituted, the very principle upon which the production and repartition of all material products is now carried on, is essentially vicious and anti-social. It is the principle of individualism, competition, each one for himself and against all the rest. It is grounded in opposition of interests, not harmony of interests, and under it everyone is required to find his place by a struggle, by pushing others back, or being pushed back by them. Socialists consider this system of private war (as it may be termed) between everyone and everyone, especially fatal in an economic point of view and in a moral.

# (Mill 1879:715)

It seems that the principle of individualism was received more positively in the United

States of America at the turn of the present century, where it was regarded as the

Actual or imminent realisation of the final stage of human progress in a spontaneously cohesive society of equal individual rights, limited government, *laissez-faire*, natural justice and equal opportunity, and individual freedom, moral development, and dignity.

(Lukes 1973:24)

In contemporary Britain, the notion of the individual is often invoked in the context of a political debate about the respective roles of the individual and society (see for instance Thatcher 1993:626). The tension between the individual and social poles of human life is not unique to politics, but can also be found within the philosophical literature and the research text (see below).

The chapter now proceeds with an analysis of parts of the research text under the heading "the principle of individuality". As in the previous chapter, the interpretation proceeds from the perspective afforded by the work of Heidegger (and related writers), and the

research based literature is integrated as and where appropriate.<sup>4</sup> Specifically, the account draws upon Heidegger's concept of existence, an account of which was given in chapter one.

# **Promoting Individuality**

Focus on the Text

The text recognises the individuality of older people by acknowledging that they differ in respect of their aims, goals and expectations. Within the text, the terms purpose and aim are used both in a global and in a more limited sense. Used globally, they can refer to a person's purpose in life.

Sister Q: I don't know really - I don't know if it is something we give enough thought to really, what's their purpose in life? I mean, we know what our purpose is for them, but actually thinking about what their purpose is, I'm not sure.

Researcher: One of the Sisters said she never used to ask things like that because she was frightened they might turn around and say, "I haven't got a purpose in life".

Sister Q: I think you might get that answer here: "My purpose is to die".

The following quotation refers to purpose in a more limited sense:

Sister N: You've got to include things like good health, really, basic needs being met like shelter, food, emotional needs being met as well, like being loved, being cared for, being wanted, things like that really, and perhaps some sort of purpose in life as well you know, like people have a job or a hobby, something that's important to them.

<sup>4</sup> Although I have focused on Heidegger's contribution to hermeneutics, he is often described as an existentialist. This chapter draws upon his and other writers contributions to the existentialist tradition.

Thus, it appears that there are shades of meaning to purpose, ranging from shortterm objectives, through pass-times, hobbies, occupations and jobs, to a broad goal towards which the whole of one's life is oriented.

If we move beyond attitudes to behaviour, it appears that treating people as individuals first involves a demonstration of respect for their purposes:

Sister L: A difficult question, and without going away and thinking about it, off the top of my head, treating them like an individual, not like children, like an individual and have time to sit and listen to what they want, what are their expectations, what do they want out of life. Lets face it, the majority that come here only have 5 years to live, and I don't think we should make any hard and fast rules. I think its important to sit down and think about what are their expectations, what would they like to do, what they want to achieve.

Having recognised the existence of individual purposes, it is then necessary enable

the person to express them.

Researcher: How exactly do you treat them as individuals? What is important?

Charge Nurse S: We try to take into account all their preference, as far as you can with a ward routine - as far as is possible to take into account all their individual preferences for dressing, washing and so on...

The text shows that in practice, the recognition and expression of individual preferences often involves the issues of choice and control, and these issues will now be discussed.

# Individuality, Choice and Control

The related issues of choice and control appear throughout the text. Sister K felt that freedom of choice in decision making was important because it characterised self responsibility and gave individuals control over their own lives. Further probing exposed her assumption that self responsibility, self control and expression of the self through choice were self evidently good. The axiomatic nature of self determination can also be seen in other parts of the text: it is demonstrated by Sister P, who felt that treating people as individuals was an important way of promoting the quality of life. When asked to justify this statement, she argued that people must be treated as individuals because "that is what they are", and echoed the sentiments of the many informants whose opening remarks at interview were that the "quality of life is an individual thing". Sister T went a step further, suggesting that freedom of choice and the right to self determination were defining characteristics of humanity and gifts from God.

Sister N: I think the most important word I would suggest is an element of choice... Choice has got to be the most important thing, I'd say.

The range of issues over which choices could be made was enumerated several times:

Sister K: Everything from when you have a meal, to when you have a wash, to when you get up on a morning, to whether you decide to take some medical advice or not... or where you're going to live, everything. From getting up on a morning, to deciding whether you're going to move from your home into an old people's home.

## And

Sister T: Choice in where they sit to eat their meals, choice in what time they get up and go to bed, choice in what they eat. Then similar to choice is control - that they should have some control over what's done with them, particularly in hospital, that they're given some control over what treatment they have.

Some informants were asked to explain why choice was such an important issue in

the quality of life.

Sister T: I think because of the way it's linked with control. If we have choice we have control over ourselves. And if control over ourselves is removed, then you don't feel you're a person. You're dehumanised, somehow.

Researcher: So is there some kind of link between quality of life and being a person?

Sister T: Well you can make them less of a person by taking away their control and choice. I think they're then less of a person.

Sister T has asserted that choice and control have ontological significance. This view is confirmed by Macquarrie, who argues that in choosing:

What is really chosen is *oneself.* It is out of its decisions that the self emerges. A self is not given ready made at the beginning. What is given is a field of possibility, and as the existent projects himself into this possibility rather than that one, he begins to determine who he shall be.

(Macquarrie 1972:185)

It is easy to see that major life choices such as ones career path or the decision to parent shape the emerging self, but the data suggest that everyday choices can also have ontological significance. An extract from the interview with Sister K offers a concrete example of this process. The extract concerns choice of clothing, a material artefact whose symbolic significance was indicated in the previous chapter.

Researcher: So somehow it seems as if you are saying that an important part of quality of life is having choice.

Sister K: Yes.

Researcher: And one of the things we make choices about is how we dress. Because I suppose that's how we express ourselves?

Sister K: That's me. I dress quite loudly. I like to dress quite brightly because that's part of my personality, and I'm sure its the same with everybody else.

If, as this informant argues, clothing is important as a sign of the self, it may follow that decisions about dress may have deeper implications: Researcher: And when people come into hospital and we take their clothes of them, we take more than their clothes off?

Sister K: Yes.

Researcher: I'm just checking that I've got your story right.

Sister K: Yes. We take more than their clothes. I think so anyway.

Researcher: We take their choice away from them.

Sister K: Yes. And we take responsibility away from them.

Researcher: Responsibility for what?

Sister K: Perhaps responsibility is not the right word. By taking their clothes off them you make them vulnerable, so they become dependent on us.

Researcher: Right.

Sister K: And because they're so dependent on us we take responsibility as well. That's what I mean.

Sister R. also understood that clothing was an important marker of human being. She had developed a system where patients could have name-tags put into their clothes within an hour of their arrival in hospital, in order to prevent institutional clothing being worn or a night spent in hospital pyjamas.

Other members of staff were also concerned with the practicalities of providing choice. At the simplest level, it was recognised that time is an important raw material if choice is to be provided.

Sister Q (describing personalised clothing): You need to have someone to put them away, and you can have five or six bags of clothing waiting to be sorted and put into the ward, and you think, well you just can't do it, so you resort to ward stock, and you might have six bags there full of clothes for this person and you can't find any. So you need to have somebody to do that. Time was also regarded as an important prerequisite to the development of the kind of relationship within which people could most easily be treated as individuals. In an unrecorded interview, Sister Y said that the most important component of care was sitting down and chatting with patients, as it allowed you to get to know them as people as well as patients. This kind of relationship was also promoted when care was organised appropriately. It seems that the staff seem most able to treat people as individuals when care is organised in such a way that a nurse has responsibility for a particular group of patients over a period of time.

Sister Q: We try to treat everybody... we work very much in groups on the ward, so we've got four groups of mixed ability patients, and one nurse is allocated to that group in the morning, So she knows who she's looking after, there are her patients, and its for her to ensure that the care is given. I think that helps a little.

The organisation of care will be discussed in more detail in the next chapter.

It has been shown that the text links the quality of life of the older person to control and the exercise of choice. Empirical literature relating to this issue will now be discussed.

# A Brief Review of the Literature Related to Control and the Well-Being of the Older

#### Person

Within psychology, control has been defined as the individual's perception that he or she can execute (or has the potential to execute) some action that changes an aversive stimulus (Miller et al 1989). Early experimental studies into control conducted by psychologists in the 1960s and 70s are reviewed in Averill (1973), Miller (1979), and Thompson (1981). These reviews conclude that reactions to the presence or absence of control are not easy to predict because they depend upon the meaning of the situation to the individual (Averill 1973). Folkman (1984) proposes that the meaning of a situation is determined by a two-stage process of appraisal. In primary appraisal, the person judges whether the event is a threat to their well-being. This judgement is influenced by the controllability of the situation and the person's belief in their ability to influence outcomes (locus of control). Secondary appraisal involves assessment of the available options and coping responses in each specific situation. This is influenced by individual coping strategies and self-efficacy beliefs (Bandura 1977).

Individual's perceptions of control can influence their health (Langer 1983, Moore and Schulz 1987), self esteem (Langer 1983, Moore and Schulz 1987), anxiety (Lefcourt 1982), depression (Langer 1983, Moore and Schulz 1987), activity (Arling 1986, Langer 1976), and life satisfaction (Arling 1986, Moore and Schulz 1987).

The construct of control is highly relevant to the present study because there is evidence that institutional regimes of the type found in some nursing homes are likely to lessen resident's actual (Storlie 1982) or perceived control over their environment (Gifford 1987, Langer 1983, Palmore et al 1985). A range of studies has shown that perceived loss of control is associated with deterioration in the health and well-being of older people. Wolk and Telleen (1976) found that satisfaction and developmental task accomplishment of a group of 129 elderly people were inversely related to the perceived level of constraint of the residential setting.

Langer and Rodin (1976) conducted a field experiment to assess the effect of control on a range of measures related to the well-being of older people in nursing homes. Residents allocated to the experimental group were given a communication emphasising their responsibility for themselves, whereas the control group was given a communication stressing the staff's responsibility for them. In addition, the former group was given the freedom to make choices and the responsibility of caring for a plant rather than having decisions made and the plant taken care of for them by the staff. Rodin and Langer report that measures of alertness, active participation and general sense of well-being showed a significant improvement for the experimental group. Rodin and Langer (1977) reported that the beneficial effects set in motion by the experimental treatment were still visible eighteen months later: they even report that the death rate was reduced in the experimental group.

The work of Rodin and Langer contains certain methodological flaws that limit confidence in their findings. They failed to demonstrate that members of the experimental and control groups were equivalent in respect of their locus of control. Cicirelli (1987) later reported that people with an external locus of control were better adjusted to institutional life, and Hickson, Housley and Boyle (1988) and Mancini (1981) have reported a significant association between higher life satisfaction and internal locus of control. Rodin and Langer's control and experimental groups were also situated on separate floors of the building. They acknowledge that there was not a great deal of communication between floors, and it is possible, for we are not told otherwise, that each was serviced by its own team of nurses. Subsequent nursing research (Baker 1978) has demonstrated that the well-being of resident patients can be influenced by the leadership style of senior nurses, and the presence of a dynamic nurse leader on the experimental floor could easily explain the perceived effect.

More recent studies into the effect of control-relevant interventions, conducted in more tightly controlled circumstances, have supported some of the findings of Rodin and Langer. Banziger and Roush (1983) randomly allocated nursing home residents to one of three groups. The control relevant group received a message invoking responsibility and were given the chance to care for a bird-table; the dependency group were given a message invoking dependency and were not given the opportunity to care for a bird-table; whilst a third group received neither intervention. The researchers found that the control relevant group scored more highly on a measure of life-satisfaction, whist there was no difference between the scores of the other two groups. Finally, Chowdhary (1990) found that the sense of control and self esteem of institutionalised older men were enhanced when they were given control over the choice of clothing to wear.

It should be noted that the decline in perceived control associated with institutional living is greatest among the less well educated and more functionally impaired (Arling, Harkins and Capitman 1986, Ryden 1984).

### The Limits of Individuality

#### Focus on the Data

Although the promotion of individuality through the provision of choice is regarded within the text as self-evidently desirable, there is recognition that under a range of circumstances the choices offered to older people in hospital care might be severely limited. Hence, the note of caution expressed in the following extracts:

Sister N: Choice has got to be the most important thing, I'd say, that people can choose to some extent...as far as is possible, I do believe that people should have a choice.

In this section of the chapter, the limits to choice will be discussed. It will first be shown that the staff believe that aspects of the organisational structure can limit the choices available to older people; second, a range of deliberate strategies used by the staff themselves to limit choice will be described, and third, the ways in which they justify the use of these strategies will be explored. Finally, the tension between forces that tend to promote individuality, and those that tend to suppress it, will be placed in the context of Heidegger's work.

# LIMITING CHOICE

Ward Sisters identified certain aspects of the organisational structure as limiting factors in the provision of choice. Commonly, it was argued that understaffing or shortage of time restricted care to the provision of the basics. Sister K spelt out resource problems in some detail.

Sister K: ....lack of physical resources... you have the expertise to prevent someone from developing an uncomfortable pressure sore, but you don't have the equipment, thus the development of the pressure sore will reduce their quality of life. If you don't have enough staff, if you only have enough to rush around everywhere, and make sure everyone is clean and dressed or being fed, and not enough time to have any social talk or negotiations, then that prevents you from giving them quality of life. And then there's the expertise of the staff. If they don't have the... professional knowledge base they won't know what's the right thing to do and to treat. And if they don't have the skills in terms of interpersonal skills, they won't be able to enhance people's choice and help them to feel encouraged or motivated... so I think resources on all these levels have a great input.

Choice could also be restricted by Health Authority policy such as restriction of smoking facilities (Sister N). The text expresses doubt as to whether restrictions of this kind work for the long-term benefit of the patient. This is illustrated through reference to health education.

Sister K: I think the key is helping people to help themselves to do the things they want to do when they want to do them. It's difficult because there are some circumstances, like health education really, that's contrary to that. But it's difficult to promote health education... if its not going to satisfy someone. I just think about myself... if someone said to me "You must loose three stone", it would absolutely devastate me, because part of my quality of life is being able to eat what I want when I want, and to enjoy it. Like elderly men who smoke a lot, and doctors say "Stop smoking", but that's an enjoyment and a pleasure to them. I just think as long as they have the two sets of facts in front of them, then that's their decision.

Sometimes, people are prepared to forego their choices in order to please other people. Sister O described the case of an elderly woman who had requested a side-room because she enjoyed the solitude and was able to read there in peace. However, her husband was upset by her apparent isolation, and so she spent more and more time in the communal areas of the ward "to stop the nurses getting into trouble" and to please her husband. This case illustrates the way in which freedom of choice is limited by situational factors (Benner and Wrubel 1989).

There were several other ways in which choice could be restricted. As Sister N commented, some patients were too ill to recognise the alternatives available to them, and therefore to choose. In this context, Sister P discriminated between the provision of choice and the exercise of choice, suggesting that patients should always be offered a choice as "just to do things for them could be degrading". As we have seen, the psychological literature defines control as the individuals perception that he or she can bring about change. In cases where older people are genuinely unable to make a choice, for whatever reason, then the provision of information can also ameliorate the stressful consequences of loss of control, to some degree (Johnson 1975, Wilson Barnett 1980).

There were also circumstances in which sisters felt themselves justified in deliberately restricting the choices they offered to patients in particular phases of illness. In the exercise of choice, an elderly person will sometimes select a course of action that is felt to be inappropriate or unwise by the staff involved in their care. This causes the potential for conflict. The kind of circumstances where this might happen were described by Sister U.

Sister U: Its very difficult because a lot of the elderly live on their own....sometimes they don't want anyone intruding into their home. It can be quite a problem because we've had a lot of elderly that don't want home helps going in because they don't want them to know what's in the house, they don't want them to see their pension book. It's very difficult because you're taking that patient's independence away.

The nature of the conflict in these cases was nicely summarised by Sister T.

Sister T: Most things are achievable. Where it becomes more difficult is where I feel a certain course of action would be therapeutic and important for their treatment and they don't.

In cases such as these the text provides evidence for a range of possible outcomes. One logical possibility is that the staff will concede to any choice made by patients. The text does not suggest that any of the hospital-based sisters or other staff advocated or practised such an approach: all of those who discussed this issue seemed prepared to accept that there were circumstances in which it was legitimate to override or modify the wishes of the patient. A range of different mechanisms might be employed.

Coming to a Compromise

Coming to a compromise is a mechanism whereby the nurse restricts the choices available to the patient to a number of options from which he or she may choose. Sister T described this approach in the context of rehabilitation:

Sister T: It might be that you come to a compromise with the patient whereby they walk to one end of their bed and get the wheelchair there. And so though you've said to their initial response that they couldn't walk at all, "No, that isn't an option", then you've given them an option of what distance they do walk; or you might say you've got to walk one way, and do they want to walk to lunch, or would they rather wait and walk back? But whatever, you can still provide options, so you can still provide choices, but you're limiting it. I think that's a more constructive way forward.

Massive Encouragement

There were circumstances in which the staff felt themselves to be justified in compelling a patient to do certain things. Sister T, once again, describes circumstances in which she might take this action:

Sister T: In situations of acute illness, and at the beginning of rehabilitation when it is such an effort for somebody they don't want to try. For example with walking, they want you to wheel them because they can't possibly walk, and yet once you've been teaching them to walk, and making them walk increasingly by stages you eventually find that they are not only able to walk but can do it by themselves. And then that gives them more choice because then they can choose when to get up and where to go.

In circumstances such as these the sisters felt justified in restricting the choices available to a patient by compelling them to walk to the toilet, but then pushing them back in a wheel chair. Sister P called this "massive encouragement", and felt it was justified if it resulted in such an improvement in the patient's condition that eventually their range of options was enlarged. If on the other hand the patient was terminally ill or no improvement could realistically be anticipated, no such restriction on choice would be imposed.

Forcing and Physical Restraint

It is apparent that despite the emphasis placed by nursing staff on the principle of individuality and the freedom of choice, there were circumstances in which some nurses were prepared to impose their own aims and goals and to completely over-ride those of the patient:

Do you think that there are circumstances where we are right to Researcher: take decisions for the patient, to take away their choice?

Yes, I'm sure we do all the time anyway. It's like putting a Sister Q: patient into a Buxton chair<sup>5</sup>. We've got a man who wanders around. That's OK. He lies on the floor. That's no problem because we've not got many who walk, but it gets to a point where he's rushing around and he's likely to either fall and knock himself or knock something over and hurt somebody else. So at that time we say right. OK, he's got to go into a chair, so we are really restricting him in a way, restraining him. I don't like the word restrain, but we're protecting him, protecting other people, so we put him in a chair.

In the most extreme case, nurses were prepared to use physical force in order to

impose their will upon that of the patient.

<sup>5</sup> A Buxton chair is a large, upright chair with wheels. It is possible to clamp a table in front of the patient and to tip the chair back, effectively preventing the patient from walking.

Sister Q: This man we're talking about, he's had a stroke so all down his left side he's got no movement at all. Now ideally, you should approach him from his left side. You approach him from this side he's not going to hit you, and see if you can get it done... and try to get it done as quickly as possible, really. The more you try to communicate with him the more he's hitting you, and there comes a time when you think, "Lets get on with it, stop him doing this", and we do it pretty quickly and ask for help, two of us to do him".

It is noted in passing that strategies such as forcing can only be used with any degree

of success in an institutional setting. Sister R, who was a district nurse, was asked what would happen if attempts were made to force people in their own homes.

Notes from an unrecorded interview: Sister R reckoned forcing did not happen so much in the community as patients are in their own home. She said that patients might perhaps do what you are forcing them to do while you are there but not when you weren't. She felt there was little use in trying to force compliance - it was much better to try and get them to cooperate, otherwise they just tended to lie to you.

Sister V., another district nurse, made a similar point. She said that forcing "just

could not be done" in the community, as patients would just tell you to leave.

## Controlling Information

Limiting the older persons ability to choose can happen in a covert, as well as an

overt way. Sister K argued that the provision or retention of information could be a subtle way

of shaping the choices made by patients.

Sister K: I think we play at informed choice. We pretend that we do it. We pretend that we give adequate information and enable patients to make a choice, but I don't think we do really. I think we just give them what we want them to know. Generally, nurses are extremely bad at communicating and laying, unbiased, both sides of the story, putting information at the patient's disposal.

Other parts of the text agree that nurses are selective in the information that they pass on to patients. Although, for instance, Social Worker W felt that it was right *in principle* 

to give patients full and complete information, he accepted that there were cases where this might not be desirable in practice. The decision about how much information would be given was taken in the context of the nurses relationship with the patient, often after an assessment of the capabilities of the patient to understand, or of "how much he wanted to know", had been made.

Sister M: Yes, within their capabilities I don't think you should upset patients with unnecessary information, and there is a lot of unnecessary information when you are talking about prognosis and diagnosis -"Well it might be this", or "We ought to check that"- before you really know, and I think you've got to be careful, you know: "We are doing tests to see what might be wrong" is better than "We think it might be such and such", which is unnecessary chitter for the patient.

Sister Q worked on a ward which served as a final home for many of its residents.

This was one piece of information of which she did not want the patients to be aware:

Research Assistant: the line, really?	So everybody here has accepted that this is the end of
Sister Q: Yes.	
Research Assistant: Do you think the patients know?	
Sister Q: I don't	know. I'd like to think no, they don't.
Research Assistant: Why?	
Sister Q: Becau	se I'd hate to think it was like a death sentence."
Research: Assistant: A dumping ground?	
Sister O: Yes	ts been said its the last step, and the only way you'll get

Sister Q: Yes. Its been said its the last step, and the only way you'll get out is in a box, stuff like that. And, while looking after somebody who's dying is important, that looking after them while they are living is more important really.

Research Assistant: You said sometimes you don't want them to know as it would be like a death sentence, so you don't really believe in some cases....?

Sister Q: No, what I mean is, if somebody is dying, elderly, frail and dying, well yes you are, are you comfortable is the issues. What I mean by that is I'd hate somebody to think I'm going into (names ward) tomorrow to die. You might say yes you will, but it might be this year, or next, or five years time. So while it's part of what we do, its only a little part. I'd hate to think they think its a death sentence coming here, but yes, realistically its the last stop.

## The Paradox of Individuality

The foregoing analysis of the principle of individuality reveals a clear tension between the expressed beliefs, and the actions, of caring staff. On the one hand, hospital staff have strongly endorsed the promotion of individuality through the facilitation of patient choice; whilst on the other, they describe a range of mechanisms through which older people are effectively denied the opportunity to choose. This conflict might be called the paradox of individuality. The text shows that many of the staff were aware of this paradox and sought to justify or explain it. Staff who sought to justify their choice-limiting actions often did so on altruistic grounds. This is shown in the following case, where Sister Q was defending her use of the Buxton Chair:

Researcher: So its like physical danger, really?

Sister Q: Yes. It's when we feel he's going to be a danger to himself or others. So he's in a chair now. He might not like being in a chair, but we feel he's safer like that. But whether it's right....I think we're always going to be doing that, and I think as long as you can say it's in the patient's best interests, then for me its OK. As long as its not in the nurse's best interest, as long as it's for the patient, then that's it. There are patients who are in Buxton chairs, and it's not on here, well I hope not on here, at least not when I'm on, and it's often for the nurses. So I think that's wrong.

It is interesting to note that in the original quotation, this informant took care to redefine restraint as protection. She also seems to be unsure as to whether it is a proper course of action to take ("but whether it's right...."). Finally, she is at pains to distance herself from the use of Buxton chairs, claiming that they are not used on her ward but another, and even if they are used on her ward it is not when she is there, and then always for the benefit

of the patient (although on wards other than hers it might be for the benefit of the staff). It may be that this distancing of self from an action that self has undertaken results from conflict arising from the espousal of the principle of individuality, and actions taken which effectively deny choice; but ultimately, the informant justifies the occasional use of restraint in the Buxton chair on the grounds of altruism, or "being in the best interests of the patient". Other members of staff argued in the same way:

Note of an unrecorded interview with physiotherapist: Her goal was to make patients carry on and be as independent as possible. She felt that those who did not want to be independent were lazy or had a mental problem. In the long term forcing patients was for their own good.

## Limiting Choice and the Ethos of Expertise

We have seen that the individuality of the older person in hospital can be impaired by the controlling activities of the nursing staff, as mechanisms such as massive encouragement and forcing are brought into play. The paradox of individuality is that the staff who employ these controlling mechanisms are often enthusiastic advocates of the individuality of the older person. It has been shown that staff sometimes attempt to resolve or explain this paradox by claiming that their actions are taken for the greater good of the patient. Sister K offered a rather different analysis, arguing that the restriction of patient choice was a routine affair that had little to do with altruism. She claimed that control and choice were often taken away from people as soon as they are admitted to hospital, giving two examples: medication, and clothing.

Sister K: I think medication is about the clearest example.

Researcher: Right.

Sister K: We automatically assume it's best for that patient, as soon as they get through the doors, to take their tablets off them, and start giving them out of the trolley... and that's a big responsibility taken away from the patient. Researcher: So is there something about just being in hospital that takes away this kind of control?

Sister K: I think the minute you walk through hospital doors that....that responsibility and control is taken away from you. Simply by taking off your clothes and putting you in pyjamas or a white gown in casualty. You strip them of their identity in a way, by putting a white gown on.

Researcher: So there is more in taking somebody's clothes away than just removing what they're wearing?

Sister K: Yes.

This informant argues that nurses assume responsibility for their patients because they have an ethos of expertise which is strengthened through association with the medical profession. One consequence of this ethos is that autonomous and questioning patients are found to be threatening.

Sister K: I think we feel that people.... we're the experts and we know best. And if they (the patients) say "Well, I don't want to do that, and I don't think you know best", then that's quite threatening.

Researcher: It's a threat to our professional ego?

Sister K: Yes, yes.

Researcher: Lots of times people have come into hospital and said, "I want to die"; and we don't respect that choice.

Sister K: We think that they must be wrong.

Researcher: Yes, we say they must be depressed.

Sister K: And doctors won't accept that. Doctors find that really very difficult to accept, that somebody makes that choice. Its like going against their Hippocratic Oath, or whatever, and because we're still a sort of semi-extension of them we don't help. We don't help to put the patient's point of view.

The quotation is of interest because it links the paradox of individualism to carers' professional belief systems, and thus to the wider social context within which care is practised. Sister K felt that it was not simply the actions of individual members of staff, but the social structure of the hospital itself, that constrained the exercise of choice by patients.

Researcher: The institution has a particular goal, and the goal is that you will come in here, and you will get healthy, and you will go out again?

Sister K: Yes. You will do it as quickly as possible, and with the least possible problems, and the least difficulty, and you've got to be... got to be a happy patient that doesn't ask questions, and you can't be incontinent, and you can't be difficult.

At the heart of Sister K's analysis is her perception that the personal goals of the older person in hospital may conflict with medically defined priorities. She implies that the real purpose of the controlling strategies identified above (negotiating, forcing, etc.), is to shape the goals of the older person to those of "the system"; or failing this, to completely override them. She argues that this process of shaping begins during admission to hospital as mechanisms are brought into play to accomplish and signify the change in status from independent person to hospital patient. These mechanisms may include dressing the person in night-wear, and controlling their access to medication. The person who conforms to medical priorities and goals may come to be regarded as a "model patient", although the cost of this achievement is increased vulnerability and surrendered autonomy. People who are reluctant to subscribe to the goals of the hospital may occupy the alternative role of "difficult patient".

Sister K: "The problem I have on the ward when they're difficult patients is when they feel they're out of control. That's when you have most problems, when they feel that they haven't got any responsibility and haven't got any control. And we label them "difficult patients".

There will be further discussion of the relationship between the organisation of care and the quality of life of the older person in the next chapter.

#### The Principle of Individuality: Focus on the Philosophical Literature

Aspects of Heidegger's work usefully inform the forgoing discussion. First, the relationship will be explored between the principle of individuality and the Heideggerian concept of existence.

It was noted in chapter one that the concept of existence is central to Heidegger's work. It was shown that Heidegger's statement that "the essence of Dasein lies in its existence" (Heidegger 1962:42) is not to be taken as indicating the obvious fact that each human being is real, or that he or she occupies a point in space. As Cooper (1990:4) explains, Heidegger's technical use of the word "exist" draws upon its derivation from Greek and Latin words which mean "to stand out from", and refers to the belief that a person is always already "beyond" or "ahead of" whatever properties characterise him at a given time.

No complete account can be given of a human being without reference.... to what he is in the process of becoming - without reference, that is, to the projects and intentions which he is on the way to realising, and in terms of which sense is made of his present condition. As Heidegger puts it, the human being is always "ahead of himself", always "unterwegs", (on the way).

### (Cooper 1990:4)

I argue that the principle of individuality, as discussed in the research text, is congruent with this concept of existence. The text asserts that the individuality of older people is recognised as their differing goals and expectations are acknowledged, and that their individuality is promoted as the staff preserve and enhance their ability to make choices about their lives.

However, it is clear from the text that certain attitudes of and actions by the staff, such as physical restraint, information restriction and forcing, neither acknowledge nor promote the individuality of the older person in hospital care. The existentialist tradition also provides an interesting perspective on this feature of the text.

We have seen that for Heidegger, human being is being-in-the-world: that the physical world is saturated with meaning, and that the relationship between the human being and that world is one of necessary interdependence. For Heidegger, it is equally the case that there is a social dimension to human being, which he describes as being-with-others. (Part of Heidegger's purpose in developing the concept of being-with-others was to refute the Cartesian problem of other minds. This argument will not be explained here as it is peripheral to the research project).

For the existentialist, individuality and sociality constitute inescapable poles of human life. Cooper (1992) notes that on the one hand, the person is a free, meaning giving, existing individual; whilst being on the other hand a necessary participant in a public, social world. Between these poles, it is possible for the individual to live either an authentic or an inauthentic life. Here; explains Cooper, the word authentic reflects the meaning of the Greek word from which it derives, which means one who does things for himself. In the German, this word is translated as "eigen", which means "own", as in "ownership". Macquarrie asks,

What is the criterion by which one distinguishes an authentic from and inauthentic being-with-others? Authentic being-with-others is precisely that mode of relation to the other that promotes existence in the full sense; that is to say, it lets the human stand out as human, in freedom and responsibility. On the other hand, inauthentic being-with-others suppresses the genuinely human and personal. Whatever kind of relation to the other depersonalises and dehumanises is an inauthentic one. Thus there is a paradox involved here. A purely individual existence is not possible and could not properly be called an "existence"; yet existence with the others is to be called authentic to the degree that it lets individuals be free to become the unique persons that they are. True community allows for true diversity.

(Macquarrie 1972:121)

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The complementary notions of authentic and inauthentic being-with-others enable us to evaluate the various ways in which the staff justify the limitations which they place on the older person's ability to choose. Techniques such as massive encouragement, which place temporary restriction on the older person's facility of self determination, are sometimes justified by staff on the grounds that they enhance the range of options available in the future. Other techniques, such as forcing and physical restraint, even though they may be justified in altruistic terms, do nothing to promote the future independence of the person, although they probably make life a little easier for the staff. These two approaches correspond with Heidegger's description of two forms of solicitude: "that which leaps in and dominates, and that which leaps forth and liberates". The former, inauthentic form of solicitude "takes over for the other that with which he is to concern himself. The other is thrown out of his position: he steps back, so that afterwards, when the matter has been attended to, he can either take it over as something finished and at his disposal, or disburden himself of it completely". The alternative, authentic form of solicitude "leaps ahead" of the other, "not in order to take away his care but to give it back to him authentically as such for the first time... it helps the other to become transparent to himself in his career and to become free for it" (Heidegger 1962:158).

# Conclusion

This chapter has explored various aspects of the principle of individuality. It has been shown that members of staff claim that individuality is an important characteristic of older people. Various approaches to promoting individuality have been discussed as they appear in the text, and reference has been made to the literature of the psychology of control. It has been shown that, despite their enthusiastic approval of the principle of individuality, there are a number of circumstances in which staff feel justified in limiting the choices that older people in hospital care can make. Finally, individuality has been linked with Heidegger's concept of existence.

# PART IV

# **APPLYING THE FINDINGS TO PRACTICE**

In part four, the focus of the thesis begins to change from the text to nursing practice. There are two chapters. Chapter six is concerned with the implications of the findings for the organisation and management of care in nursing homes. This chapter includes some new material from the text. Chapter seven states a number of practice standards, and describes the way in which they were developed.

#### **CHAPTER 6**

## PATTERNS OF NURSING CARE

The purposes of this chapter are to describe the general features of an approach to the organisation of nursing home care that will promote the quality of the lives of the residents; and to contrast this with an alternative approach that will inhibit the quality of their lives. The chapter works out the implications of the principles that the quality of life can be conceptualised as the quality of being; and that practices that tend to promote the quality of being will also tend to promote the quality of life. Existing literature is drawn into the discussion as and when it is appropriate; and examples of good (and less good) practice are introduced from the text.

Approaches to the organisation of care described in the text tend to fall into one of two patterns, one of which is inimical to the quality of life, and one of which tends to promote it. The first approach can be called the "institutional" pattern of care, using a term that frequently appears in the text and is well referenced in the literature of sociology and the caring disciplines.

The second approach to care is less easy to represent epigramatically. Although the word "home" appears as an obvious choice, I have rejected it because it is often applied to settings where institutional rather than domestic norms prevail, and because I have a sense of doubt as to whether it is possible for a nursing home to act as full substitute for the home that it so often replaces. I therefore associate the second pattern of care with a rather clumsy phrase from the text, "Being in the real world".

**The Total Institution** 

Focus on the Literature

The chapter begins with a summary of the features of the "total institution" as they are

described by Goffman (1961). Goffman's total institution is

A place of residence and work where a large number of like-situated individuals cut off from the wider society for an appreciable period of time together lead an enclosed and formally administered round of life.

(Goffman 1961:11)

The characteristics of institutional living include rigidity of routine, block treatment of

residents, depersonalisation of residents, and social distance between residents and staff.

First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member's daily activity is carried out in the immediate company of a large *batch* of others, all of whom are treated alike and required to do the same things together. Third, all phases of the day's activities are tightly scheduled with one activity leading at a pre-arranged time into the next, the whole sequence of events being imposed from above by a system of explicit, formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single *rational plan* purported to fulfil the *official aims* of the institution.

(Goffman 1961:17)

Goffman's theory of the total institution has often been cited in research into the organisation of care for dependent groups (Townsend 1962, Baker 1978, Clark and Bowling 1989, Wilkin and Hughes 1987, Hughes and Wilkin 1987, Booth 1985, Willcocks, Peace and Kellaher 1987, Stacey 1981). Miller and Gwynne's research into the organisation of residential homes for people with physical handicaps offers a clear picture of the institution at work (Miller and Gwynne 1972). Miller and Gwynne argued that the primary task of these homes was to act as warehouses for people who are socially dead until their physical death.

The warehousing model is principally concerned with the prolongation of life with little concern for its quality. The emphasis is on cure and the application of medical and nursing care to a passive and dependent patient who accepts the institution's definition of his or her problems, and strategies for care. The principal feature of the warehousing model is the application of staff determined routines without regard to the individual characteristics of the patient.

The text makes frequent reference to institutional patterns of care. In this section, institutional roles, institutional patterns of work, and institutional forms of relationship, are discussed.

# The Institutional Role of Patient

Focus on the Text

Sister M suggests that two possibilities face the person entering an institutional system in which there is limited opportunity to exercise choice:

Sister M: Well, there are two things to not giving the patient choice; first you get a rebellious patient, if they've got... what it takes. They'll rebel, and do their damnedest to work against you. Or they'll just become institutionalised: "Can I go to the toilet, nurse - is it time to go to the toilet nurse", that kind of thing.

Research assistant: You said institutionalised. What does that mean?

Sister M: Whereby the institution is the most important thing, and they have to conform to the institutions...

Researcher assistant: Routine?

Sister M: Right. You'll have your dinner at twelve, you'll go to the toilet at half past, you know...

This passage suggests that at an early point, the individual will be faced by the limitations to choice implicit in institutional life. Implied by this passage and more explicitly stated in other parts of the text is the suggestion that the institution has particular goals. The precise nature of these goals will vary according to the purpose of the institution. In the care of older people, they may well be the goals of cure as medically defined, or rapid completion of nursing work. Typically, the goals of the institution take precedence over the goals of the individual, ("the institution is the most important thing...").

Certain mechanisms exist to encourage the individual to conform to the goals and routine of the institution. These include removal of the element of choice in terms of what will be worn, how the day will be structured and the environment arranged, and so forth. The consequences to the individual of institutionalisation through lack of choice are described by Sister SW:

Sister Q: I think... probably they'll lose a lot of their identity. I don't think it would be too nice, really. I mean, we do that to some extent now. The patients don't have any choice in meals, the clothing is picked out by nursing staff, and you don't really get to know them as people, do you?

When asked why choice was taken away from people during institutionalisation, Sister K answered:

Sister K: Because its easier for us. Its easier for us to take control and responsibility than to let them have it. I think its easier. Its easier and quicker for us to make decisions than for us to have to sit down and talk to somebody and allow them to make their own decisions.

Sister L agreed that the physical work of nursing was made a lot easier if patients were denied choice. However, from the point of view of the institution, the removal of choice accomplishes a more important function than to make life easier for the staff. As we have seen, the removal of the choice of clothing that occurs when a person dresses in hospital attire has ontological significance: it signifies and accomplishes a change in role from person

to patient, and serves as a continuing reminder to the person and the institution that such a change has taken place. A person can ask questions, raise objections, disagree, ask for a second opinion, choose not to go to bed, choose not to get out of bed, administer his own medication or miss a dose, whereas an institutionalised patient is unlikely to do any of these things, and therefore will present minimal obstacles to the institution in pursuit of its goals.

# The Institutional Role of Nurse

#### Focus on the Text

Throughout the data there is evidence that the processes of institutionalisation apply to staff as well as to patients, and that the institutional mode of organisation demands a pattern of behaviour from nurses that constitutes a role. This role, like that of patient, is also oriented to the achievement of institutional goals. At times, pressure to achieve these goals can take an overt form.

Notes from an unrecorded interview with Sister L: A lot of the reasons for reducing choice is pressure on nurses. e.g. to get everyone up and dressed and in the dayroom with no time to talk to anyone. L cited a case where Dr A. (the consultant) "gave her a row" for beds not being made, and not everyone being dressed, and contrasted it with the days when the old school of nurses was on duty for a ward round. Dr A. was very impressed with everyone being sat by their beds and washed. Sister L felt very guilty because she knew that everyone would have been got out first thing and washed and dressed with very little choice, but the consultant liked it.

Aspects of the behaviour of those working within the institutional role of nurse can be described as routine or ritualistic.

Sister U: The longer ones, staff and patients, become very institutionalised, and you can see this if you go into a new area and staff just do things routinely, and its very hard to break that routine, because they say, you know, "We've always done in like this".

The institutional role of the nurse is reinforced by the uniform. The text suggests that

a nurse who wears a uniform will not be seen as an individual but as a role occupant.

Sister L: Unfortunately nurses are stereotyped. A lot of people feel threatened, you're in uniform, you know what you're doing, you've been trained. Little do they know! And I think they can feel very threatened. Its those sorts of barriers that we are starting to break down. They know us by our first names... they know us as people rather than "the nurse". I felt it very strongly when I first came here as a Sister. It took me ages even for the staff to call me (uses first name)... I felt it was a big battle I'd helped to break down, really. After all, you're only a person.

This informant found the uniform an obstacle to her attempts to relate as person to person rather than as nurse to patient. Nevertheless, she was prepared to admit that the uniform could act as emotional armour in the stressful world of nursing.

Research assistant: Do you think its important to some nurses, this hiding behind a barrier?

Sister L: Yes, probably, I know when I first qualified at sister level, not so much here, but when I was on the acute area, coronary care, reception unit, we had an awful lot of stand-bys, crashes, deaths, and at that stage, I found it so much easier that I was in uniform, that I knew what I was saying, explaining, while I felt that if I was out of uniform, I would have cracked up with them. Yes, it was like a pillar. Yes, it did give me a bit of support.

A recurring theme in the context of institutional nursing is that of "busy-ness". Busy-

ness refers to the complexity and pace of nursing work. It emerges in many interviews as

mitigation for institutional patterns of care.

Research assistant: And the staffing levels - do you think they are important?

Sister L: Yes, I do. I mean, we're running on six and four, so even the nurse in charge has got to give hands-on care. Not that I'm against that, but I think you're trying to give the hands-on care, be in charge of the ward, co-ordinate the students, co-ordinate the agency staff, how many hats do you have to wear? You know in that morning, everyone is under pressure, and so the psychological care goes out of the window you know. I just find myself -awful - you go home and think, "What have I done this morning?" I even cut conversations short because you know you haven't got time to develop something a patient's trying to tell you because you haven't got the time to investigate or to dig a bit deeper and find out more about them, and it's not

usually until the afternoon that you've got the time to go back to them, and by that time they think you're not interested... the telly probably plonked on, Radio One is blaring out and nobody is listening to it, they're all sitting there dozing. I just think its awful, I really do.

## Patterns of Relationship

The text suggests that the nature of the human relationships experienced by older people has a direct bearing on the quality of their lives.

Sister T: Somehow the way we relate to each other is important.

Researcher: Yes.

Sister T: And most people don't feel happy unless they are in relationships.

Patterns of relationship can be described either as expressive or utilitarian An expressive pattern of relationship is defined for the present purpose as one whose effect is to recognise and confirm the humanity of the other. An example is provided in the discussion that followed Sister T's introduction of the concept of "social talk".

Researcher: Why is social talk important?

Sister T: Because - I don't know - because that's what we do. We do talk to people for pleasure and contact, not just to find out information and to give instructions. It's something to do with forming relationships with other people which we need.

Further information is also found in the interview with Sister N, who was asked what was important in relationships:

Sister N: Things like, as I've said, to be loved, and feeling a part, as it were.

Research assistant: And how can you do that, something like being loved?

Sister N: I think you can. I think it depends on what you mean by love. I don't mean love in marriage particularly, but perhaps being cared for is a more appropriate word, I think. I've got some excellent staff in this day hospital, and I think they do care about the patients.

Research assistant: Involvement?

Sister N: Yes, like I said before, having time to spend with people, and using the time that is there to spend with patients as opposed to sitting in the dayroom drinking coffee.

In contrast, the goal of the utilitarian relationship is to accomplish some task.

Sister L: If all your basic needs are met, also your mental needs, its very important to get to know the person individually, to see what their mental needs are.

In this case, the purpose of getting to know the person is "to see what their mental needs are". Such a relationship can be defined as utilitarian because it is constructed with the specific goal of the discovery of a class of need. Whilst it is clearly legitimate for a nurse-patient relationship to contain a task-focused dimension, the text asserts that expressive relationships are also important. However, the expressive dimension is particularly at risk in the institutional pattern of care, where activity is driven by the need to get through the work.

The nature of both expressive and utilitarian relationships is informed by Buber's work. Buber (1958) writes that there are two primary ways in which one person can relate to another: "I-Thou", and "I-It". In the relationship of I-Thou, each person in the relationship is "open" to the other. The other is not regarded as an external object, or as a means to some end, but stands as an end in himself. As Macquarrie explains:

A true relation preserves the other in his otherness, and his uniqueness. It leaves room for him to be himself, so to speak. Unlike possessive affection on the one hand or mystical love on the other, the dialogical relation does not permit one side to be merged into the other. Buber is particularly insistent that we have respect for the other and try not to change him in accordance with our idea of what he ought to be. Still another idea is "confirmation". I am confirmed by the other, that is to say, I really become myself through the relation to the other. Here again is the insistence that there can be no "I" without a "Thou".

(Macquarrie 1972:110)

It is equally possible for relationship to take the form "I-It". When this occurs,

We relate to another person not in wholeness and in openness but turn him into a thing, an instrument. Extreme instances of this are slavery and prostitution. But it happens continually in a thousand more subtle ways, wherever there is exploitation or discrimination or prejudice, and persons are treated as less than personal.

(Macquarrie 1972:108)

Staff claimed that the pressure of work often restricted their interactions with patients

to the utilitarian type.

Sister L: I even have to cut conversations short because I know I haven't got the time to develop something a patient's trying to tell you, because you haven't got time to investigate or to dig a bit deeper and find out more about them.

and

Sister N: I've worked on many wards where you do the very basics for people, and there's no time to spend with people, no time to be interested in what they do, what's happening to them at home, how they feel, even to sit down and talk about the weather.

The following quotation suggests that pathology, as well as social structure, has its

impact on interpersonal relationships:

Sister L: Mrs J. is a classic case. She had a severe stroke and her relatives visit every day, and what do they do? They sit at the bottom of the bed and talk among themselves. I'm not saying they don't talk to her, but its very much a case of "What do we say to Mother now?" So they just tend to sit there and vegetate...

The final observation to be made about the institutional approach to the organisation of care is that it seems to be context dependent. The institutional roles, patterns of behaviour and relationships that have been described in this and previous chapters seem only able to flourish in a dedicated establishment such as a hospital or nursing home. In an unrecorded interview, Sister R., a district nurse, argued that the institutional practice of forcing patients was much less likely to happen to patients who were being nursed in their own homes. She acknowledged that patients might comply when the nurse was present, but would simply do as they chose when she left.

I argue that care that the institutional pattern of care is inimical to the quality of life. Classically, the institutional approach superimposes its own agenda upon that of the older person, suppressing self-determination and the expression of choice; it replaces ontologically significant material artefacts such as clothing and personal possession with functional alternatives; it reduces human relationship to a utilitarian minimum; and it replaces meaningful activity with idleness. In each of these ways, the institution undermines the status of the older person as a human being.

However, the text also suggests many ways in which staff sought to promote the quality of the lives of older people in their care. Because no word is readily at hand, the phrase "Being in the real world" is introduced from the text to characterise the activities, attitudes and orientation which together are important if care is to be conducive to a life of quality. The nursing home that promotes the older person's "Being in the real world" will not simply act as a warehouse, but will recognise that home is an important locus of personal meaning, and that it represents the "territorial core" of the social and geographical world.

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# Promoting the Quality of Life: Being in the Real World

Sister L: If you're going to be in hospital for a long time and you're not acutely ill, you don't need to be tied to that bed area, I think it's important to see about getting the patient out and seeing the real world.

At the heart of the "real world" approach to care is the intention to maintain and enhance an individuals capacity to function as a human being.

Note from an unrecorded interview: Sister Q felt that by the time patients had reached the age of most of hers they had built up a life and a social structure. This could soon be eroded by hospitalisation and would be difficult to rebuild. She felt that it was important to help patients to maintain contact with their life outside the hospital, as this would help them to continue life outside on discharge.

and:

Research assistant: Do you think continuity with normal life is important?

Sister M: Yes I do, but it's not always possible.

Research assistant: Why do you think its important?

Sister M: One thing is its this attitude thing again, so the patient realises there is something going on outside these four walls, relates to husband, children, grandchildren, all the rest of it. It does keep them in touch with the outside world if they can talk to visitors, see the news, read a newspaper, all these things.

Research assistant: Remain an individual, not just a patient?

Sister M: Yes, Mrs Smith with three tiny grandchildren.

Research assistant: As opposed to the lady with the stroke in the first bed on the left.

Sister M: Yes.

The phrase "the real world" also reflects the continuing interest that many older patients had in the world beyond the ward doors. This interest is made evident in a number of comments made at interview. For instance, Mr H and Mrs Z simply missed being able to get out and about. Mrs C kept an interest in the prices of food in shops, and professed herself "Absolutely staggered" at the news that the price of cheese was one pound fifty a pound. She added, "By hell, I can remember the days when you could get the best that was made for one and sixpence a pound". In a similar way, it was also evident that she enjoyed disparaging the modern music on the radio.

Central to "real world" care is the belief that one is most likely to enjoy a life of quality without the institutional setting.

Researcher:

If you could do one thing to improve the quality of the patient's

lives on this ward, what would it be?	
Sister K: don't think.	Um, I'd knock the four walls down, I wouldn't have the ward, I
Researcher:	Right. A bit drastic, I think?
Sister K:	I don't think I'd have the ward.
Researcher:	What would you have?
Sister K:	I'd have everybody I think at home.

Although the recommendation to "knock the four walls down" may be more rhetorical than realistic, the theme of homeliness persists throughout the text. Several of the caring staff echoed the feeling that a life of quality was most likely in the person's own home, and it was because their work enhanced this possibility that the staff from the day hospital felt that they made a significant contribution to the care of elderly people.

Sister N: It's not really a ward but a day hospital. I think a lot of what we do here to maintain quality of life is to maintain people in the community so that they can choose to go on living at home if that's what they choose to do, instead of being taken to an institution as such. So I think that's a really important part of how we maintain quality of life. And the same goes for, like carers. We have patients in for a day so carers can have a rest, and perhaps feel fresher and more able to meet their relatives needs when they go back home, so I think that's really important.

Of course, there are those for whom an independent life in the community is not possible, even with the support of the day hospital. In these cases, the text suggests that it is important to make the residence as "homely" as possible.

Notes from an unrecorded interview: Sister Y felt that to increase patient's quality of life in the long term it was necessary to make hospitals more homely.

Considerable attention was paid to the nature and importance of home in chapter four. It was shown that home is an important locus of meaning for many of the older people who were interviewed during the course of this research. It was argued that the quality of homeliness is an aspect of the phenomenon of attachment to place, which is itself a characteristic of our being-in-the-world. The discussion explored the following aspects of home: physical, social, and autobiographical insideness; home as a locus of autonomy; personal possessions; the continuity of living patterns; and privacy.

Whether the home is conceptualised as a territory to be defended, a locus of personal control, a zone of self expression, a reservoir of personal possessions, or as playing a part in the self-interpretive processes of human being, there is little doubt that for many people it is a place of great personal significance. If the value of an older person's home is at all dependent upon its particular geographical location, upon the social possibilities that it represents and the autobiography that it symbolises, then it is unrealistic to expect that it can easily be recreated in a nursing home. Nevertheless, there are certain principles that ought to be respected if the home is to reflect domestic rather that institutional ideals (Willcocks, Peace and Kellaher 1987).

The text contains evidence of attempts by the staff to address the various dimensions of homeliness. Particular attention is given to promoting interpersonal relationships, and meaningful activities, as shown in the next section. A subsequent section examines aspects of the literature that are related to this issue.

# **Promoting Interpersonal Relationships**

The text explores the quality of the relationship between the older person in care and their family and friends. Many of the older people interviewed felt that the role of the staff was restricted to the physical aspects of care, and clearly valued visits from family and friends, both for the continuing contact the provided with the real world, and for their own sake.

Research assistant: When they (your sisters) come and see you, what do you chat about?

*Mrs I:* Oh; all sorts of things, really, that have happened in the past, and things. And where they've been in the morning or afternoon, what they've bought, and one thing and another. Just little everyday things. So like, when you go home from work and you see your mother or your wife or what, well you have your tea and sit down and chat, and little everyday things, don't you? Well, that's what we chat about.

From the perspective of the nursing staff, Sister Q also suggested that the person's

quality of life can be enhanced if relatives are involved in care.

Research assistant: Do you think it improves a patient's quality of life to have relatives involved?

Sister Q: Yes, I'm sure it will do.

Research assistant: Why do you think that is?

Sister Q: Because they'll be getting more out of a one-to-one than I can give. With his wife here he's talking about his family, what's been happening, stuff that we don't know, stuff that we can't talk about. We can't go much

beyond the weather, what it's like, stuff like that. We might be able to say when she's coming, but we can't add any stuff like about what his son has been doing over the weekend, and other little bits.

The text discloses considerable variation in the amount of care that relatives are prepared or able to undertake, with some being able to make a substantial contribution whilst others are reluctant even to visit. Clearly, there may be many reasons for a person's reluctance to involve themselves in care. However, it has been argued that some of those who are able to make a contribution might be inhibited by institutional patterns of care (see above). Sister L was taking deliberate steps to resolve this problem:

Sister L: We've got the relative's action group under way now, and that has been brilliant. And so in many ways because the nurses are under pressure, not only on the ward, but also in trying to get some sort of stimulation, why not get the relatives a bit more involved? Things are already starting to look up. We're trying to devise a better service for relatives on the ward, so it will make them enjoy their visit, and probably encourage them to visit a bit more. So we're trying to improve facilities, like have an area where they can sit and take Mum or Dad out of the area of the bedside or the dayroom.

A number of benefits were attributed to the meetings of the action group. They included the following:

- Teaching relatives about the principles underlying care.
- Teaching the safe use of equipment such as wheel-chairs.
- Finding out what the relatives feel about the facilities of the ward, and standards of care.
- Understanding how to position people after a stroke.
- Identifying various grades of staff.
- Having talks about the roles of different members of the ward team.
- Enhancing the relatives' confidence.

Staff also attempted to promote interaction between older people themselves. Sometimes, formal discussion groups were set up to fulfil this purpose:

Sister L: The other morning we set up a talk theme about the 1930s, so we set it up and they all sat round , and afterwards, me and Nicky (another member of the nursing team) went in and talked about it. It only took fifteen minutes of nursing time afterwards to discuss how they all felt about it. Even the likes of (names a patient) was talking about a boy-friend she'd got. He was killed in the second world war. She started to fill up and got really upset.. It's a side to (names person again) that you don't see. I mean, because she's demented I sometimes think we treat her like a child.

Some staff also attended to the social aspect of mealtimes.

Sister Q: There are patients who need everything doing for them, feeding. There are others who can maybe use a spoon but perhaps one that might use a knife and fork. So we've got different degrees even among this, so we have the ones who feed themselves sat together, then the ones who maybe need help sat together, and that's to kind of promote something with the ones who are perhaps able to feed themselves, are more presentable, are able to chat with one another. Alright, so maybe they can't understand each other, but there is some communication going on there. On another table there are some who are quite active and fight, but there is some interaction there and I feel its important that that's happening. And as well, when they go sitting in the day-room, if they are not going to communicate you want them looking out so at least they can see you, or they might be sat next to somebody whose going to touch them, or what ever. So we try to do that.

## Promoting Meaningful Activity

Interviewed patients consistently complained that hospital life was boring. Mrs R. was unable to pursue her normal hobby of reading and spent a lot of time looking out of the window instead. Mrs BB complained that it was difficult to pass the time, and she too spent time looking out of the window. Similar complaints were made by Mrs I and Mr D.

In response to this problem, some members of the nursing staff described efforts that they made to stimulate and usefully occupy patients.

Sister L: What else do we try to do here? Certainly the activities we do in the afternoon, and try to stimulate any interests they've got. They do get very institutionalised.

Research assistant: Are they running now, the activities?

Sister L: We have got a set programme for Monday to Friday, and then at the weekends, because you don't have the pressure from the rest of the team, the activities are fitted more into what the patients want to do, and not into pigeon holes of what staff we've got and what time we've got, so it's a bit more individual on the weekends.

The next extract from the text identifies several important aspects of the organisation

of activity and is therefore reproduced at length.

Sister N: I suppose stimulation is quite an important part of what we do to maintain people's quality of life, you know... so instead of just sitting around and not really doing anything, we do try and stimulate people into making good use of their faculties that they've still got, to whatever level we can gear it towards. You know, people that are quite confused, it's still important for them to feel that they're achieving something, that they can still answer simple quiz questions.

Research assistant: I saw your quiz cards in the office.

Sister N: Yes, and to work to a higher level for people who aren't confused, just depressed you know, much more difficult things, but still helping them to feel they've achieved something, they've gone through a quiz and been able to answer some questions, they've made some item of craft or whatever, just an end product to say, "This is what I've done".

Research assistant: Yes, at the end of the day, to say, "I've done this".

Sister N: Yes.

Research Assistant: So what specifically do you do here then?

Sister N: Quite a lot of things, really, quite a wide range, because we do gear it to different levels of how people are, like people who are organically ill and people who are functionally ill, there's a very specific difference there, because people come (to the day hospital) on different days depending on which category they're coming into; so on the days its more organically ill people then its things like art work, very simple craft work, some reality orientation, but if someone said that to me I'd ask them what they meant, it covers such a wide spectrum of things... Just general stimulation about things that have gone by,

about the war, how they used to live, but also bringing it back into how they live today in comparison to how they lived in years gone by, and just simple word games like finishing proverbs, and things like that we do for the organically ill.

For the functionally ill we can do much more difficult craft work, some quite intricate sewing, and knitting things; things like collecting rose petals and making scented baskets, things that look really nice, and much more difficult quizzes. We've recently done a really good group on reminiscing about the war, and what people were doing when war was declared, you know, getting down to much more specific things rather than a general discussion.

Several observations can be made about this extract. The first is that the staff felt that activities were important both as a means of maintaining the abilities of elderly people, and as a way of giving a sense of satisfaction through accomplishment. Second, it is noted that efforts were made to tailor the activities to the needs and abilities of the client group, where possible by developing an interest that was already present. Third, there was a wide range of activities from those such as sewing, which demanded practical skills, to those like quizzes and reminiscence, where the emphasis was more on intellectual and social skills.

Finally, it is noted that activities were not always so formally organised as described above, but that they sometimes arose from the everyday interaction of staff and patients. Sister O described a nursing auxiliary who used to sing at the top of her voice and, encourage people to sing back to her. Sister O was of the opinion that spontaneous, everyday activities of this type should be included alongside a more carefully planned programme.

### The Effects of Moving into a Nursing Home

### Focus on the Literature

The consequences for an older person of moving to new accommodation are not easily predicted. A number of studies have focused on mortality rates following relocation. In their literature review, Guttman and Herbert (1976) found evidence that elderly people die at excessively high rates during the first year, and particularly during the first three months following relocation. This applied whether relocation involved movement from the community into a mental hospital, from the community into a residential home for elderly people, from one institution to another, or from one ward to another within the same institution. On the other hand, Coffman (1981) felt the two decades of research had only produced equivocal evidence as to whether relocation was likely to affect the survival of older people, and under what conditions. His meta-analysis of twenty six relocated groups found no general relocation effect, and no systematic effect of age, sex, mental and physical status, choice, preparation, environmental change, or mass versus individual transfer on post-move mortality. Coffman agrees with other researchers in this field that relocation is a significant event in the life of an older person, and conceptualises is in terms of Selye's theory of stress. Selye's observation that

The same stress which makes one person sick can be an invigorating experience for another

(Selye 1976:vii)

enables Coffman to explain that

There are some institutionalised persons whose lives are so unstressed that relocation pure and simple would be revitalising... there are some so nearly exhausted with stress that relocation... would kill.

### (Coffman 1981:495)

Carp (1966) also comments that the outcome of relocation may be anything from total disorganisation and destruction of adaptive capacity to an increased sense of mastery and an improvement in adaptive resources.

The idea that the impact of the stress of relocation will be mediated by its meaning is supported by the text. There is evidence that for some older people, the move to a nursing home will represent an increased sense of personal safety and confidence, whilst for others, it represents a disastrous loss of independence. In the management of a nursing home, it would therefore seem logical to tailor the admission procedure to the individual needs of the older person. In the next section, therefore, some of the issues relating to relocation to nursing homes will be discussed with a view to the development of standards of practice. The discussion will involve the period preceding the transfer, aspects of the move itself, the continuity of living patterns, the importance of personal possessions, and privacy.

### The Period of Preparation for the Move

Rutman and Freedman (1988) found that the meaning of home to people who are in the midst of the relocation process had never been examined, and therefore took this as their research question. The study was conducted in Toronto, and the sample was constituted by sixty three older people who had applied for rent subsidised apartments. The Philadelphia Geriatric Center Multilevel Assessment Instrument was used to assess a range of psychosocial and other variables, and open ended questionnaires were used to explore the meaning of the present home and attitudes to relocation. Each instrument was administered at the time of application for a new apartment and again twelve months later. On the second occasion, approximately one half of the applicants had been relocated while the other half had not. It was therefore possible to make comparisons between the two groups.

The finding of the study that is of particular interest here relates to perceptions of choice and control. It was found that respondents who were still on the waiting list after one year showed no decline in the variables measured by the PGC Multilevel Instrument, whilst those who had already completed the move increased their scores on measures of morale, overall psychological adjustment, overall social interaction, mobility, housing, neighbourhood

and overall environmental satisfaction. The researchers comment that whereas the traditional literature on the impact of relocation has tended to highlight health and psychological decrements as a function of moving, their own data suggest that the process of moving need not result in declining well-being and performance. They partially attribute their own findings to the fact that eighty two percent of the respondents perceived that they had a degree of control over the relocation process. However, the recency of the move for the relocated group is unreported, and it is possible that their optimistic responses constitute a cognitive restructuring of their situation. Another difficulty with this study is that the respondents involved were relocating to non-institutional accommodation. Nevertheless, the work of Rutman and Freedman offers a degree of empirical support to the ethically based belief that older people should both have and believe themselves to have control over the process of relocation to nursing home accommodation, and this should be reflected in nursing home policy and practice.

The Process of Moving to a Nursing Home

Porteous (1976) paints a grim picture of the process of admission to a nursing home:

The transfer of an individual from "felt home" to "euphemistic home" is usually traumatic... Trauma is induced not only through the sense of loss of home but also because of the quality of life in institutions. In contrast with the homes their occupants have left, euphemistic homes lack warmth and privacy.

### (Porteous 1976:388)

It is difficult to know the extent to which this statement is descriptive of reality because there is little British research into the process of admission into nursing homes. Standards for care must therefore be elaborated from theoretical principles and supported by generalisation from studies that are tangentially relevant. The contribution of Shulz and Brenner (1977) to the literature of relocation is theoretical rather than empirical. They examined the literature relating to moves from institution to institution, and home to home, and then proposed that an individual's response to the stress of relocation is largely determined by the perceived predictability and controllability of the events surrounding the move, and differences in controllability between pre- and post-relocation environments.

Gutmann and Herbert (1976) examined the impact of relocation on eighty one male extended care patients who were moved from an old hospital building due for demolition to a new site. They found that with the careful preparation of patients, relatives and staff, the mortality rate of their sample was significantly lower than might have been expected.

It is therefore suggested that older people who are preparing for admission to nursing home accommodation should be given information about the events surrounding the move, and should also have the opportunity to influence these events through the exercise of choice.

### Continuity of Living Patterns

In Gutmann and Herbert's study, care was taken to limit the disruption of the pattern of everyday living following the relocation exercise. This finding can logically be applied to the nursing home setting in so far as patterns of living are a function of choice, because it has been shown that home is a locus of autonomy. One would therefore expect a nursing home to possess mechanisms through which the continuity of living patterns could be assured.

### The Importance of Personal Possessions

It has been argued that the objects which the home contains and by which it is in some degree constituted play an important role in the interpretive process of human being. It follows that the loss of personal possessions can be one of the most significant aspects of moving into institutional care, and several writers make this point. Carp, for instance, comments that

The surrender of furniture and other possessions was very important not only because the objects were missed, but as items in themselves and as reminders of the family events associated with them, but also because their absence and the substitution of cheaper and less distinguished furnishings was a continual reminder of loss of status.

#### (Carp 1966:89)

Frankl (1955) has commented that when all of a person's possessions are taken away, the person has nothing with which to form an external link with his former life, and Goffman (1961) has pointed out that in total institutions, the loss of personal possessions prevents the individual from presenting his usual image of himself to others.

Kalymun (1983) found that although older people were prepared to reduce the amount of their belongings when relocating, bringing part of their former lives with them in the form of personal objects helped them to feel emotionally whole. Schmitt, Redondo and Wapner (1989) found more significant and optimal functioning in elderly people who took transitional objects from their old homes into nursing homes, and Altman (1975) noted that people in hospital are comforted by having personal objects about them which serve as reminders of home. This evidence suggests that encouraging individuals to retain personal possessions when moving into an institutional setting will increase the likelihood of a positive outcome.

It is as if possessions permit a healthy degree of personal control or competence in a relatively uncontrollable environment and thereby foster positive attitudes and adaptive behaviour.

(Furby 1978:324)

### The Importance of Privacy

Control of access to the home environment is made possible through the definition and defence of territorial boundaries. Respect for these boundaries reflects the function of the home as a zone of personal autonomy. There is evidence that access to private dwelling space is the typical expectation of older people in Britain today. Wilcocks, Peace and Kellaher (1987) observe that the majority of the very old (eighty plus) live in their own houses in the community, and one half of these live alone. Only two percent of those aged eighty to eighty four, and five percent of those aged over eighty five have non-relatives in their households. The policies and practices of the nursing home should therefore demonstrate respect for privacy.

### Conclusion

This chapter has described two types of approach to the management of care in nursing homes: the institutional, which undermines the quality of life, and an alternative approach that will tend to promote it. In the next chapter, some of the implications for practice of the latter approach are specified in more detail, as practice standards are developed.

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#### **CHAPTER 7**

## **DEVELOPING STANDARDS FOR PRACTICE**

### Introduction

In this chapter, the implications of the theoretical work that has gone before are related to the contingencies of nursing practice. This is necessary because nursing is a practice profession (Dickoff, James and Wiedenbach 1968) whose clinical focus provides the ultimate justification for research and scholarly work.

In principle, the concept of the quality of life as quality of being might relate to practice in a number of different ways. It might for instance provide a perspective from which to evaluate the likely impact of policy changes; suggest new directions for practice development; provide an organising framework for education; or prompt new research questions. I have chosen to illustrate the professional relevance of the concept by developing and stating a series of normative standards for practice. The chapter contains a brief discussion of the nature of practice standards. This is followed by a description of the method by which the standards were developed. Finally, a series of specimen standards is given in order to illustrate the general approach. The chapter begins, however, by discussing the need to address standards of care in nursing homes, and by examining any tensions that might exist between the hermeneutical foundations of this study and the standards that are presented below.

The United Kingdom Central Council for Nursing, Midwifery and Health Visiting has recently published an occasional report which summarises the important issues arising from cases heard by the Professional Conduct Committee, concerning the conduct of practitioners, and standards of care in the nursing home sector (UKCC 1994). Statistics collated by the UKCC and presented in this report show that professional misconduct cases in nursing homes constitute the largest single cause of complaint to the Council, being almost

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100% greater than any other area of practice. Aspects of misconduct discussed in this report include physical abuse, administering excess doses of tranquillisers, administration of unprescribed medications, leaving residents in soiled beds, verbally abusing residents, and failing to promote the dignity of residents.

Two of the report's recommendations are of particular significance here: that owners and matrons should develop a system for quality assurance which systematically evaluates the standards of care delivered to residents; and that matrons should ensure that staff are supervised and supported in respect of the key elements of nursing care so that high standards of care might be delivered.

The findings of the UKCC reflect earlier work by Harman and Harman (1989), who reported the first ninety-six cases of the Registered Homes Tribunal. Although the findings do not directly relate to nursing homes, they show the vulnerability of older people in institutional settings.

Many of the cases are simply shocking. There are cases of neglect and callousness bordering sometimes on cruelty. Residents have been verbally punished, bound in chairs, forced to hand over DHSS benefits under duress, left unattended for lengthy periods on commodes, and allowed to fall downstairs in circumstances far from satisfactory.

### (Harman and Harman 1989:68)

These reports show that standards of care are a most important issue in both the registered home and nursing home sectors. The findings of the research that are reported in this thesis ought in principle to inform professional practice in nursing homes. The problem is, however, that nursing research is generally remarkable for its lack of impact on nursing practice (Tierney 1991). A number of explanations have been advanced for this phenomenon. Hunt (1984) suggests that some of the reasons could be regarded as deficiencies in nurses themselves: for example, their lack of knowledge of research and their

disinclination to believe the findings. Other reasons identified include lack of encouragement and incentive for nurses to apply the findings of research to their practice; and Greenwood (1984) has suggested that

Clinical nurses do not perceive research findings as relevant to their practice because frequently they are not relevant.

(Greenwood 1984)

This dissertation has many of the classical characteristics of research that will not influence practice: its presentation as a PhD thesis will reduce its accessibility to clinical nurses, it is highly theoretical in nature, and its implications for practice are not readily apparent. The standards presented later in this chapter are an attempt to resolve this difficulty by relating the research to nursing practice.

Although there is clearly a need to address standards of care in nursing homes, and despite the fact that research is often not related to practice, a critic might still argue that the development of practice standards is inappropriate in a thesis that is grounded in philosophical hermeneutics and has rejected the view of the quality of life as a social fact. The critic might repeat Sutcliffe and Holmes' (1991) argument that no individual can or should make judgements about the quality of the life of another person, and might condemn the standards presented below for being based on one person's interpretation of interviews with a small number of older people and their professional carers.

The hermeneutical foundations of this study enable these criticisms to be refuted. The hermeneutical emphasis on the social, historical and contextual nature of knowledge and understanding is reflected throughout the present study in the assumption that the quality of life cannot be reduced to a list of a-historical features that can be isolated, described, measured and manipulated. It should therefore be understood that the standards are not intended as a formula, or as a "cause" whose "effect" would be the automatic restitution of the quality of life of some older people, as this view would contradict the entire thrust of this dissertation.

Hermeneutics' emphasis on the social nature of knowledge also rejects the radically subjective view, bordering on solipsism, that regards the quality of life as a completely private and idiosyncratic affair. The hermeneutical approach rejects the Cartesian view of the person as a private, disconnected subject standing apart from an objective world, and assumes that common language, habits, skills, practices, situations, meanings and embodiment make it possible to understand others as participants and members of a common humanity, language, and culture group. Hermeneutics' emphasis on the social nature of knowledge and practice is illustrated in the degree of professional consensus that constitutes an acceptable standard of professional nursing care, and what constitutes cruelty. The standards presented below represent an attempt to capture and portray this consensus.

It is accepted that care must be taken when extrapolating the findings of a qualitative project that incorporates the views of a particular group of people, expressed at a specific time and place. However, the standards also incorporate the findings of a substantial body of empirical literature, and are firmly grounded in a philosophical tradition.

### The Nature of Standards

The World Health Organisation defines a standard as an explicit statement of conditions to be fulfilled in qualification of a stated objective or policy (World Health Organisation 1982). This definition coincides with one taken from the Oxford English Dictionary:

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Standard: a definitive level of excellence, attainment, wealth or the like, or a definitive degree of any quality, viewed as a prescribed object of endeavour or as the measure of what is adequate for some purpose.

(Oxford English Dictionary 1989)

Three characteristics of nursing practice standards are noted. First, standards can specify the implications of theoretical knowledge for nursing practice. Second, standards have a normative function: they suggest what ought to be done in the practice setting. Third, standards have a role to play in the evaluation of care, for the word "standard" sometimes refers to an exemplar that embodies the defining characteristics of an object, against which other objects can be assessed.

The development of the standards presented in this chapter has been informed by the work of Donabedian (1966), who found it useful to evaluate the quality of medical care in terms of structure, process and outcome. Structural attributes are the characteristics of the setting or the conditions under which nursing care is delivered (Hagen 1976). They include the physical characteristics of the patient environment, the material and human resources available, the mode of care organisation, and the attitudes and perceptions of staff (Attree 1993).

Process relates to nursing intervention: to what the nurse does to and with the patient. Valentine (1989) proposes that evaluations of the process of nursing provide a useful predictor of its quality. This assumption is embedded in formal quality assessment tools such as QALPACS (Wandelt and Ager 1974), and Monitor (Goldstone, Ball and Collier 1983).

Donabedian (1966) argues that measurements of the outcome of care will be the answer to the question "what good, if any, are we doing ?" Classically, outcomes have been defined in terms of the "5 D's" of death, disease, disability, discomfort and dissatisfaction (Lohr 1988). Shaw (1987) claims that measures of outcome are of limited usefulness because of the difficulty of establishing a causal link between process and outcome. Despite this difficulty, desired outcomes are often included in nursing standards (Kitson 1989). Their use in this research is justified by the weight of evidence that nursing actions have a clear impact on the quality of the lives of older people in nursing home and other forms of long stay accommodation.

The standards described below are validated by the research that is described in the earlier chapters of the thesis. The process of converting general recommendations for practice into normative standards was as follows. First, ten issues were listed that were shown by the research to be associated with the quality of life.

- 1. Activities, including the activities of daily living.
- 2. Choice and control.
- 3. Clothing.
- 4. Contact with the real world
- 5. Information.
- 6. Patterns of activity.
- 7. Personal possessions.
- 8. Place.
- 9. Privacy.
- 10. Relationships

A matrix was then developed in order to explore the relationships between these factors in a systematic way.

0	1	2	3	4	5	6	7	8	9	10
1	-		-	-		-	_	-	-	-
2		-	-	-	-	_	-	-	-	-
3			-	-	-	-	-	-	-	-
4				_	-	-	-	-	-	-
5					-	-	_	-	-	-
6		А				-	-	_	-	-
7							-	-	_	-
8								-	-	_
9									_	-
10										-

Table 5.A matrix relating various factors

Each cell in the matrix relates two different factors. For instance, the cell marked "A" relates factors six (patterns of activity) and two (choice and control). The matrix was used to generate ideas which might form the basis of standards. The resulting "proto-standards" are listed in appendix four at the end of the dissertation.

The next stage was to develop and state a number of formal standards. Clearly, it would never be possible to give a complete or final list of standards for practice in the area of nursing home care. I have therefore chosen to give a limited list of standards that relate choice and control to various other factors, in order to illustrate the general approach and to indicate the form that standards take. The standards are presented in the structure - process - outcome format, as described by Kitson (1989).

# **RELATING FACTOR TWO:** Activities of daily living: (Dressing).

	PROCESS	OUTCOME
The policy of the home requires clothes to be labelled with their owner's name. Each resident's clothes are stored separately in their own wardrobe / drawers / storage area. The policy of the home permits the person to participate in the care of clothing, including mending and ironing.	Clothes are labelled with their owner's name on or before the date at which the person becomes resident in the home. When dressing, the dependent person is invited to make a choice from a selection of their clothes.	Residents wear their own clothing. Items of clothing are not shared between residents. Wherever possible, <i>residents</i> choose items of clothing to wear from their wardrobe. The person who wishes to participate in the care of their clothing is able to do so.

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# **RELATING FACTOR TWO:** Activities of daily living (mealtimes).

STRUCTURE	PROCESS	OUTCOME
The policy of the home is that residents may choose where to eat their meals. Tables and chairs of corresponding height are available for those who wish to take their meals away from the main dining area.	Preferences are established when the person first becomes resident, and are checked before meals.	The person chooses where to eat their meal.
A menu system is in operation in the home. Special diets are available for those who need them.	The person is informed of the range of dishes that is available at mealtimes. Where the person is unable to communicate, the staff make every effort to establish preferences by speaking to relatives and friends. Staff make every effort to assist the person make a selection from the choice available, and are careful not to choose on their behalf.	At meal times, the person chooses from a range of available dishes. The person controls the quantity of food that is set before them.
In order to maximise the intake of food by residents, the policy of the home is that snacks are available between meals. A supply of fruit, crisps, chocolates etc. is available to residents.	Staff offer snacks to the residents between meals.	The person is able to eat snacks between meals.

# RELATING FACTOR TWO: Activities of daily living: (bathing and toileting).

STRUCTURE	PROCESS	OUTCOME
It is the policy of the home that privacy and dignity are maintained whilst washing and toileting.	Staff knock on the door and wait to receive permission before entering a bathroom or toilet that is in use by a resident. Routine rectal examinations to discover cases of constipation are not performed. Residents are always decently dressed when other residents, visitors, and staff not immediately involved in care are present.	The person's privacy and dignity are maintained whilst bathing and toileting.
A variety of bath-types, showers, and wash basins is available in the home. Tuition is available in safe bathing techniques. There is an emergency call system.	Staff establish preferences for bathing and washing when the person enters the home, and regularly thereafter.	The person chooses the mode and frequency of bathing and washing.
It is the policy of the home to maintain and promote independent washing, and bathing and toileting. Grab rails and other safety features are available in the bathroom and toilet in order to promote independent use by residents. Bathroom and toilet doors are labelled for ease of identification.	Except in the case of therapeutic training programmes for continence, visits to the toilet are made at the instigation of the person, not in response to a staff- led routine.	The person washes, bathes and uses the toilet without assistance whenever possible.

## **RELATING FACTOR TWO: Place.**

STRUCTURE	PROCESS	OUTCOME
The home is well lit. Rooms are marked according to their function.	The person is shown around the home on admission.	The person is familiar with the layout of the home.
There is a policy of free access to all public areas of the home. Walking aids are available to those who need them.	A physiotherapy service is available to assess the need for and prescribe walking aids. Support from staff is available for the person whose mobility is restricted. Methods of restraint (verbal, chemical or physical) are not used.	The person has free access to all public areas of the home. The person has access to the grounds of the home.
The policy of the home specifies that people may bring personal possessions into the home, and that they will be consulted about the placement of decoration and the placement of furniture.	People are asked for their opinions about the placement of furniture, and the decoration of rooms. People are informed that they may bring valued personal possessions into the home	The person influences the placement of furniture within their room. The person influences the style of decoration of their room. The person introduces personal possessions into the home.

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# **RELATING FACTOR TWO:** Contact with the real world.

STRUCTURE	PROCESS	OUTCOME
The policy of the home is that family and friends may visit at a time of the resident's choosing. Writing equipment and stamps are available. A telephone is available for the use of residents.	Staff will assist with letter writing. Staff will read letters to those who require assistance. Residents can offer a drink and light meal to visitors who call.	The person maintains contact with friends and family.
The policy of the home is to encourage residents to maintain registration with their own general practitioner and dentist	Staff will help the person to contact their general practitioner or dentist. Staff will arrange transport and an escort if the person wishes to visit their own general practitioner or dentist.	The person maintains registration with their own General Practitioner and Dentist. The person contacts their own general practitioner and dentist when requiring treatment
The policy of the home is that residents who wish to will maintain their interest in current affairs. Televisions and radio sets are available in the home.	A range of newspapers is delivered to the home. Residents can select television and radio stations, and the staff will change channel if requested. Opportunities exist to discuss current affairs.	The interested person is informed about the news and current affairs.

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# **RELATING FACTOR TWO:** Activities (recreational).

STRUCTURE	PROCESS	OUTCOME
A range of recreational activities is available within the home.	Residents are asked about preferred recreational activities before entering the home.	The resident is able to participate in a range of recreational activities.
Transport and escorts can be arranged for those who wish to participate in activities outside the home.	Forthcoming activities are publicised in advance.	Family and friends participate in social and recreational events.
A programme of supervised exercise is available for those who wish to participate		

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# **RELATING FACTOR TWO:** Personal possessions.

STRUCTURE	PROCESS	OUTCOME
The policy of the home is that people may keep valued personal possession, including items of furniture, and artefacts of various sorts.	People are informed of the policy before admission to the home, and are encouraged to bring cherished possessions with them.	The person has valued personal possessions with them in the home.

### CHAPTER 8

## **EVALUATION AND RECOMMENDATIONS FOR FURTHER RESEARCH**

This final chapter offers a critical evaluation of the research. It discusses the usefulness of hermeneutics as an organising framework, identifies the limitations of the study, and makes recommendations for further research.

## The Value of Hermeneutics as an Organising Framework

Philosophical hermeneutics has provided an effective organising framework for the study. It has offered a critical perspective on the social scientific literature of the quality of life, informed the methodological decisions that were taken during the study, and influenced the findings.

## Hermeneutics as a Critical Perspective

It was shown in chapter one of the dissertation that Heidegger is responsible for important developments within the theory of philosophical hermeneutics. These developments include his critique of the Cartesian tradition with its associated dichotomies of mind versus body, subject versus object, and fact versus value (Cooper 1991); and his description of three non-cognitive preconditions which constitute the "fore-structure" of understanding.

Heidegger's critique of the Cartesian tradition offers a powerful tool with which to examine the social scientific literature of the quality of life, because many of the features of this literature (such as the subjective - objective debate) indicate an underlying Cartesianism. The hermeneutical approach reveals that the subjective - objective debate is not just a methodological dispute, but one that also reflects ontological assumptions.

Philosophical hermeneutics also supports the argument that the validity of claims to measure the quality of life cannot be detached from the contexts in which those measurements are made. Social indicators of the quality of life arise in the context of a debate about the impact of economic policy; medical outcomes research is conducted by practitioners who are committed to the therapeutic interventions whose effects they are trying to measure; and the idea of the Quality Adjusted Life Year arises in the context of a highly political debate about the allocation of financial resources within the health service. In each case, the context directly influences the ways in which the quality of life is defined, operationalised and measured.

These arguments were explored in depth in chapter two and will not be repeated here. However, philosophical hermeneutics also influenced methodological decisions that were taken during the empirical phase of the study. The implications and consequences of these decisions will now be discussed.

### Hermeneutics and Method

Inevitably, the researcher who undertakes a project with an empirical element takes methodological decisions. In the present case, these decisions were influenced by the study's hermeneutical orientation. As we have seen, however, the philosophical hermeneutics of Heidegger and Gadamer does not constitute a method in itself, although it does have methodological implications. The next section of the discussion evaluates these decisions by comparing the results with those that might have been obtained if the alternative research strategy of "grounded theory" had been employed.

The most fundamental methodological decision that the researcher takes does not involve practical issues such as sampling or data collection, but concerns the theoretical or philosophical orientation that he or she adopts. My decision to employ philosophical hermeneutics as an organising framework was not made at the beginning of the research process, but gradually evolved as background reading tended to convince me that the meaning of the quality of life is a conceptual problem that cannot be solved through the rigorous application of statistical techniques. As I moved towards the qualitative end of the methodological spectrum, I considered using the "grounded theory" approach of Glaser and Strauss (1967). Grounded theory is the popular name for a cluster of techniques that is associated with the sociological school of symbolic interactionism. Its authors recommend it as an approach to the development of new sociological theory.

The grounded theory approach is typified by concurrent data collection, analysis and sampling. The first sampling decisions are dictated by the research question and the field of study. Data are commonly collected by field observation and interviewing, and are then sorted into descriptive categories. The analytical process consists of comparing the content of categories and exploring the relationships between them. New theoretical structures are said to "emerge" during this process. Subsequent sampling decisions and data collection are controlled by this emerging theory.

I eventually rejected the grounded theory approach in favour of hermeneutics because the latter provided a critical perspective on the literature and also promised to inform the content of the research. However, there are sufficient similarities between grounded theory and the approach that I have taken for it to act as a comparator against which the methodological decisions that were taken.during this research can be evaluated.

### Sampling and Data Collection

The sample consisted of various categories of staff and patients from a range of different hospital facilities. This sample was selected because I did not wish to prematurely exclude any group that might reasonable claim an interest in the quality of life of older people in hospital care. The initial sampling frame was appropriate because all of the groups within it contributed useful data.

Preliminary analysis of the data produced a large number of analytical categories, listed as appendix C. One feature of the approach taken is that, whilst some of the analytical categories are instantiated throughout the data, others are only supported by relatively sparse references. This does not necessarily represent a problem, because the conceptual importance of a category is not always proportional to the frequency of its appearance. Although it would have been possible to further develop the properties of central categories by undertaking a second phase of data collection using a procedure akin to theoretical sampling, this would probably have entailed the premature deletion of certain categories from the category list.

This prompts a critical reflection on Glaser and Strauss's technique of theoretical sampling. The suggestion that emergent theory should dictate sampling decisions and secondary data collection assumes that it is possible to identify the emergent theory at an early point in the analytical process, whilst the researcher is still in the field and fresh data are there to be collected. In my case, the analytical process took a long time, as I was only able to identify some of the analytical categories after a lengthy period of reading and reflective thought. This problem was undoubtedly exacerbated by the part-time nature of the project. Premature decisions about the respective importance of analytical categories might have led me to discount valuable data.

The final observation to be made in this section concerns the relative values of interview data from different sources, and the fact that in the discussion, quotations from professionals are cited more frequently than those from elderly people. This difference can partially be attributed to the greater familiarity of most staff members with the role of interviewee. However, it should also be noted that staff and elderly people approached the

topic of the quality of life from different perspectives. Whilst staff members were familiar with the organisation of care, elderly people had experience of lives disrupted by admission to hospital and residence in an institutional setting. Consequently data from older people are often of considerable conceptual significance, whilst data from staff tend to be of greater practical significance.

Analysis

There are significant differences between the hermeneutical approach to analysis and grounded theory. The first difference concerns the role of the researcher in the analytical process. In a popular textbook on nursing research, Benton suggests that

The grounded theory method is ideally suited to the investigation of those topics about which there is little prior knowledge. The method... requires that you approach data collection without a preconceived framework. Without an open mind, there is a danger that significant material will be ignored since data are not seen as fitting the existing model.

(Benton 1991:129)

The tradition of philosophical hermeneutics reveals the futility of arguing that it is possible to collect or to analyse data with an "open mind". Indeed, Heidegger's analysis of the fore-structure of understanding, and Gadamer's discussion of the role of prejudice, demonstrates that understanding necessarily requires a "preconceived framework" of some kind.

I also argue that Benton is too hasty to dismiss the role that existing theory can play in the analytical process. Although it is clearly inappropriate to attempt to force round pegs of data into square theoretical holes, experience suggests that at times, existing theory can sensitise the researcher to important aspects of the text, and provide a useful organising structure for its analysis. The final comment concerns Glaser and Strauss's suggestion that theory emerges from the data during analysis. The notion of emergence credits the text with a degree of autonomy that it does not possess. It suggests that theory is in some sense embedded in the data and waiting to be uncovered, and runs contrary to the hermeneutical view that meaning is not simply a characteristic of the data, but an outcome of the fusion of the horizons of the text and its interpreter.

#### The Effect of Early Decisions Upon the Shape of the Study

Decisions taken at an early point in the research process influenced the final shape of the study by committing the research to a certain direction whilst simultaneously closing off other options. This section describes these decisions, and tentatively suggests what other options might have been taken.

It is useful to consider the research in terms of the hermeneutical circle. It was shown above that the hermeneutical circle describes the interdependent relationship between a whole and its constituent parts. The structure of a sentence provides a useful illustration. As Palmer (1969) comments, we understand the meaning of an individual word by seeing it in the context that is provided by the whole sentence, whilst the meaning of the sentence is dependent upon the meanings of the individual words that it contains. Palmer acknowledges that the concept of the hermeneutical circle appears to involve a logical contradiction. If we cannot understand the parts until we have a sense of the whole, and if our understanding of the whole is dependent upon our prior understanding of the parts, then it is difficult to see how understanding can ever get of the ground.

Palmer suggests that this problem is eventually resolved as the whole and the parts come simultaneously into view as one takes a kind of "leap" into the centre of the hermeneutical circle. It is also the case that understanding has a "fore-structure" which enables us to anticipate the eventual meaning to some extent.

In retrospect, it can be seen that the thesis presents a specific case of the hermeneutical circle. The research contains a number of interlocking parts. The most important of these are the empirical data, the philosophical literature of the hermeneutical tradition, and the empirical literature of a number of social scientific disciplines. Each of these parts contributes to the meaning of the whole, whilst the whole provides an overarching context which gives relevance to the individual parts.

At the beginning of the research process, the situation was rather different. I had no idea of the ultimate shape of the whole, and although I knew that I was likely to find some of the parts in "the literature" and others through empirical work, I had little idea of what those parts might look like or how they might eventually fit together. In short, the whole and many of the parts were completely hidden from view.

My first step in conducting this research was therefore to look for a focus for my understanding of the quality of life. This focus was not readily apparent in the literature, and so I sought it through the collection and analysis of data. The first decisions that I took in the empirical phase of the study concerned the composition of the sample and the mode of data collection. The consequence of these decisions was that the research addressed some issues at depth, whilst simultaneously excluding others. During my discussion of Heidegger's contribution to philosophical hermeneutics I argued that the human being is constantly faced by a range of possible courses of action: by a "space of possibilities" that closes off certain courses of action whilst maintaining others as "live options". This is as true of the researcher as it is of others.

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Some of the consequences of these practical decisions can now be described. The sample consisted of older people who were undergoing care in a range of hospital settings, and various members of the staff of those hospitals. Although the decision to retain the data when the research question was changed has been justified above (see page eight), it remains the case that there may be differences between the experiences of life in a hospital ward and in a nursing home. These differences would be reflected in the data. It is likely, for instance, that a greater proportion of nursing home residents have actively chosen to move into a home and are paying a fee to stay there. At interview, it is possible that such people would be more inclined to emphasise the benefits of nursing home accommodation such as an enhanced sense of safety, rather than negative consequences such the loss of autonomy that was reported by the informants of this study.

My decision to collect data through individual interviews has also had an impact on the shape of the study. It has tended to focus the research on the experience of the individual, whilst neglecting the communal aspects of life in a nursing home. The balance between the needs of the individual and the group would make an interesting topic for further study.

### External Validity

The question of external validity can be applied to the research at different levels. At a general level, my discussion of the quality of life as the quality of being has drawn upon Heidegger's analyses of being-in-the-world, interpretation, existence, and authenticity. The validity of the general principle of the quality of life as the quality of being is therefore supported by the hermeneutical tradition within which these ideas are expressed, and it can therefore be applied with some confidence to other groups. These general ideas have then been related specifically to the care of older people in institutional care. Being-in-the-world and interpretation have informed a discussion of the importance of places and personal possessions; and the ideas of existence and authenticity have supported a discussion of individualism. At this more specific level, the findings are closely related to the experiences of my informants, and must be applied to other groups with circumspection. Having said that, it is probably still reasonable to generalise beyond the informants to the general population of older people in institutional care, because the findings are also supported by a substantial body of literature from other empirical studies.

In summary, if an attempt was made to relate the quality of life as the quality of being to a different client group, such as young people with a mental handicap, one could expect the general principles to still apply. The members of this group would still have their "being-in-the-world": physical objects would be valued not only for their function but for their meaning, although the range of those meanings would probably differ from those expressed by older people. Equally, it would be found that their being had an interpretive dimension, although the interpretive possibilities available to the members of this group would once again differ from those available to older people in institutional care.

### An Assessment of the Limitations of the Study

The thesis closes with an assessment of the limitations of the research, and makes recommendations for further work. The word "limitation" is interpreted to mean "boundary". Consequently, this section assesses both the strengths and weaknesses of the research.

One of the strengths of the thesis is its critique of the literature of the quality of life. Although there is a huge body of published literature relating to the concept the quality of life, it is rare for an attempt to be made to summarise and criticise its major characteristics. Chapter two recognised the literature's preoccupation with the issue of measurement, the consistency of the belief that the quality of life is a social fact, and the persistence of the subjective-objective dichotomy. Each of these features was taken as symptomatic of underlying Cartesian assumptions, and an alternative approach, which reflects hermeneutical insights and is congruent with the eudaemonistic tradition, was described.

Another of the strengths of the dissertation is its extensive discussion of the implications of philosophical hermeneutics for the conduct and analysis of qualitative interviews. This section provides a useful bridge between the theoretical literature of Hekman (1984, 1986), Thompson (1990) and others who discuss the principles of hermeneutical research, and the methodological literature of qualitative analysis.

Finally, the research is unusual in that it relates the findings to clinical practice. Although the standards that are presented in this section are unremarkable in themselves, they are valuable because they are grounded in and justified by a coherent philosophical approach.

If an assessment of the limitations of this study were to be based on the normal standards of positivist research, it would identify as problematic the small sample size, that the sample is unrepresentative in a statistical sense, and that the study lacks objectivity because it displays the influence of the researchers perspective. However, these criticisms are inappropriate in a hermeneutically grounded study that has criticised the basic assumptions of positivism. For the sake of completeness and clarity, certain limiting features of the study are identified in the following list. Some of the items on this list are the inevitable consequence of the hermeneutical foundations of the research, whilst others can be attributed to the researcher.

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- The standards do not represent a list of universally valid, a-historical principles which will ensure the quality of life.
- The researcher has both criticised and assumed the continuing existence of the institutional pattern of care.
- The study does not give a complete or exhaustive account of the features of the quality of life as the quality of being.
- The analytical procedures have been described in a rather tentative way.
- The research is non-reproducible.
- Although I have extensively justified the inclusion of a programme of social research in this study, and demonstrated that this research is congruent with an established and growing tradition in which many disciplines participate, I recognise that some scholars within the field of hermeneutics may find this approach anomalous.

### **Recommendations for Further Research**

Four ideas for further research are given. First, it would be useful to develop more practice standards of the kind that are described in chapter seven. These could then be validated through application in the practice setting.

Second, it would be possible to take some of the ideas that are presented in chapters four and five and develop them in more detail. For instance, chapter four discussed the meanings that personal possessions have for older people. This approach is different from that taken in the nursing literature, which tends to discuss the environment in a scientific way. Research which focused on the meanings of personal possessions for older people, and for other nursing client groups, would therefore be a valuable addition to the literature.

Third, it would be useful to focus on aspects of being that are discussed by Heidegger but have not featured in this research. Death is one such case. It would be valuable to discover how older people in nursing home care are affected by the deaths of their coresidents, and to contrast this with the effect of the death of a friend upon those who live in their own homes.

Fourth, it would be possible to compare the findings of the present research with those of a study to explore the quality of the lives of a different client group from the perspective of the quality of being.

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## APPENDIX A

## TRANSCRIPTION OF THE INTERVIEW WITH SISTER K

Researcher: So ...the topic is the quality of life. Can you tell me what that phrase means to you? In connection with elderly people? There is no such thing as a wrong answer.

Sister K: Erm....I think its really individual, isn't it?

Researcher: Right

Sister K: My quality of life.... what's important to me.... its different to what's important to you. So I think its really an individual thing, and I don't think I can describe it really. I can describe what it means to me.

Researcher: Right.

Sister K: But not what it means to an elderly person really.

Researcher: So you thing that there are different things for every person as far as quality of life is concerned?

Sister K: Yes. Some people are happy at home, in appalling circumstances. Perhaps in a back to back house with no heating, in dirty surroundings and they're happy. That's their life, and they're happy with that life. Myself, for my quality of life, its being independent and having a job and a career and what have you

Researcher: Hmmmm....

Sister K: That's what's important for me, but its not necessarily important for anybody else. Its like somebody surviving in the community just managing and people saying they're at risk. But if they're happy and they're coping, and they feel that they've got a useful valuable life

Researcher: Yes

Sister K: Who are we to say that they haven't got a good quality of life?

Researcher: So I can think of an old lady I know. She lives in an absolute hovel, and there are newspapers and unwashed pots all over the place, but to her, she is living an independent life.

Sister K: Yes

Researcher: And that for her is the key thing. She would rather live in squalor on her own than in a spick and span old people's home.

Sister K: That's what I mean. Other people wouldn't be happy with that. They would want to go into an old people's home. I think too often we decide what is right for somebody.

Researcher: Right

Sister K: And we make the decisions.

Researcher: So.... how important is the freedom to make decisions?

Sister K: I think that's all important. I think that responsibility and control are all important.

Researcher: Responsibility and control of ....?

Sister K: Of your own life.

Researcher: Right.

Sister K: The problem I have on the ward when they're difficult patients is when they feel they're out of control.

Researcher: Yes.

Sister K: That's when you have the most problems. When they feel that they haven't got any responsibility and haven't got any control. And we label them "difficult patients".

Researcher. Yes. Because they don't fit in with what we're wanting.

Sister K: Its like the work on "The Unpopular Patient" by.... I've forgotten the name.

Researcher: Stockwell.

Sister K: You see it so often. Say this patient's heavy or this patient's incontinent, they're avoided.

Researcher: So it sounds like what you're saying is that an important part of quality of life is control.

Sister K: Yes.

Researcher: Or perhaps the ability to make your own decisions. Is that right?

Sister K: Yes. That's what I think it is.

Researcher: So, control over what?

Sister K: Everything.

Researcher: What's everything?

Sister K: Its everything from when you have a meal, to when you have a wash, to when you get up on a morning, to whether or not you decide to take some medical advice or not, or where you're going to live. Everything from getting up on a morning to deciding whether you're going to live in an old people's home.

Researcher: Hmmm...

Sister K: Everything.

Researcher: Hmmm

Sister K: And what you're going to wear.

Researcher: So all those little choices that we all make every day as we go through life?

Sister K: Yes.

Researcher: So when you are working as a nurse on the wards.... is that one of the major ways that you try and promote the quality of life?

Sister K: Yes.

Researcher: How do you do it?

Sister K: Oh, its difficult.

Researcher: Why is it difficult?

Sister K: It's difficult because you're working in an institution, and other people decide things. Other agencies outside of the ward decide on such things as meal times.

Researcher: Right. So you haven't got control over that environment.

Sister K: I think that you can as a nurse do a lot more than nurses have been doing in the past about giving patients control. I think that's to do with our training. I think we think that we have the responsibility for these patients so its our responsibility to do everything for them. We take responsibility away from the patients. Lots of times we just do things. We just assume that's what's best for them.

Researcher: Hmmm...

Sister K: I think medication is about the clearest example.

Researcher: Right.

Sister K: We automatically assume it's best for that patient, as soon as they get through the doors, to take their tablets off them, and start giving them out of the trolley. And that's a big responsibility taken away from that patient.

Researcher: So is it something about just being in hospital that takes away this kind of control?

Sister K: I think the minute you walk through hospital doors that...

Researcher: Yes

Sister K: That responsibility and control is taken away from you. Simply by taking off your clothes and putting you in pyjamas or a white gown in casualty. You strip somebody of everything. You strip them of their identity in a way, by putting a white gown on.

Researcher: So there is more in taking somebody's clothes away that just taking off what they are wearing.

Sister K: Yes. Have you ever had it done?

Researcher: Oh yes.

Sister K: It's foul.

Researcher: You see, I have my own views on this, but I'm just trying to explore yours.

Sister K: I think its foul. I've only ever once had a medical examination, and it was the most embarrassing thing that I've ever been through. It was the time when I felt least in control.

Researcher: Yes.

Sister K: Because I felt not only that I was physically naked, but I felt mentally naked as well.

Researcher: Mentally naked?

Sister K: It was a terrible feeling.

Researcher: What do you mean by mentally naked?

Sister K: I felt so vulnerable.

Researcher: Vulnerable?

Sister K: Yes. I'm sure that's not just me. It can't be just me, that must be everybody that comes into hospital. I'm sure that it happens in other situations as well.

Researcher: Yes.

Sister K: It must happen in other places and situations. I just know that it happens in hospitals. I suppose its like your first day at a new job, isn't it, as well.

Researcher: Hmmm.

Sister K: Unknown territory. I suppose that's a similar sort of situation.

Researcher: I wonder why we do that to patients?

Sister K: Because it's easier for us. Its easier for us to take control and responsibility than to let them have it. I think it's easier. Its easier and quicker for us to make decisions than for us to have to sit down and talk to somebody and allow them to make their own decisions.

Researcher: Yes. Because what they decide might not correspond with what's convenient for this organisation.

Sister K: That's it. Its like the white gown business you see. Its a bugbear. I find that unnecessary.

Researcher: Yes.

Sister K: When you query it, its because its easier for the doctors to examine somebody. Like white gowns in X ray. It's the first place I've ever worked in that everybody has to have a white gown on to go to X ray. At other places they've let them go in their night clothes or in their own clothes. And I find it astounding that we dress somebody in a white gown with a big slit down the back.

Researcher: Yes.

Sister K: And all their bum sticking out. And to go through the hospital showing it off to everybody. Its amazing. And again its because its easier.

Researcher: Hmmm. So somehow it seems as if you're saying that an important part of quality of life is having choice.

Sister K: Yes.

Researcher: And one of the things we make choice about is how we dress. Because I suppose that's how we express ourselves.

Sister K: That's me: I dress quite loudly. I like to dress quite brightly because that's part of my personality, and I'm sure its the same with everybody else.

Researcher: And when people come into hospital, when we take their clothes off them, we take more than their clothing off them.

Sister K: Yes.

Researcher: I'm just checking that I've got your story right.

Sister K: Yes. We take more than their clothes. I think so anyway.

Researcher: We take their choice away from them.

Sister K: Yes. And we take responsibility away from them.

Researcher: Responsibility for what?

Sister K: Perhaps responsibility is not the right word. By taking their clothes off them, you make them vulnerable. So they become dependent on us.

Researcher: Right.

Sister K: And because they're so dependent on us we take responsibility as well. That's what I mean.

Researcher: That's interesting. So is there anything else you want to say about that particular area?

Sister K: What, about clothes?

Researcher: Yes.

Sister K: Yes. I think that every patient should come into hospital and have their own clothes and their own underwear and be able to have them washed in the laundry if its necessary and not get them lost, and not have to wear pool knickers and not have to wear pool vests, but to be able to wear their own things. I think they're terrible, terrible, these pool clothes. It smacks of, I don't know, prison and workhouses and....

Researcher: Hmmm... Yes. Is there anything else you want to say about that topic? Choice, clothes, being in hospital or institution?

Sister K: I think - I think we play at informed choice.

Researcher: Right.

Sister K: I think we play at it.

Researcher: Tell me about that then.

Sister K: We pretend that we do it. We pretend that we give adequate information and enable patients to make a choice, but I don't think we do really. I think we just give them what we want them to know.

Researcher: Right.

Sister K: and steer them to make the decisions that we want them to make.

Researcher: So its a kind of sop to our conscience?

Sister K: Yes. I used to think it was just Doctors, but now I think its nurses as well.

Researcher: Do you?

Sister K: Yes. There are a lot of nurses that are just an extension of Doctors.

Researcher. Aha.

Sister K: I think that they, you know, pander to that. I think that general nurses are extremely bad at communicating and laying, unbiased, both sides of the story, putting information at the patient's disposal. And I think if a patient comes to us and says "I don't want to do what you suggested", we find that threatening.

Researcher: How does it threaten us?

Sister K: I think we feel that people, we're the experts and we know best. And if they say, 'Well, I don't want to do that, and I don't think you know best', then that's quite threatening.

Researcher: Its a threat to our professional ego?

Sister K: Yes, yes.

Researcher: Lots of times patients have come into hospital and said, "I want to die", and we don't respect that choice.

Sister K: We think they must be wrong.

Researcher: Yes, we say, "Oh they must be depressed".

Sister K: And Doctors won't accept that. Doctors find that really very difficult to accept, that somebody makes that choice.

Researcher: Hmm.

Sister K: It's like going against their Hippocratic oath, or whatever. And because we're still a sort of semi-extension of them, we don't help. We don't help to put the patient's point of view.

Researcher: Yes. I suppose this is still touching on choice, isn't it?

Sister K: Hm.

Researcher: It's the institution again, which has a particular goal, and the goal is that you will come in here, and you will get healthy, and you will go out again.

Sister K: Yes. You will do it as quickly as possible, and with the least possible problems, and the least difficulty, and you've got to be.... got to be a happy patient that doesn't ask questions, and you can't be incontinent, and you can't be difficult.

Researcher: Yes.

Sister K: You've just got to be the model patient. If you're confused that's even worse.

Researcher: What's a model patient then?

Sister K: A model patient is someone who doesn't ask questions, is independent, who comes in perhaps for a hernia operation, gets it done and goes home with no difficulties. I think that's a model patient.

Researcher: Yes.

Sister K: No complications. And they've got to be able to look after themselves so there are no problems with discharge. The Doctors say you can go home today and that's it.

Researcher: So that would be somebody who fits in with the goals of this organisation and enables it to do what it thinks it's supposed to be doing. And the opposite would be?

Sister K: Someone whose not independent, who perhaps has problems with continence, has probably difficulty managing at home. It would be better if they were immobile as well and overweight, and they as questions.

Researcher: Why is it those particular kinds of problems that make them not a model patient?

Sister K: I think it's what puts nurses out. They've got to put some effort into it, haven't they. You've got to put some effort into helping that patient help themselves. I think.

Researcher: I've always got to be careful in this interview not to put words into your mouth, but it seems to me that those are the kind of problems we find it difficult to do anything about. We like to be confronted with problems that we can solve, and there are some problems that are very difficult to solve so we don't like to hear about it.

Sister K: I think that depends on the nurse and the type of nursing that is done. I wouldn't say that was necessarily true.

Researcher: No.

Sister K: I think on care of the elderly wards it's not seen quite in the same light as perhaps on a medical ward. I think its to do with the nurses education. I don't see incontinence as an insurmountable problem.

Researcher: Yes.

Sister K: And immobility is not an insurmountable problem.

Researcher: I see. A nurd that you wentioned - that's not right - a word that you mentioned earlier on [laughter] is happiness. Do you think happiness is anything to do with the quality of life?

Sister K: I think happiness is individual. I think some people are "happy", in inverted commas, being miserable.

Researcher: Yes.

Sister K: So it's an individual thing.

Researcher: Do you mean by that that there is no particular set of circumstances that will make everybody happy?

Sister K: Yes. What makes me happy does not necessarily make you or my next door neighbour happy, or what ever.

Researcher: If you are happy, is it likely that you will have a good quality of life?

Sister K: Yes.

Researcher: Right. The two are somehow linked.

Sister K: I think so. I don't think that I can personally think of a situation that I feel I had a good quality of life if I wasn't content and happy.

Researcher: Yes.

Sister K: But then again that's personal. I could have a good material quality of life - you know, we were saying that money is not everything - but I'd not necessarily be content or happy.

Researcher: Why not?

Sister K: Well, there might be something missing from my life, that you cannot solve by putting lots of money. Or lots of ... things like electrical implements, or the nice house or swimming pool. Companionship, friendship.

Researcher: Relationships?

Sister K: Relationships. I mean, other people survive quite happily without, are content without, a stable or steady relationship or what ever. That again I think is individual. It's a difficult concept to describe.

Researcher: It is, isn't it?

Sister K: I don't think I knew what they would do, really.

Researcher: What kind of thing can you do, on a ward like yours, to promote quality of life?

Sister K: I think the key is helping people to help themselves to do the things they want to do when they want to do them, how they want to do them. It's difficult, because there are some circumstances, like health education really, that's contrary to that. But it's difficult to promote health education, if it's not going to satisfy someone. I just think that about myself. Obesity is against, you know, you're likely to get heart disease, and so they say. But if someone said to me, 'You must loose three stone', it would absolutely devastate me, because part of my quality of life is being able to eat what I want when I want and enjoy it. Its an enjoyment for me, I love it. Its a bit like balancing the two, health education role and often elderly people, they've, like elderly men who smoke a lot, and Doctors say 'Stop smoking', but that's an enjoyment and a pleasure to them. I just think as long as they have the two sets of facts in front of them, then that's their decision. My decision is to be fat and happy, content at that. So I don't know, a ninety-three year old man who smoked twenty cigarettes for the last seventy years or what ever, you've got to say 'Stop smoking' to him, it's like taking a part of his life away. Its a difficult thing because it costs the heath service so much money. Its a difficult concept, but that's personal. I've forgotten what I'm saying now.

Researcher: We were talking about things you can do to promote quality of life.

Sister K: I was talking about...

Researcher: Helping people to achieve their own...

Sister K: Their own...

**Researcher: Preferences?** 

Sister K: Yes, preferences.

Researcher: Individuality.

Sister K: Yes.

Researcher: Express their individuality

Sister K: And to, helping them to achieve an optimum in their life. The best they can do. In certain people its simple things, isn't it, other people its moving house or what ever.

Researcher: So, so far, if I can summarise it, big issues like choice, individuality, and helping people express their individuality, and those are the kind of things.

Sister K: But those, they're big issues but they affect little things.

Researcher: Yes.

Sister K: Affect all, affect everyday life, don't they.

Researcher: So they're big issues in themselves, but on a day to day basis....

Sister K: Yes, you make choices every day, don't you.

Researcher: So do you try and promote quality of life by giving people choice, then?

Sister K: Yes, we try and make sure they've got two lots of facts and are able to make a choice.

Researcher: An informed choice?

Sister K: An informed choice, yes. Its no good making a choice if you haven't got the full facts. You're just not doing yourself, your not the patient's advocate, are you?

Researcher: No.

Sister K: You're not solving any problems in the long run, just making more.

Researcher: You mentioned health a minute ago. Where does health fit into quality of life?

Sister K: I think that's individual as well. My health is important to me, you know, apart from like, health education aspects of eating too much. I think that some elderly people go all their lives and never have an illness, then suddenly they get to ninety or whatever. But other people have illness from the word go really, and some people adapt to illness really well and others don't. And like I nursed a lady who had ended up having an above knee amputation, she had some hard skin on her foot, applied some Pickles ointment to this dry skin, and it.....

Researcher: Made her leg drop off?

Sister K: Yes, just ate her foot away. That was in between the tenth of the month and the sixteenth of the month, by the sixteenth she'd lost her leg. But that didn't affect her quality of life, in some ways it improved her quality of life.

Researcher: Did it?

Sister K: Yes, in a strange way it did. Because it made her realise that, what she could do. You know, she had adversity, and its a big thing loosing a part of a limb you know, and she just accepted it, really accepted it, and dealt with it you know, and went to go home, and is walking now with an artificial leg, and she has got a fuller life now than she did before. Whereas other people just like, don't deal with it as well. A little thing and its, you know, devastation. But that's personal, you know, individual.

Researcher: So you can't say there's a clear relationship between health and the quality of life? If you're very healthy you'll have a very good quality of life, if you're very ill your quality of life is likely to be...

Sister K: I think its, I don't think you can...

Researcher: Are there any other ways you promote quality of life on the ward?

Sister K: Apart form encouraging choices and encouraging responsibility, I don't know. I suppose on a day to day thing you encourage some kind of a social meeting between patients, but that's not everybody's cup of tea either.

Researcher: But for those whose choice it is?

Sister K: We try to, to encourage socialisation and activity, but then again that's not everybody's choice. I don't ... I once worked with a sister who felt hospitals should be made as uncomfortable as possible so that people didn't get to like it, because she felt that old people liked hospital, and if you made it uncomfortable they wouldn't like it, and would want to go home. I think that's a bit hard myself.

Researcher: That's the principle of lesser eligibility that they based the workhouse system on. Made it as horrible as possible in the workhouse so that no one would want to go there.

Sister K: Yes, I think a bit hard really.

Researcher: Yes, I think it is.

Sister K: It's not so long ago that I worked on this ward, I think that part of, part of my life is socialising, and the same for everybody, or choice, whether to socialise or not. And to make something stark and horrible and ... I mean you're in hospital and you're ill, you're not going to enjoy it, to make it less comfortable is like doubling the burden.

Researcher: But, is this what you are saying, as long as it fits in with people's individual choices and plans, for their lives, you try for as far as is possible, to promote relationships, to put them in positions where they can talk to each other.

Sister K: Yes, within... because its got limitations within a hospital situation, within the situation on the ward as they are, with shortages, nurses, things... you only need to have one nurse off sick and it throws it all out. The best laid plans go through the window.

Researcher: Hypothetically, if you were looking after a patient that was unconscious, how would you promote their quality of life?

Sister K: That's difficult.

Researcher: If you think it's stupid don't bother...

Sister K: That's a difficult one, um, in that situation you have to make, you have to plan and make choices in care, don't you.

Researcher: Right, care.

Sister K: But I think you can help with quality of life, things like, you know, making sure lights are turned off at night, so they know the difference between day and night, they're all things that help promote quality. I suppose the physical things that you do even when you're talking

to someone, and communicating and touching them, that all helps I think. You've still got to communicate, that's a difficult one, about choice.

Researcher: Some people I've spoken to use the word "the basics".

Sister K: There's no such thing as 'the basics'. It makes me really angry, there's no such thing as the basics. It's all important. Everything we do is all important to that patient. It gets me so angry when people say it's only basic nursing care. I could spit at them, because I'm a professional person and I plan and deliver that care, and evaluate that care. And it's not basic to that patient. You're as, a lay person sees a nurse as an expert in what I was saying before. We take, they give us control because they're vulnerable, responsibility. So it can't possibly be basic, because it's all important to that patient. It makes me spit.

Researcher: So it's basic because it's fundamentally important.

Sister K: Yes, its not basic in that its not important.

Researcher: What kind of things do people put under that "basic" label?

Sister K: Pressure care, mouth care, eye care, taking someone to the toilet. Things that a lot of nurses feel is not their role because its basic.

Researcher: To do with maintaining hygiene?

Sister K: Maintaining hygiene, yes, activities of daily living, its basic and therefore not important for a nurse to do. Steam comes out of my ears.

Researcher: I can see it.

Sister K: It really makes me angry, because I think that's what a nurse, nurses role is. To assess your patient, plan the care, deliver the care, evaluate the care that you give, and you are all important to that patient. The decisions you make about the care will determine, you know, them getting better and that. And things like pressure care depends what, if you don't do pressure care and someone gets a great big pressure sore, gets septicaemia and dies,

Researcher: Yes, there's nothing more important than that.

Sister K: No, no, mouth care, its important just to assess that patient and what that patient needs. How can, what is the point in giving nurses three years training in assessment then to let somebody whose not a nurse do it, who hasn't got that training.

Researcher: I'd like to pick up again on one of the words you've used there, because I have this idea in my mind that in the nursing vocabulary there are all kinds of words that we use all

the time but nobody ever gets them out and has a look at them and says, "now what does this word mean?" Now you picked up the word basic, and I've got several bees in my bonnet. When I was wording on the ward there were several phrases that people tended to use, like "fine", that was a word I used to throw people out for, saying, somebody was fine.

Sister K: I do it myself.

Researcher: We all have different words, don't we?

Sister K: I say that myself, and then think on a bit, I don't necessarily mean the same to the person I'm saying it to.

Researcher: The word I've got in mind is the word "care".

Sister K: Oh.

Researcher: Have you got any idea what the word "care" means? Its a word we use an awful lot.

Sister K: What care means to me?

Researcher: Yes, that's what I want to know.

Sister K: Care means to me helping a patient to help themselves.

Researcher: Helping a patient help themselves.

Sister K: Yes.

Researcher: To do what?

Sister K: To live their life to the fullest,

Researcher: Right. Is that somehow linked with the quality of life? How?

Sister K: Because everybody, part of the quality of life is living your life how you want it to the fullest that you can possibly live it. That's not very good grammar.

Researcher: Oh, I don't care about the grammar.

Sister K: But that's what I'm trying to say, that's what we care about.

Researcher: So tell me that again.

Sister K: Care is, I suppose, helping somebody to help themselves, and to help someone live their life as fully as possible.

Researcher: Right.

Sister K: I meant the fact that, like you send one patient home who's independent, and they go home and they have a really full life, they go out visiting and what have you, that's their, that's good quality of life for them. But then you might send somebody home whose immobile, Whose wheelchair bound, but because they're at home with their own family in their own surroundings, then they are living their life to the, the most, as fully as they possibly can. It's independence isn't it, having some independence, so they gain some control and responsibility.

Researcher: I suppose there are some people whose choice is that somebody cares for them, and that they give responsibility.

Sister K: There are, and we can't say that's wrong, as long as its an informed choice then surely it doesn't matter.

Researcher: If you could do one thing to improve the quality of life of patients on this ward, what would it be?

Sister K: Um, I'd knock the four walls down, I wouldn't have the ward, I don't think.

Researcher: Right. A bit drastic I think?

Sister K: I don't think I'd have the ward.

Researcher: What would you have?

Sister K: I'd have, I think everybody at home, or somewhere where they are happy. I think hospital wards, personal opinion, that acute care of the elderly ward is a nonsense, because if you're acutely ill then there's no reason why you can't go to an acute medical ward, because you go into an acute medical ward for a physicians services. I think that you can, rehabilitation can be carried out in a person's own home, because you can't do it properly in a hospital situation, you're doing it in ideal circumstances, somebody's home isn't ideal. And long stay hospital wards shouldn't exist. Certainly not with thirty odd patients and very few nurses.

Researcher: Well that answers the question, knock the place down.

Sister K: I think there's a place for, elderly people who are acutely ill should be treated in an acute medical ward, to me it shouldn't matter if they are fourteen or ninety-eighty. If they are acutely ill, then...

Researcher: They need acute medical services.

Sister K: They need acute medical services and they should get them. I don't think that the institution classifies people, though they say it doesn't happen but it does, it does, you'll get a very different type of patient on this ward than you'll get at (names hospital). And that shouldn't happen.

Researcher: Is there anything else you'd like to say about quality of life?

Sister K: No, I don't think there's anything else.

Researcher: Have you covered all the important areas?

Sister K: I don't think I've missed anything out that I think is important. Perhaps to just say, if someone is acutely ill, if they are old or not then they are entitled to be nursed by trained nurses, because that's why we as nurses are educated, to set a patient, provide care and what have you. And we are supposed to spend three years doing it. And that's what we should do, all be trained nurses, nothing but the best for everybody, whether you are a tiny baby or an older person.

Researcher: Right. Thank you.

## **APPENDIX B**

## TRANSCRIPTION OF AN INTERVIEW WITH MRS B

Research Assistant: Oh, the Guinness will do you some good.

Mrs B: Yes.,

Research Assistant: Now, one of the things I wanted to ask you is, are you happy here in hospital?

Mrs B: Yes.

Research Assistant: You are?

Mrs B: Yes. Why?

Research Assistant: We're just trying to find out if we can make the hospital better in any way.

Mrs B: They are doing all they can for me.

Research Assistant: Is there anything you miss?

Mrs B: Miss?

Research Assistant: Yes.

Mrs B: Friends like. When I go to swallow I can't eat. I chew it round and round and round and it will not go down.

Research Assistant: The last bit going down is the problem?

Mrs B: Yes. I've told them about it so they took some tests.

Research Assistant: Yes. Its waiting now.

Mrs B: Yes, and I'm waiting to come in for my cataracts.

Research Assistant: Have you had one done yet?

Mrs B: No. That's what makes me so dizzy, see?

Research Assistant: Yes. What do you like about being in hospital?

Mrs B: Well, I don't love it, but when you're on your own you can't do nowt for yourself.

Research Assistant: So, is that the best thing, people doing things for you?

Mrs B: Yes.

Research Assistant: What do they do for you?

Mrs B: They look after you, don't they. They feed you. I have somebody very strict who looks after you. And my arm...

Research Assistant: It aches?

Mrs B: Yes, its broken. And they look after me. I'm always frightened at night time because that's when it happened.

Research Assistant: What happened, you fell over?

Mrs B: I fell backwards going to the toilet. I must have got out of bed the wrong side, like.

Research Assistant: Yes. So do you feel safer in hospital?

Mrs B: Yes, up to now. When I get better I want to go home. I want to go home. Everybody likes their own home. I miss my telly and all that.

Research Assistant: What do you like about your own home?

Mrs B: My telly and that. Comfort and my friends.

Research Assistant: Do you not watch telly here, then?

Mrs B: I don't know where it is. I don't think I could enjoy it here.

Research Assistant: Why not?

Mrs B: I don't know. I couldn't tell you. I don't like to be in a crowd.

Research Assistant: You live by yourself, don't you?

Mrs B: Yes.

Research Assistant: Do you think that's important, you get used to being by yourself?

Mrs B: Yes, I think that's it. Not as I want to be by myself. I want people to come by and see me and have a chat. They do. They come in and have a cup of tea and chat.

Research Assistant: What, your friends, that?

Mrs B: Yes.

Research Assistant: Do they come in here?

Mrs B: Well, I've only had one come in here this week. I'm expecting someone coming today. I don't know whether they will. You see, I've got two sisters and one's nearly blind. She can't come unless somebody brings her, and she has no family. And the other one lives at (mentions a hospital), and I think that's upset me. I lost mine just before Christmas, and it was one birthday in October, and she lost hers on my birthday, same way as he went, in a coma.

Research Assistant: So why don't they come in, because they can't make it in here?

Mrs B: I really don't know. Yes, I think they can, but they might be busy. It isn't time for them to come yet. Somebody's promised to come this afternoon.

Research Assistant: That'll be nice, then. Do you miss them, not having visitors?

Mrs B: Course I do. I do, love.

Research Assistant: Yes. Is there anything you don't like about hospital? Food, for instance?

Mrs B: No, they do their best. One thing I don't like is you have to keep asking for the commode all the time when you can't go your self. I've been trying to find it myself this morning. I don't know where it is. I get mixed up. I don't know my way around yet. If I can go on my own, I'll be happy, I won't have to ring everybody.

Research Assistant: You'll be happy if you know how to get to the toilet.

Mrs B: Yes.

Research Assistant: Do they not tell you, then?

Mrs B: Well, I've only been once. I've been asking for the commode all the time, thought I'd try and go by myself, and one of the nurses caught me and said, "What are you doing". I said "I'm trying to, to take it off". She said, "You're too independent, you're not twenty, you're eighty nine".

Research Assistant: You look well for eighty nine.

Mrs B: She said, "Come on, I'll show you", but we were waiting outside and she said "Come on, I'll take you back". And I said I just don't know which way to go now. Anyway, she brought me back.

Research Assistant: Aye.

Mrs B: But I shan't go again, I'll ask for a commode.

Research Assistant: Too much trouble.

Mrs B: Its too confusing, too far for me to walk, and I can't get my breath.

Research Assistant: Is there anything else you don't like?

Mrs B: No, they are very friendly. And they are very good, the nurses, I don't know what we would do without them, God knows, I don't.

Research Assistant: They are friendly. Is that important, do you think?

Mrs B: I do think so.

Research Assistant: Why?

Mrs B: Well if they are not friendly, when they help you, you feel uncomfortable don't you?

Research Assistant: Yes.

Mrs B: They are very good, you only have to ask them. But they've such a lot on, you have to wait such a long time, and sometimes you can't wait, and without being vulgar, I've had diarrhoea for three weeks, and it was just clearing up, and its coming back again.

Research Assistant: What, so the nurses are sometimes a bit busy?

Mrs B: Well they are, they've such a lot you see. Very good, see, very, very good. They don't lose their temper. If you don't be nasty with them, they'll be good to you. You can't afford to be nasty to them. And I wouldn't be nasty to them, they are not servants.

Research Assistant: Yes.

Mrs B: Some thinks they are servants you know, and they should do this and that, will they shouldn't. If it wasn't for them, I don't know where we'd be.

Research Assistant: If you had the choice, where would you rather be, at home or in hospital?

Mrs B: Oh at home, naturally.

Research Assistant: Do you think everyone thinks that way?

Mrs B: Oh yes, they can't wait to go home. But I won't go home till I'm steady enough. I thought he might let me out, but no. He was saying something about Monday. I'll see how you go on for Monday. They've been having me walk up and down that thing, turning around, and coming down holding those things.

Research Assistant: Oh, like the stairs?

Mrs B: No, not stairs.

Research Assistant: A ramp?

Mrs B: Yes, because I can't go upstairs. I suffer with my heart as well, see?

Research Assistant: Um, why do you think people like home so much?

Mrs B: Well, I don't know. Everybody loves their home, don't they? I think so.

Research Assistant: But why?

Mrs B: I don't know. I can't tell you. It wouldn't be natural not to like your own home, would it?

Research Assistant: You get used to it, I suppose.

Mrs B: That's right, yes. Yes, I miss my friends.

Research Assistant: You miss your friends?

Mrs B: Yes.

Research Assistant: Is there anything you think you'd like in hospital that you don't get?

Mrs B: Not really no. They do their best for you. I was surprised when they came round. I've been in here before, it were on a Friday, and they said "Who wants a Guinness", and I said "I don't think I can have one", and they said I can.

Research Assistant: Grab it quick.

Mrs B: That's what the young fellow who'd come to see me said. He's coming this afternoon, a friend of ours. He used to look after us both, before he died. He said, "She'll have one".

Research Assistant: No need to ask.

Mrs B: No. Another time I was in I can't, and I couldn't eat anything, and I said, Sister said, "How is it you can't eat", and I said "I don't know, I'm not a big eater, nor I used to be when I worked in mill". I said, "I don't know, I can't". She said, "Are you fretting", and I said, 'No, not really'. She said, 'I'll ask you a fair question, are you used to a drink?'. I said, "Oh yes, every night I've always had a drink", so she said, "Right, right, you shall have one every day, you must have one at twelve o'clock noon and at six o'clock with your dinner, like". Well, someone brought my husband in a car, 'cos he couldn't see you know, and as he was walking down someone said, "Will you take her this". He looks, and says, "Its a bottle of beer", she says, "Yes, she can have it, make sure she has it". He says to the man who brought him, "Make sure? She'll grab it with both hands!"

Research Assistant: Surprised he didn't drink it before you got it.

Mrs B: Oh yes.

Research Assistant: Do you ever get lonely in hospital?

Mrs B: No, not really, because there's always people around. I got lonely at home lying in bed and not able to sleep. Night after night, couldn't sleep, couldn't sleep at all.

Research Assistant: Do you sleep well here?

Mrs B: Not too bad, not a great deal, I sleep through the day a great deal, good job I sleep through the day.

Research Assistant: Yes.

Mrs B: I've been asleep this morning, and I've been in bed this afternoon. Only just got up to go to the toilet.

Research Assistant: Why do you think you sleep so much in hospital?

Mrs B: I don't know, maybe its because you've got someone there and you're contented in case something happens. You get a little nervous in case you fall, I've had that many falls, you see. I've only been home since just before Christmas. I had three broken ribs before then.

Research Assistant: Do you get lonely at home, at all?

Mrs B: No, only at night when I'm by myself and there's nobody to get to me at night if I'm poorly, then I do. Otherwise no, I've got my telly, its a nice colour telly.

Research Assistant: You do a lot of that then, watching the telly?

Mrs B: I like a lot of quizzes. Don't like a lot of gun shooting, or owt like that, boring. I like quizzes.

Research Assistant: Yes. Do you answer the questions?

Mrs B: No. I can do to myself though, sometimes.

Research Assistant: I must admit I can hardly ever answer the questions. What are your plans from here then?

Mrs B: I don't know.

Research Assistant: What do you want to do next, from hospital?

Mrs B: Only go home, that's all, nothing, just lead an ordinary life.

Research Assistant: Yes. To get home,

Mrs B: Yes.

Research Assistant: Have you got relatives living near you?

Mrs B: Well, I've two sisters, one lives not far from me, but she's nearly blind. There's two busy roads, she can't cross them.

Research Assistant: That's a problem.

Mrs B: The other one's just lost her husband at (mentions hospital). She says she'd come too, but, it'd upset her to see me I know. But she'll come and see me when she can. I might not be in, because he said something about he might let me go on Monday, but he'll see how I go on.

Research Assistant: So how did you break your ribs?

Mrs B: I fell.

Research Assistant: At home?

Mrs B: Yes, went dizzy when I stood up. I think its to do with my eyes as much as anything.

Research Assistant: What, you think once your cataracts have been sorted out it'll be better?

Mrs B: I think so, but there's such a long waiting list.

Research Assistant: That's right, yes.

Mrs B: They told the lady who took me down from social security that they couldn't do no more. I'm on a waiting list, but if they got any worse, she'd to ring up, and they'd try to put me to the front.

Research Assistant: Yes.

Mrs B: So it'll just have to do.

Research Assistant: Have you met your Doctor yet?

Mrs B: No, not yet. My own Doctor?

Research Assistant: No no, the hospital Doctor.

Mrs B: Oh yes.

Research Assistant: Who is he?

Mrs B: (Gives name)

Research Assistant: Have you been in hospital before?

Mrs B: Yes.

Research Assistant: Quite a while ago?

Mrs B: Yes, oh aye. I've been in (mentions hospitals), and here.

(At this point the woman in the neighbouring bed joined in the conversation and the interview was brought to a halt).

## APPENDIX C

# **ANALYTICAL CATEGORIES**

Presentation of most of the following categories follows the following pattern: the title of the category is followed by a brief description of the category content. A number of illustrative quotations are then given. The locations within the text of the various referents of that category are then stated. The initials of the interviewee are followed by the relevant paragraph numbers of the inscription.

CATEGORY TITLE: THE AIMS OF CARE

<u>Category Content</u>: This category is a compilation of the aims of care expressed by nursing staff. Direct quotations are not given, but the following aims of care are articulated in the text.

- 1. For a person to live their life comfortably.
- 2. To have a comfortable, pain free death.
- 3. To rehabilitate to a position where the person can return home.
- 4. To make the patient independent.
- 5. To maximise and realise potential.
- 6. To improve the persons quality of life.
- 7. To get the patient fit for discharge where they want to go.
- 8. To not make the person conform to a rigid hospital pattern.
- 9. To aid recovery.
- 10. To improve sociability and confidence.

- 11. To maintain people in the community.
- 12. To look after carers.
- 13. Not to do the patients any harm.

References: Sister L:1,7; Sister K:5; Sister Q:9,66; Sister U:10.

CATEGORY NAME: ATTITUDES OF STAFF

<u>Category Content</u>: This category suggests that the attitudes of staff to patients are important (quotation one) and illustrates some of the attitudes held (quotation two). The attitude of kindness is particularly valued by older people themselves (quotation three).

<u>Illustrative Quotation One</u>: Charge nurse S: I think the most important thing about staff is that they have the right attitude. They don't necessarily need to have skills in doing different things...its the attitude they approach the job with that's important.

Illustrative Quotation Two: Staff nurse X: I mean this lady here, Nellie, she's useless.

<u>Illustrative Quotation Three</u>: Mrs F: Oh, they're very kind. If I ring the bell, somebody comes and looks after me.

Research assistant: Yes?

Mrs F: In the last hospital, and I'm not mentioning any names, if you wanted a nurse you had to shout. And everybody shouted, and they didn't come.

References: Sister L:6,42,; Charge nurse S:26; Sister O:8,13,11; Sister P:6,8; Sister M: 9; Sister Q:30; Staff nurse X:6,7.Sister Y:8; Mrs A:3; Mrs I:1; Mrs F:1,2,4,12.

CATEGORY NAME: THE BASICS

<u>Category Content</u>: 'The basics' refers to the physical dimensions of need and to the aspects of care through which these needs are met.

<u>Illustrative Quotation</u>: Sister T: And I think that quality of life, thinking in the context of nursing elderly people in hospital, the basic needs have got to be met. You can't say they've got good quality of life if they're lying in wet beds.

Researcher: Right. First question. What are the basics?

Sister T: Warmth, not being in the cold, in a draft, having their nutritional needs met, being in some way clean and dry, and that the surroundings are acceptable.

References: Sister L: 1,6,42,45; Sister N: 2,13,15; Charge nurse S: 6; Sister O:1; Sister K:115,116; Sister T:6; Sister P:1.

CATEGORY NAME: BEING AN INDIVIDUAL

<u>Category Content</u>: Within the text, there are many references to 'being and individual'. It is claimed that the quality of life is an 'individual thing'; 'individuality' is seen as an innate property of the human being; and 'individualised care' is valued. Quotations are selected to demonstrate references to 'individual' (quotation one); and to show that informants were generally unable to justify or explain the importance of being an individual but took it as an axiom (quotation two).

<u>Illustrative Quotation One</u>: Sister O: Treating people as individuals increases the quality of their lives. Not treating them as individuals and telling them what is happening is detrimental to their quality of life.

<u>Illustrative Quotation Two</u>: (Notes from and unrecorded interview): Sister N suggested that people should be treated as individuals because they are individuals. Sister N felt there was difficulty going on from this point as it was hard to analyse.

References: Sister K:9,10,39; Sister T:10,18,19,33,46; Sister L:2; LC:2,3; Sister O: 1,2,10; Sister Q: 10, 16, 50, 53; Social worker W.

CATEGORY TITLE: BUSY-NESS

<u>Category Content</u>: Nursing staff sometimes use the words 'busy' and 'busy-ness' to characterise their work. This category identifies the nature of business (quotation one), indicates some of its consequences for patients and staff (quotations one and two), and shows some of the ways in which staff tried to mitigate these consequences (quotation three). Patients also commented on the busy-ness of nurses (quotation four) and used it to justify their exclusive attention to the physical aspects of care.

<u>Illustrative Quotation One</u>: Sister O: Often nurses are so overstretched that they only have time to do the physical care, and little time to interact with patients.

<u>Illustrative Quotation Two</u>: Researcher: Why do you think they're just dumped in the dayroom then?

Sister L: Cos it makes nursing easier for us, because I think the nurses are pressurised enough just giving the physical care. Even the nurse in charge has got to give hands-on care. Not that I'm against that, but I think you're trying to give the hands-on care, be in charge of the ward, co-ordinate the students, co-ordinate the agency staff, how many hats do you have to wear? You know, in the morning, everyone is under pressure, and so the psychological care goes out of the window, you know. I just find myself,....awful....you go home and think, 'What have I done this morning'....I even cut conversations short.

<u>Illustrative Quotation Three</u>: Sister L: The other morning we set up a talk and theme about the 1930s, so we set it up and they all sat round, and afterwards me and Nicky went in and talked about it. It only took 15 minutes of nursing time afterwards to discuss how they felt about it.

<u>Illustrative Quotation Four</u>: Mrs C: Everything is done according to, how they do it is according to the staff they have got, you see.

References: Sister L:12, 14, 42, 44, 45; Sister P:4; Sister O:5; Sister Q:25,26; Staff nurse X:12; Mr H:3; Mrs Z:3; Mrs C:34.

CATEGORY NAME: CHOICE

<u>Category Content</u>: Nursing staff suggested that freedom of choice was important to the quality of life (quotation one), and the range of issues over which choice was to be made were enumerated several times (quotation two). These informants also described a number of circumstances that restricted their ability to offer choice to the older person (quotation three), and sometimes argued that there were therapeutic reasons for limiting choice (quotation four). Elderly patients also valued choice. Mrs A complained that it was not available at meal-times (quotation five).

<u>Illustrative Quotation One</u>: Sister N : I think the most important word I would suggest is an element of choice. Choice has got to be the most important thing, I'd say.

<u>Illustrative Quotation Two</u>: Sister K: Everything from when you have a meal, to when you have a wash, to when you get up on a morning, to whether you decide to take some medical advice or not.... or where you're going to live, everything. From getting up on a morning to deciding whether you're going to move from your home into an old person's home.

<u>Illustrative Quotation Three</u>: Sister T: ...lack of physical resources....you have the expertise to prevent someone from developing an uncomfortable pressure sore, but you don't have the equipment, thus the development of the pressure sore will reduce their quality of life. If you don't have enough staff, if you only have enough to rush round everywhere and make sure everyone's clean and dressed and being fed, and not enough time to have any social talk or negotiations, then that prevents you from giving them quality of life.

<u>Illustrative Quotation Four</u>: Sister T: In situations of acute illness, and at the beginning of rehabilitation when its such an effort for somebody that they don't want to try. For example with walking, they want you to wheel them because they can't possibly walk, and making them walk increasingly by stages you eventually find they are not only able to walk but can do it by themselves. And then that gives them more choice because then they can choose when to get up and where to go.

Illustrative Quotation Five: Research assistant: Do you get to choose your meals?

Mrs A: No, you don't choose them. We have what's given.

References: Sister L:2,8; Sister N:7,17,21,31,41; Mrs AA:12; Sister O:5,23; Sister K:7,8,9,10,27,29,58, Mr H:1,8; Mrs G:2,16; Mrs BB:3; Mrs A:3.

CATEGORY NAME: CLOTHING

<u>Category Content</u>: This category asserts that clothing is important for the quality of life, and describes mechanisms through which older people in hospital care can have access to their own supply of clothes. Quotation one shows that the staff are sensitive to the expense involved in purchasing sets of clothing to be worn by elderly people in hospital.

Illustrative Quotation One: Research Assistant: Do you have individualised clothing here?

Sister Q: Yes

Research Assistant: Do you find it works?

Sister Q: Yes, because we make it work. There are one or two who don't, [that is, elderly people who don't have their own clothing] and its very difficult. Like this man, he has had a stroke, and you don't know how long he's going to live. Now, I know he's been through a lot of systems, he's lost a lot of clothing, the homes, the hospitals he's been into, so its difficult, and he's got a wife whose still got the upkeep of the home, presumably, so you feel a bit... asking them for more when you know they've given quite a bit. You don't know how long he's going to be living, and you want fifty pounds for clothing. You have to think about it quite carefully.

References: Sister K:47,50,51; Sister Q:50-53; Staff nurse X:5.

#### CATEGORY NAME: THE COMMUNITY

<u>Category Content</u>: This category asserts that people's quality of life can best be promoted by enabling them to live in the community. 'The community' usually refers to the person's own home. The following illustrative quotation discusses the role of the Day Hospital in keeping people in the community.

<u>Illustrative Quotation</u>: Sister N: It's not really a ward but a day hospital. I think a lot of what we do here to maintain quality of life is to maintain people in the community so that they can choose to go on living at home if that's what they choose to do instead of being taken to an institution as such, so I think that's a really important part of how we maintain the quality of life.

References: Sister N:7; Mrs AA:73; Sister K:6,131; Sister M:41,42; Sister Q:12,19.

CATEGORY NAME: CONTINUITY OF HOSPITAL AND HOME LIFE

<u>Category Content</u>: This category asserts that it is desirable to maintain a degree of continuity between life at home and life in institutional care, and recognises that this can be difficult to achieve (quotation one).

<u>Illustrative Quotation One</u>: Sister M: (Continuity with home life) is important but it's not always possible.

Research Assistant: Why do you think it's important?

Sister M: One thing is its this attitude thing again, so the patient realises there is something going on outside these four walls, relates to husband, children, grandchildren, all the rest of it. It does keep them in touch with the outside world if they can talk to visitors, see the news, read a newspaper, all these things.

References: Sister L:1; Sister O:19; Sister M:23-25; Charge nurse S:4; Sister Q:12; Sister Y:4.

CATEGORY NAME: DIFFICULT PATIENTS

Nursing staff sometimes described some of their patients as 'difficult' Some staff suggested that difficult patients were those who rebelled against the restrictions associated with hospital care. Both of these aspects of the category are illustrated by the illustrative quotation given.

<u>Illustrative Quotation One</u>: Sister K: The problem I have on the ward when they're difficult patients is when they feel they're out of control.

Researcher: Yes.

Sister K: That's when you have most problems, when they feel that they haven't got any responsibility and haven't got any control. And we label them 'difficult patients'.

References: Sister K:11-16; Sister T:32; Sister M:33; Sister Q:32; Sister U:18,19; Mrs CC:8; Sister Q:16; Staff nurse X:11,14;

CATEGORY NAME: THE ENVIRONMENT

<u>Category Content</u>: This analytical category asserts there to be a relationship between the quality of an older person's life and their physical environment. It holds that the hospital constitutes a poor residential environment (quotation one), but that it can be made more homely with effort. Some staff suggest that changes in the environment create new possibilities for care (quotation two), and recognise that the environment offers opportunities to enhance the older person's sense of control (quotation three).

<u>Illustrative Quotation One</u>: Researcher: If you could do one thing to improve the quality of the patient's lives on this ward, what would it be?

Sister K: Um.... I'd knock the four walls down. I wouldn't have the ward, I don't think.

Researcher: Right. A bit drastic, I think?

Sister K: I don't think I'd have a ward.

Researcher: What would you have?

Sister K: I'd have everybody I think at home, or somewhere where they are happy. I think acute care of the elderly wards is a nonsense, because if you are acutely ill then there's no reason why you can't go to an acute medical ward, because you go into an acute medical ward for a physician's services. I think... rehabilitation should be carried out in a person's own home, because you can't do it properly in a hospital situation. You're doing it in ideal circumstances. Somebody's home isn't ideal. And long stay hospital wards shouldn't exist.

<u>Illustrative Quotation Two</u>: (From an unrecorded interview) Sister O described how a move to a new ward with four toilets instead of the previous two enabled her to stop toilet 'rounds' and start 'demand' toileting.

<u>Illustrative Quotation Three</u>: (From an unrecorded interview) Sister O said that she liked her patients to have a permanent bed-space where she would encourage them to put up pictures and posters of their choice.

References: Sister L:8,11,15,19,43; Sister N:22; Sister O:2,12; Sister K:4,53; Sister P:9; Sister O:7; Staff nurse X:25; Sister Y:2.

CATEGORY NAME: FORCING

<u>Category Content</u>: Forcing means compelling people to do that which they do not want to do. The first illustrative quotation describes the practice of forcing, and the second illustrative quotation show the practice is defended by staff. The third quotation is from an woman who may have experienced this practice.

<u>Illustrative Quotation One</u>: Sister Q: This man we're talking about, he's had a stroke all down his left side he's got no movement at all. Now ideally, you should approach him from his left side. You approach him from the side he's not going to hit you and see if you can get it done... and try to get it done as quickly as possible really. The more you try to communicate with him the more he's hitting you, and there comes a time when you think, 'let's get on with it', stop him doing this, and we do it pretty quickly and ask for help, two of us to do him.

<u>Illustrative Quotation Two</u>: Research Assistant: Why do you think we do that, sort of force them?

Sister Q: Um, I think because we think they'd be better up. They might not think they would be but we think maybe they would get a bit more responsive if they were sat up in a lounge rather than in bed.

<u>Illustrative Quotation Three</u>: Mrs DD: They shout at you, and they shout at you only because you don't want to drink a lot. And I'm silly, because I like to do what I'm told.

Research assistant: But you don't like drinking?

Mrs DD: I don't seem to be able to drink. But you have to drink so much a day, so they don't let you dehydrate. It's 'cos you can't get it, and you can't ask them to get it.

References: Sister L:14,36; Sister M:13; Sister Q:34-38; Sister U:15; Staff nurse X:10; Sister N:7,8; Mrs DD:9; Mrs I:9.

CATEGORY NAME: GETTING USED TO THE MESS

<u>Category Content</u>: It is argued that staff can become accustomed to providing a lower standard of care for institutionalised patients than they would accept for themselves.

<u>Illustrative Quotation</u>: Sister L : That's what I want to emphasise, that your say (she was reporting what she said to agency and other temporary staff) is as important as anybody's, infact more so, because we're blase. We come to work and go home and get used to the

mess, and we get used to a certain standard, whereas they are coming on and its them that sees things.... Its really important to find out how they feel.

References: Sister L:8,9,25; Sister Q:66,67.

CATEGORY NAME: GIVING PATIENTS INFORMATION

<u>Category Content</u>: The staff felt that patients needed information if they were to make choices and be treated as individuals (illustrative quotation one). The text also shows that elderly people appreciated in when they were given information.

Illustrative Quotation One: Sister K: I think... I think we play at informed choice.

Researcher: Right.

Sister K: I think we play at it.

Researcher: Tell me about that, then.

Sister K: We pretend that we do it. We pretend that we give adequate information and enable patients to make a choice, but I don't think we do really. I think we just give them what we want them to know.

Researcher: Right.

Sister K: And steer them to make the decisions that we want them to make (later) I think that general nurses are extremely bad at communicating and laying, unbiased, both sides of the story, putting information at the patient's disposal. And I think if a patient comes up to us and says 'I don't want to do what you suggested', we find that threatening.

References: Sister K:58-66; Sister T:8; Sister O:1,12; Sister M:35,36; Sister Q:56,58,60,65; Social worker W:14; Sister Q:3,7,14; Sister V:2; Mrs G:1,6

CATEGORY NAME: HAPPINESS IS INDIVIDUAL

<u>Category Content</u>: This category expresses the idea that relationship between a person's circumstances and their expressed level of happiness is unpredictable.

<u>Illustrative Quotation</u>: Researcher: Do you think happiness is anything to do with the quality of life?

Sister K: I think happiness is individual. I think some people are 'happy', in inverted commas, being miserable.

**Researcher: Yes?** 

Sister K: So its an individual thing.

Researcher: Do you mean by that that there is no particular set of circumstances that will make everyone happy?

Sister K: Yes.....

References: Sister K:82,88; Social worker W:12; Sister R:2

CATEGORY NAME: HOME

<u>Category Content</u>: Elderly people who interviewed during the course of this research often expressed a desire to return home or regretted that this was no longer possible. The following quotations were taken from the interview with Mrs A.

Illustrative Quotation: Researcher: Where would you rather be then?

Mrs. A: At home.

Later in her interview she was asked:

Researcher: What sort of things do you think about?

Mrs A: I think about am I going to stay here all the time or am I going to go home. They never mention about me going home.

Researcher: They don't say anything?

Mrs A: No

Researcher: Not at all?

Mrs A: No, nothing about going home.

Researcher: Do you talk about it?

Mrs A: Yes. I say to them, 'When am I going home?', but they say 'All in good time'.

References: Mr H:4; Mrs G:3,16; Mrs BB:1,27; Mrs B:4; Mrs A:1,7,14; Mrs I:2,6; Mrs F:10; Mr D:8.

CATEGORY NAME: IMPOSING YOUR OWN VALUES

<u>Category Content</u>: Staff claimed to be reluctant to impose their values upon those of the patient.

<u>Illustrative Quotation</u>: Sister Q (talking about giving choice to demented patients): Yes, they can't tell you if they don't want sugar or they don't want that. But, saying that, I don't think often the choice is given anyway.

Research assistant: Really, no. You have to put your own values on it if they can't tell you what they want.

Sister Q: Yes, I suppose, but even that's wrong really, imposing your own values on somebody else. We tend to do it, but its not ideal.

References: Sister M:22; Sister Q:13; Social worker W:6; Sister R:3; Sister Y:8

CATEGORY NAME: INSTITUTION

<u>Category Content</u>: Institution and institutionalisation are words used to describe an approach to the organisation of care that can arise in the field of elderly care. Important issues arising from the data are institutional roles, routine or ritualised care, and patient perception of loss of control. Each of these aspects is illustrated in the first illustrative quotation. At least one elderly patient was able to articulate the need to obey the rules of the institution (quotation two).

<u>Illustrative Quotation One</u>: Sister M: Well there are two things to not giving a patient choice. First, you get a rebellious patient, if they've got... what it takes. They'll rebel and do their damnedest to work against you. Or they'll just become institutionalised: 'Can I go to the toilet, nurse? Is it time to go to the toilet nurse?' That kind of thing.

Research Assistant: You said institutionalised - what does that mean?

Sister M: Whereby the institution is the most important thing and they have to conform to the institutions...

Research Assistant: Routine?

Sister M: Right. You'll have your dinner at twelve, you'll go to the toilet at half past, you know...

<u>Illustrative Quotation One</u>: Mrs C: It's all, you have to obey, you're one of a community here and you have to obey the rules. And you quite understand that the job is difficult enough for the nurses as it is, so you try to make it as easy for them as you can - by being acquiescent in everything, you see.

References: Sister U:27; Sister K:39,41; Sister L:7; Sister P:3; Sister O:6; Sister M:27; Sister Q:28,40; Social worker W:1; Sister R:1,14; Mrs C:17,18.

CATEGORY NAME: SOCIAL ISOLATION

Some of the elderly residents of hospital wards complained that they were lonely (quotation one). Visits from family and friends were welcome because they reduced this problem (quotation two).

<u>Illustrative Quotation One</u>: Mrs I: I get lonely because I'm sat in this room all afternoon, on my own, you might say. If you go down to the day-room they have the television on, they have the radio on, they might have a cassette on, and everybody shouting and screaming. I mean, you can't listen or look or do anything.

<u>Illustrative Quotation Two</u>: Mrs F: Well if I do get lonely I've got plenty of friends I can ring up to say, because you see I've got a telephone, two or three telephones, I'm lucky.

Research assistant: Is that at home?

Mrs F: Yes

Research Assistant: How about in hospital, do you ever get lonely here?

Mrs F: Well, I don't think I've had time to get lonely here. There's always somebody popping in. One or two times you do wish, 'Oh, I wish so and so was here, so we could have a chat' you know? But that passes.

References: Mr H:2,8,15; Mrs Z:3,11; Mrs BB:5; Mrs F:13; Mrs I:4,7,16 17; Mr D:9.

#### CATEGORY NAME: MODEL PATIENTS

<u>Category Content</u>: Staff defined a model patient as one who fitted in well and adapted to the institution's goals (quotation one).

<u>Illustrative Quotation</u>: Sister K: Its the institution again, which has a particular goal, and the goal is that you will come in here, and you will get healthy, and you will go out again. You will do it as quickly as possible, and with the least possible problems, and the least difficulty, and you've got to be... you've got to be a happy patient that doesn't ask questions, and you can't be incontinent, and you can't be difficult.

Researcher: Yes

Sister K: You've just got to be the model patient. If you're confused, that's even worse.

Researcher: What's a model patient, then?

Sister K: A model patient is someone who doesn't ask questions, is independent, who comes in perhaps for a hernia operation, gets it done, and goes home with no difficulties. I think that's a model patient.

Researcher: Yes

Sister K: No complications, and they've got to be able to look after their selves so there are no problems with discharge. The doctors say you can go home today, and that's it.

Researcher: So that would be somebody who fits in with the goals of the organisation and enables it to do what it thinks it's supposed to be doing. And the opposite would be?

Sister K: Someone who's not independent, who perhaps has problems with continence, has difficulty managing at home. It would be better if they were immobile as well, and overweight, and they ask question.

References: Sister K:73-76; Sister T:32; Sister L:11; Sister O:11; Sister M:31; Social worker W:12

CATEGORY NAME: NURSES UNIFORMS

<u>Category Content</u>: The text contains many references to nurses' uniforms. It is suggested that a uniform identifies a person as the incumbent of and institutional role, in this case, that of 'nurse'. Thus, wearing a uniform can have implications for the relationship between nurse and patient (quotation one), and can also act as a defence-mechanism for staff (quotation two).

<u>Illustrative Quotation One</u>: Sister L: Unfortunately nurses are stereotyped. A lot of people feel threatened, you're in uniform, you know what you're doing, you've been trained.

<u>Illustrative Quotation Two</u>: Sister L: Mind you, some nurses tend to hide behind that label, so they feel safe, so they can have that little bit of superiority, and you know....

Research Assistant: Do you think it's important to some nurses, stress, or, you know.... this hiding behind a barrier?

Sister L: Yes, probably. I know when I first qualified, at Sister level, not so much here, but when I was on an acute area, coronary care, or the reception unit, we had an awful lot of stand-bys, crashes, deaths, and at that stage, I found it so much easier that I was in a uniform, that I knew what I was saying, explaining, while I felt that if I was out of uniform, I would have cracked up with them. Yes, it was like a pillar. Yes, it did give me a bit of support.

References: Sister L:29, 31, 32, 33, 34, 54; Sister R:11; Sister V:13

## CATEGORY NAME: ORGANISATIONAL FACTORS THAT INHIBIT THE QUALITY OF LIFE

<u>Category</u> <u>Content</u>: This category contains reference to aspects of the Hospital's organisational structure that inhibit the promotion of the quality of life.

<u>Illustrative Quotation</u>: Sister L: Get rid of things like this (waves a batch of receipts to be countersigned by her and sent to the finance office)... Example, I've just gone along to order flowers for the ward, artificial ones to be made up. Because its going to cost over fifty pounds, the bill I've got is three hundred and fifty pounds, I've got to then only pay fifty pounds at a time. So how do you go along to a shop and say 'Sorry, I can only give you fifty pounds at a time?' I can see the logic in that they are trying to protect me for fraud, theft, loss, I know that and I can see the reasons, but I still think that there should be a little more flexibility in management.

References: Sister L:36,38,39,40; Sister K:43; Sister O:13

CATEGORY NAME: PATIENT'S EXPECTATIONS

<u>Category Content</u>: The material in this category discusses the relationship between expectation and outcome. Staff assert that those with low expectations of life are more likely to have their expectations satisfied (quotation one). It is also argued that prospective patients who hold the view that the hospital is a kind of work-house may begin to adopt a dependent role even before their admission (quotation two).

<u>Illustrative Quotation One</u>: Charge Nurse S: I think if somebody has a profound stroke and they want to be independent, and to be doing all the things they were doing before, if they

enjoyed walking the dog and things like this, then like I say, they've got an expectation that's never going to be realised. That's what I mean. It will affect their whole attitude to life.

<u>Illustrative Quotation Two</u>: Research Assistant: Do you think a patient's expectations of his hospital stay affects how he feels about it?

Sister M: The role of expectations, preconceived ideas, I think that you have this, a lot of hospitals have got the old work-house approach, you go in there, you only get out feet first... (detour)... Oh yes, if they expect they are coming into a ward like the work-house, they think its the work-house. They immediately think that they are dying before they get here. If the person thinks that its an old person's ward, then 'I don't want to be in there, you'll get like them before you know where you are'. But I think they very quickly take on the hospital role, some of the patients.

# References: Charge nurse S:52-57; Sister U:71; Sister M:31; Sister Q:48; Social worker W:13; Sister U:2; Mrs CC:7; Sister R:15,16; Sister V:16; Sister N:10

CATEGORY NAME: PRIMARY NURSING

<u>Category Content</u>: Nursing staff felt that the implementation of primary nursing would assist them to promote patients' quality of life.

<u>Illustrative Quotation</u>: Sister L (in the context of a discussion about conversations between nurses and patients): Again, I think that area's got a lot better since we've got primary nursing. You've got the continuity so you can control and develop conversations because they're seeing you every day. I must admit, that side I have enjoyed.

References: Sister L:26,47,51; LC:7; Sister M:20; Sister Q:19-21

## CATEGORY NAME: PROVIDING NEW EXPERIENCES

<u>Category Content</u>: This category shows that some staff felt it was important to offer their patients new experiences, and accordingly organised various trips and outings.

<u>Illustrative Quotation</u>: Sister L: Yes, its nice to get out of the clinical environment and into an environment that's more like home. Somewhere enjoyable to sit because there's plenty to see, they've got the flowers, the shrubs, the changing of the clouds and the weather, rather than just looking at the four walls of the day room or the day area. I'm just trying to think what else we're trying to do in terms of improving the quality. We're having a French Week next week, so we're going to be in fancy dress in the afternoons, so you can guess what the fancy-dress is going to be like for French Week.

References: Sister L:2,3,14

CATEGORY NAME: PURPOSE IN LIFE

<u>Category Content</u>: Reference was made within the text to the 'purpose in life' of elderly people. This phrase was used both in a restricted sense to refer to the purpose of the admission to hospital (quotation one), and in a more global sense akin to Maslow's notion of 'self-actualisation'. (quotation two). There is also evidence that staff tended to avoid addressing their patients' purpose in life, as defined in this broader sense, because to do so would be painful and emotive (quotation three).

<u>Illustrative Quotation One</u>: Research Assistant: Would you say there is any one thing that is important to a patient's quality of life?

Sister M: Any one thing, what do you mean?

Research Assistant: Like choice, or dignity?

Sister M: Most patients come into hospital not wanting to stay, they want to go home. That is what we should always keep at the forefront of what we are doing for this patient, and get them to agree that is what we are doing.

<u>Illustrative Quotation Two</u>: Sister T: Fulfilment is, has to be the end product, not the end product, the point you're trying to reach, and I would see my fulfilment as forming a relationship with God.....

(later)

Researcher: What does it mean exactly, fulfilment?

Sister T: Well it's more than being satisfied, its more than being contented, its to do with feeling you are fully developing your potential.

Researcher: Developing your potential.....?

Sister T: And its to do with growth. I think fulfilment is a state, its not.... its a dynamic state.... you don't reach fulfilment and stop.

Researcher: So it implies change?

Sister T: And growth of some kind. And it seems to, it must therefore have an element of future in it, which is where I perhaps find it difficult to think of in relation to elderly people. But, future can be this afternoon, it doesn't even have to be next year, it can be this afternoon or tomorrow.

#### Illustrative Quotation Three

Research Assistant: One of the Sisters said she never used to ask things like that because she was frightened they might turn around and say, 'I haven't got a purpose in life'.

Sister Q: I think you might get that answer here: 'My purpose is to die'.

References: Sister N:2,9; Sister T:15,9,35,36-45; Sister M:16-19; Sister Q:44-45

CATEGORY NAME: THE REAL WORLD

<u>Category Content</u>: When asked how they could improve the quality of the lives of older people in hospital, staff talked about maintaining contact with the 'real world' (quotation one). Patients themselves felt that their friends, relatives and other visitors played an important role in this respect. Continuing interest in the world beyond the walls of the hospital was displayed in conversations about the price of goods in the shops (quotation two) and other contemporary issues.

<u>Illustrative Quotation One</u>: Sister L: If you're going to be in hospital for a long time and you're not acutely ill, you don't need to be tied to that bed area, I think its important to see about getting the patient out and seeing the real world.

Illustrative Quotation Two: Mrs C: Things could be improved, but I know how bad they are. Prices of things, you know, and I'm absolutely staggered to hear that cheese is one pound fifty a pound, and some of it is more than that.

Research assistant: It's gone up since the last time you bought it.

Mrs C: Oh, it will do. By hell, by lots. I can remember the days you could get the best that was made for eight pence a pound.

References: Sister L:2,15; Sister U:37; Sister R:5; Staff nurse X:34; Mr H:14; Mrs C:5,6,8,13,18,27; Mrs I:17.

CATEGORY NAME: RELATIONSHIPS

<u>Category Content</u>: The text suggests that the quality of the interpersonal relationships sustained by older people in hospital is important for the quality of their lives (quotation one). Specific material relates to patients' relationships with staff, with other patients, and with their friends, relatives and visitors.

Illustrative Quotation: Sister T: Somehow the way we relate to each other is important.

Researcher: Yes.

Sister T: And most people don't feel happy and fulfilled unless they are in relationships.

References: Sister T:10,14,20,52; Sister O:9,21; Sister K:107; Sister T:27; Sister Q:41; Sister R:6

CATEGORY NAME: SELF ESTEEM

<u>Category Content</u>: The text proposes a relationship between self esteem and the quality of life, although the precise nature of the link between these two concepts is not easy to elucidate. Illustrative quotations have been selected to demonstrate the presence of this category (quotation one), to show factors cited as promoting and inhibiting self esteem (quotation two).

<u>Illustrative Quotation One</u>: Sister L: I think some patients lose self esteem, so it's important to guide them a bit, but I still think its important to treat them as an individual.

<u>Illustrative Quotation Two</u>: In an unrecorded interview, a physiotherapist stressed the personal appearance as important in self-esteem. Clothing, nice hair, and wearing glasses and teeth and hearing aids were also important. Also tactful handling of socially embarrassing conditions such as incontinence. Patients don't want it revealed to the world.

References: Sister L:35; Charge nurse S:9; Sister U:10; Sister L:10; Sister P:1; Sister M:14; Sister Q:44; Physiotherapist: 8,9; Mrs BB:6; Sister R:15; Staff nurse X:3; Sister Y:7

CATEGORY NAME: STAFFING LEVELS

<u>Category Content</u>: It is argued that insufficient members of staff inhibit the quality of life of elderly people in hospital care.

<u>Illustrative Quotation</u>: Sister N: I think ensuring that the staff have time to spend with patients, again I feel we're very lucky in that we have got reasonable staffing levels, and that can help. I've worked on many wards where you do the very basics for people and there's no time to spend with people, no time to be interested in what they do, what's happened to them at home, how they feel, even time to sit down and talk about the weather. Because a lot of patients that live at home, on their own you know, don't even get a chance to talk.

References: Sister L:45,49; Sister N:7,41; Sister U:23,64; Sister O:15; Sister K:111,140; Social worker W:6; Sister R:5,7; Sister Y:9

## CATEGORY NAME: TAILORING ACTIVITIES TO THE PERSON'S ABILITIES

<u>Category Content</u>: This category describes how nursing staff would adapt the level of difficulty of the recreational activities they provided according to the functional ability of the person concerned.

<u>Illustrative Quotation</u>: Research Assistant: So what specifically do you do here then (in the day hospital).

Sister N: Quite a lot of things really, quite a wide range, because we do gear it to different levels of how people are, like people who are organically ill and people who are functionally ill, there's a very specific difference there, because people come on different days depending on which category they're coming into; so on the days its more organically ill people then its things like art work, very simple craft work, some reality orientation, but if someone said that to me I'd ask them what they meant. It covers such a wide spectrum of things. Just general stimulation about things that have gone by, about the war, how they used to live, but also bringing it back into how they live today in comparison to how they lived in years gone by and just simple word games like finishing proverbs, and things like that we do for the organically ill.

For the functionally ill we can do much more difficult craft work, some quite intricate sewing, and knitting things, things like collecting rose petals and making scented baskets, things that look really nice, and much more difficult quizzes. We've recently done a really good group on reminiscing about the war, and what people were doing when war was declared, you know, getting down to much more specific things rather than a general discussion.

References: Sister N:12

# APPENDIX D

## **DRAFT STANDARDS**

## Activities (including the activities of daily living), and choice and control

Activities of daily living

A range of recreational activities is available within the home.

The person is free to choose whether or not to participate in recreational activities.

The person chooses at what time to go to bed.

The person chooses at what time to rise.

Snacks are available at a time of the persons choosing.

The person can choose where to eat their meals.

A choice of dishes is available at mealtimes.

Drinks are available at a time of the persons choosing.

Alcoholic drinks are available at a time of the persons choosing.

The person chooses when to go to the toilet (i.e., toileting is not according to a rota or timetable).

Help is available for the person who needs it to go to the toilet.

The person chooses when to bathe.

The person is permitted to bathe independently, if they so wish.

The person chooses when to wash.

A walking aid is available for the person who needs it.

The person is able to use their dentures, if appropriate.

The use of dentures is restricted to their owner.

The person is able to use their hearing aid, if they need one.

The person can help with the washing up, if they wish.

# **Recreational Activities**

The person chooses whether to watch the television (i.e., it is not simply left on all of the time).

The person chooses whether to listen to the radio (i.e., it is not simply left on all of the time).

Exercise programmes are available for those who wish to join in.

# Activities, and Clothing

The person is able to participate in laundry tasks.

The person is able to participate in ironing.

# Activities, and Contact with the Real World

The person in able to participate in activities without the home. These activities might include going to church, visiting a pub, going shopping, or simply walking down the street.

# Activities, and Information

The person has access to information about a range of social and recreational activities that are available within the home.

# Activities, and Privacy

The person has access to private space within which to conduct their activities.

# Activities, and Relationship

A range of social activities is available within the home.

Family and friends of the person are free to participate in social activities within the home.

# **Choice and Control, and Clothing**

The person is able to choose what to wear (underwear, outerwear and night-clothes).

Facility is available for labelling clothes with the persons name.

Person is able to be involved in laundry tasks if they wish.

The person has access to the place where their clothes are stored.

## Choice and Control, and Contact with the Real World

The person has access to a telephone whenever they want it.

The person can spend their money as they please.

The person can maintain registration with their own general practitioner.

The person can maintain registration with their own dentist.

The person can get access to their medicines whenever they want it.

The person has access to their pension book and money when they want it.

A range of newspapers is delivered to the home.

There is opportunity to discuss current events.

There are opportunities to visit family and friends, pub, church, shops, etc.

The person may choose to walk in the grounds of the home.

The person is free to walk in the streets surrounding the home.

## Choice and Control, and Information

The person is informed of mechanisms for choice before becoming resident in the home.

## **Choice and Control, and Place**

The person has free access to all shared areas in the home.

The person may bring items of furniture into the home.

The person can choose where to sit.

The person may influence the placement of furniture within their room.

The person may influence the decorative style of their room.

The person is shown around the home when they first arrive.

Staff are available to help with mobility, for those who need it.

The toilet has rails at the side.

The bath has rails and other safety features to encourage independent bathing.

## Choice and Control, and Privacy

Members of staff knock on the door and wait to be invited in before entering the persons room.

The person is free to enjoy solitude.

When the person is having a bath, members of staff do not enter the bathroom without asking permission.

When the person is dressing or undressing, members of staff do not enter the room without asking and receiving permission.

#### **Choice and Control, and Relationships**

Chairs in the sitting room are placed so as to facilitate conversation.

The person is free to entertain guests at a time of his or her choosing.

There is a place in which the person may entertain guests in private.

The person can obtain a drink and a snack for guests.

The person may demonstrate affection to other residents in the home.

Intimate behaviour between consenting residents is not discouraged.

## Clothing, and Contact with the Real World

The person may visit the shops to select new items of clothing.

The person may select new items of clothing from catalogues.

## **Clothing, and Information**

The person is informed of the policies relating to clothing before becoming resident in the home.

The person is informed that they may select their own clothes to wear.

#### **Clothing, and Patterns of Activity**

The person selects the clothing that they wear (applies to underwear, top clothing, and night attire)

#### **Clothing, and Personal Possessions**

The person wears their own clothing.(applies to underwear, top clothing, and night attire)

Items of clothing are not shared between residents (applies to underwear, top clothing and night attire).

## Clothing, and Place

Storage space for the persons clothing is available in their room.

## Clothing, and Privacy

When dressing or undressing, the person is permitted the maximum degree of privacy that is permitted by their functional capacity.

## Clothing, and Relationships

Family members and friends are permitted to assist in dressing and undressing, at the discretion of the person.

## Contact with the Real World, and Information

Information is available about opportunities to participate in activities beyond the home.

## Contact with the Real World, and Patterns of Activity

Structured opportunities are available to discuss current affairs.

Structured opportunities are available to reminisce about the past.

Family and friends are permitted to share in the social programme of the home.

# Contact with the Real World, and Personal Possessions

The person is encouraged to keep personal possessions that represent important links with their life beyond the home.

## Contact with the Real World, and Place

Contact with the Real World, and Privacy

## Contact with the Real World, and Relationships

The person is encouraged to maintain friendships that existed before they came to live in the home.

## Information, and Patterns of Activity

The home offers a programme of social and recreational activities.

Information is available about the social and recreational activities that are available in the home.

There is a place to go for those who do not wish to watch the television.

Staff do not leave the radio or television switched on without the permission of the residents.

## Information. and Personal Possessions.

People are informed before the commencement of their residence that they may bring personal possessions into the home.

# Information and Place

## **Information and Privacy**

People are informed before the commencement of their residence that they have a right to privacy.

# Information and Relationships

People are informed before the commencement of their residence that visitors may call at their discretion.

# Patterns of Activity, and Personal Possessions

The person is permitted to use their own crockery and cutlery at meal times.

The person uses their own face cloth, towel, tooth-brush, and toiletries.

## Patterns of Activity, and Place

There is a place in which the person can pursue their preferred activities and pass-times.

## Patterns of Activity, and Privacy

There is access to private space.

## Patterns of Activity, and Relationship

# Personal Possessions and Place.

The person is permitted to bring valued personal possessions with them into the home.

# **Personal Possessions and Privacy**

The use of valued personal possessions is restricted to their owner

# **Personal Possessions, and Relationships**

# Place, and Privacy

There is a private place to be with family and friends who visit.

# Place, and Relationship

There is a place in which the person can entertain friends and family members.

# Privacy, and Relationship

A place is available in which the person can spend time with friends and family members.

#### Addendum

#### Use of the word "interpretive"

Throughout this thesis, "interpretive" is used in preference to "interpretative". Within the broader literature, the use of "interpretive" is almost universal. My choice is supported by *The Penguin Dictionary of Troublesome Words* (Bryson 1984), and *The Bloomsbury Good Word Guide* (Manser 1990), both of whom consider either word to be acceptable.

## Use of the first person

I use the first person singular throughout this thesis, from time to time. In so doing, I contradict the convention associated with positivist and natural scientific research, wherein the use of the third person is used to indicate objectivity; and acknowledge, in a manner that is congruent with the hermeneutical underpinnings of this study, that I as researcher am an important actor in the project. My use of the first person conforms with common practice in qualitative research, and is supported by Webb (1992 - The use of the first person in academic writing: objectivity, language and gatekeeping, *Journal of Advanced Nursing* 17 (6) 747-752).