

Older People's Definitions of Quality of Life and the Relevance of Various Scales

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Abstract

This thesis addresses issues related to the definition and measurement of quality of life amongst older people living at home. It consists of a literature review and an empirical study. The literature review identifies previous work in the field of quality of life definition and measurement, with particular reference to older people. It also presents a classification or taxonomy of quality of life definitions, demonstrating a lack of consensus amongst those proffering definitions of the phrase, and underpinning a discussion of factors influencing definitions.

The empirical study identifies lay definitions of quality of life among people aged 65 and over living at home in two contrasting locations (inner city and semi-rural). It highlights the multifaceted and subjective nature of the concept, but also identifies key components of respondents' lives. Essentially, the findings question the operationalisation of quality of life simply in terms of 'health'. Respondents' descriptions of their quality of life included health, but also included their families, feelings, location, working lives and retirement, social contacts, the past, material circumstances, personality, activities, daily tasks, crime, independence, the degree of control they had over their lives, services, society, the experience of old age, and transport issues. In addition they used their personal and social histories to contextualise their quality of life. The study also demonstrates the difficulties some older people face when completing some scales used to measure quality of life. In addition, some scales lacked relevance to older people, in terms of their structure and item content.

Thus this thesis addresses some of the problems of defining and measuring quality of life

amongst older people. It does not attempt to produce yet another 'quality of life' measure, but uniquely asks older people to describe the quality of their own lives, in their own words, using their own frames of reference.

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Introduction

The term 'quality of life' is in vogue. It has become popularised, even clichéd. In recent years the term has appeared in a range of media from television and magazine advertisements to political speeches and newspaper headlines. Diverse examples of promotions using the phrase 'quality of life' during the 1990's include: Philips' Whirlpool washing machines (early 90's onwards); Marks and Spencers' British beef and pork promotion in Good Housekeeping (1994); Hyundai cars (mid 1990's); Babycover (Lloyds insurance, late 90's); and Logis de France (French holiday accommodation, mid 90's). Local authorities have used the term 'quality of life' in promotional material e.g. Braintree District Council (1990); Birmingham City Council (1991); Glasgow Development Agency (1990s); and in the US, Pasadena (1990s). It has been widely used in recruitment drives e.g. Queen's Medical Centre's nursing recruitment drive (Nursing Times, 1998), ZMB recruitment consultants and NatWest (national press). And it proliferates the present Department of Health website (a search for the term conducted on 25/11/02 achieved 888 hits). On a more whimsical note, the 1992 general election even saw the establishment of political party called 'The Quality of Life Party', whose prime aim was to prevent the closure of Richmond Ice Skating Rink.

The increasing appearance of the term 'quality of life' in these formats says something about its importance to us as a concept or even an ideal. Its global standing and relentless and sometimes ruthless application in both commercial and civic settings show little sign of abating. However the term 'quality of life' is not only used in everyday speech, but also in the context of research. It has been linked to various specialised areas such as sociology,

psychology, medical and nursing science, economics, political science, philosophy, history and geography (Schuessler and Fisher, 1985; Hanestad 1990; Farquhar, 1995), and pursued in many nations, particularly those with central or planned economies (Schuessler and Fisher, 1985). Indeed, it has been suggested that the broad appeal of the concept could help facilitate communication between knowledge-oriented and action-oriented professionals (George and Bearon, 1980). A term in such multidisciplinary use begs the question ‘where has it come from?’

Hanestad (1990) believes that the term has gained currency partly because of its positive connotations, stating that ‘most people will agree that quality of life is an aim for both the individual and for groups of individuals’. However this assumes that the term ‘quality of life’, or even the concept of ‘quality’, refers only to a positive state, rather than simply ‘a state’. A dictionary definition of ‘quality’ gives it this positive connotation, but also notes its descriptive ability. The Shorter Oxford English Dictionary defines it as (in relation to ‘of things’) ‘1. An attribute, property, special feature; 2. The nature, kind, or character (of something)’ (Little et al, 1978).

The public arena (e.g. journalism, politics and advertising) tends to focus on the first, positive interpretation, whereas health and social research focuses on the second, descriptive interpretation of the term (Farquhar, 1995b). For example, Schuessler and Fisher (1985) state that most specialists agree that the term ‘quality’ has the same meaning as ‘grade’, and that grades range from high to low, or better to worse: ‘hence, one reads statements such as “Their QOL [quality of life] is improving” and “Their QOL [quality of life] is worse than ours”’.

They point out, however, that there is less agreement about the meaning of the term 'life' (Schuessler and Fisher, 1985).

In Western health care, quality of life has offset survival as an aim as we have become increasingly aware that a long life is not necessarily a good life (Hanestad, 1990). Where death is the inevitable outcome, for example when patients are in the terminal stage of a disease, quality of life has an important role to play:

'The sufferer of a potentially incurable disease is exposed to many difficulties; not only is his future unpredictable but the methods of treatment are themselves toxic, inducing many unpleasant side effects. It is, therefore, important that we are aware of the impact these can have on the quality of the patient's life, particularly in those whom cure, or improved survival, is unlikely' (Priestman, 1984).

However, even where the chances of death may be reduced, consideration of the effects of reducing that risk on quality of life remain paramount as demonstrated by the work of McNeil et al (1981). McNeil et al (1981) investigated the attitudes toward the quantity and quality of life in 37 healthy volunteers. The aim was to determine their preferences for longevity and voice preservation in the case of treatment for stage T3 carcinoma of the larynx with laryngectomy or radiation, using trade-off techniques. This carcinoma is restricted to the vocal cords, causing complete immobility of the cords but not extending to adjacent structures. Laryngectomy leads to a three-year survival rate of approximately 60% and the loss of normal speech; radiation therapy leads to lower survival (30-40% at three years) but preserves normal or nearly normal speech. Analysis indicated that to maintain their voices, approximately 20% of volunteers would choose radiation instead of surgery; the assumption here being that effects on speech affect quality of life, however the authors have questioned

whether these results were due to the effects of question framing.

Similarly, the World Health Organisation (WHO) (1985) has stressed that the prerequisite for a fuller life is not simply to add years to life, but to add 'life to years'. This can be no more pertinent for any other section of a population than the older population. A good quality of life is often the stated goal of care of elderly people (British Geriatrics Society and Royal College of Nursing, 1975; World Health Organisation, 1986). Indeed, Grimley Evans (1992) refers to claims that quality of life is *particularly* suitable as an outcome measure of health care for older people on the assumption that they will be more interested in quality of survival than length of survival from health interventions; he goes on to suggest, however, that this assumption may be partly an inappropriate projection of younger people's ideas about being old.

This thesis aims to identify previous work in the field of quality of life definition and measurement, with particular reference to older people and to develop a taxonomy of existing quality of life definitions. Further, through empirical study, it aims to identify lay definitions of quality of life among older people and examine the relevance to older people of scales commonly used to measure quality of life. Thus this thesis deals with issues high on the agenda of the ongoing debate about quality of life and its measurement, with a particular focus on older people. It has implications for those involved in both quality of life research and in health and social policy for older people. In terms of quality of life research, and in particular health services research, it calls for a consensus or, at the very least, clearer definitions of the term quality of life. It raises the issue of the medicalisation of quality of life

by questioning the validity of the operationalisation of the concept simply in terms of health status measures and scales of functional ability.

Aims of thesis

This thesis has two overall aims. The first is a context setting exercise and literature review on quality of life, and the second an empirical study of quality of life in older age. The thesis is therefore presented in two parts accordingly.

Aims of the context setting and literature review

The aims of the context setting exercise and literature review are:

- i) the identification of previous work in the field of quality of life definition and measurement, focusing on literature up to the year 2000, with particular reference to older people; and,
- ii) the development of a classification or taxonomy of quality of life definitions to demonstrate consensus, or its lack, in the field. It is proposed that the organisation of existing definitions into a framework will identify common elements and underpin the discussion of factors influencing definitions.

Aims of the empirical study

The aims of the empirical study are:

- i) the identification of lay definitions of quality of life among people aged 65 and older living at home; and,
- ii) the examination of the relevance to older people of scales commonly used to measure

quality of life.

I propose that some of the problems of defining and measuring quality of life can be addressed by asking people to describe the quality of their own lives, in their own words, using their own frames of reference (Farquhar, 1994).

PART ONE: CONTEXT SETTING AND LITERATURE REVIEW

Chapter 1: Contextualising quality of life

Chapter 1 will introduce and contextualise the concept of ‘quality of life’ by describing the origins of the concept, charting its history from the end of World War II up to the year 2000, focusing principally on its use within health-based disciplines. It will go on to discuss the definition of quality of life, organising the various published definitions into a taxonomy in order to demonstrate consensus, or its lack, in the field. The various factors influencing the various definitions will then be discussed.

The rise of ‘quality of life’

After the end of World War II, the term ‘quality of life’ became commonly used. For example, in American vocabulary, the term was initially used in reference to material goods such as a house, a car, more and better appliances, and the money to travel and retire (Alexander and Willems, 1981). Following this the use of the term gradually broadened, for example ‘quality of life’ was included in the report of president Eisenhower’s Commission on National Goals in 1960, which referred to education, concern for the individual, economic growth, health and welfare, and the defence of the non-communist world. Similarly, Bech (1987) cites President LB Johnson’s declaration at a political meeting in 1964 that ‘goals cannot be measured in the size of our bank balance. They can only be measured in the quality of lives that our people lead’. And Bauer’s work (1966) on the secondary effects of the US

national space programs on American society included the notion of 'quality of life'. The term also featured in Europe in the political discussions of the 1960s (Sullivan, 1992). Then, following the major political and social upheavals starting in the late 1960s, emphasis switched towards personal freedom, leisure, emotion, enjoyment, simplicity and personal caring. The term then served to indicate that the 'good life' represented more than simple material affluence (Campbell, 1981; Ebbs et al, 1989).

Apart from an early occurrence in 1939, Offer (1993a) identifies the first book title containing the term 'quality of life' in 1962, and a further fifteen titles during the 1960s. Most related to the 'urban experience', but one related to the wilderness, two were about the growth experience of developing countries, and two were on health. Bech (1992) cites Galbraith as noticing the need to measure the effect of the health care system on quality of life prior to this in his 1958 book 'The Affluent Society' (Galbraith, 1958). And the 1970s saw a proliferation in the number of book titles incorporating the term 'quality of life', leading to a cumulative total of just under 1700 by 1993 (Offer, 1993a).

In their review of the Canadian and American sociological literature on quality of life Schuessler and Fisher (1985) suggest that putting the start of quality of life research in the 1960s is arbitrary as although the use of the term 'quality of life' may first be located in the 60's, the concept itself has a longer history: 'concern about the good life is probably as old as civilisation. In terms of scientific inquiry, what is being done today under the heading of QOL [quality of life] research was done by earlier generations.... under various other labels.' What Schuessler and Fisher are implying here is that research into quality of life and its

components did not necessarily commence in the second half of the twentieth century. Philosophers have long been interested in what constitutes a good life, but what is unique to the modern period is the wide (and mainly uncritical) acceptance of the all-encompassing term 'quality of life' as a conceptual heading for some or all of the components of what makes life liveable. Indeed much of what passes under the heading of 'quality of life research' today might have been found under the heading of 'wellbeing', 'health' and/or 'functional ability' previously: a critique which will be resumed later.

During the post-war years of rapid economic growth and social change there were concerted efforts to measure quality of life for the purposes of social research in both America and Europe. Objective social indicators were those measurable social statistics such as divorce or delinquency rates, or possession of consumer goods such as the number of households with telephones or two cars, or perhaps, as Huxley (1986) suggests, the number of cars you have with two telephones. In other words, measures which could be taken to show changes in the societal quality of life.

However, these measures were not unproblematic. Huxley (1986) outlines their main problems as: a general reaction against trying to measure everything in economic terms and the recognition that not all groups in society were economically active, so that measurements of improvements in the quality of life had to be assessed using different indicators; and the low level of validity of chosen indicators such that the results tended towards the ludicrous. One of several examples of the latter cited by Huxley (1986) was from a study assessing the quality of life in American cities, in which the following formula was proposed:

$QOL=F(PH,PS)$. PH is physical inputs (i.e. quantifiable needs and services) and PS is psychological inputs (i.e. self-esteem, self-actualisation, happiness etc). The authors treated all psychological inputs as unquantifiable, making quality of life equivalent to assessments of material circumstances (Huxley, 1986). In a similar vein, Gehrman (1978) illustrated that because of the cumulative effect the differences in various aspects of measurement (e.g. variation in the selection, aggregation, weighting and measurement technique of indicators) a rank difference of 23 ranks could be constructed deliberately for 60 German cities in the assessment of cities' quality of life.

Thus problems with 'objective' social indicators lead to the birth of the 'subjective' social indicators movement¹. In contrast, the subjective social indicators movement set out to measure social (as distinct from economic) performance. It was argued that because people's subjective responses are real and people act on the basis of them, one should take account of these subjective responses when assessing quality of life (Abrams, 1973). Attention was focused on satisfaction and life satisfaction: a subjective assessment of overall quality of life (Huxley, 1986). Social historians (see for example Offer, 1993b) have described the broad front of reforming movements (including the subjective social indicators movement) which emerged in the 1970s, each concerned in its own way with 'the quality of life': (1) the environmental/ecological movement; (2) the consumer movement; (3) the stress on basic needs in development economies; (4) the social indicators movement; (5) 'post-materialism' (a downplaying of material values in a large educated elite subgroup in developed countries); (6) New Age (the pursuit of alternative values and therapies, rooted in the religions of south-

¹ Although some may not agree with the distinction of 'objective' and 'subjective', this is the nomenclature used in the literature.

east Asia); (7) research on perceptual biases in psychology, economics and decision theory; (8) psychographics (a shift in consumer segmentation by marketing experts from social class based demographics to a pattern based on personality types and associated lifestyles); and (9) quality of life research in medicine (Offer, 1993b).

In the twenty first century the government continues to use 'quality of life indicators' as a measure of life in Britain, in particular in relation to economic, social and environmental factors. For example, a press release from 10 Downing Street on 13th March 2002 was entitled 'Britain moving towards a better quality of life', with the subtext 'a report into quality of life in Britain shows that child poverty and vehicle crime have fallen, while household waste has increased'; it proudly reports that '10 of the 15 main indicators have moved in the right direction' (<http://www.pm.gov.uk/output/page4619.asp>).

Perhaps the greatest growth area for quality of life latterly, however, has been within medicine. For example, using the American RLIN research library network database, Offer (1993a) identified just 220 publications on ECONLIT (the academic economics database) from 1969 to 1991 (a 22 year period); SOCIOFILE (its sociological counterpart) had 1755 from 1974 to 1991 (a 17 year period); whereas PSYLIT (for psychology) had 2020, and MEDLINE had 1535 for 1991 alone. Using WEBSPIRS, comparable figures from 1/1/2000 to October 2002 were 51 for ECONLIT and 2598 for MEDLINE; in addition PSYCINFO held 958 (search conducted 25/11/2002).

The initial use of the term 'quality of life' in medicine was within health economics and

clinical trials. The economic evaluation of benefit from a course of treatment or an intervention depends on the ability to measure outcomes, and one method which has become popular with health economists and some health service managers is the QALY, or Quality Adjusted Life Year (Carr-Hill and Morris, 1991). Essentially economists apply cost-benefit analyses to the subjective experiences of illness and health. The QALY is a cardinal number representing a unit of benefit that combines a measure of life expectancy with a measure of quality of life. One year of current life in perfect health is counted as one QALY, and one year of current life with a lower level of health, 'q', (where $q < 1$) is counted as q QALYs; the value of a future year of life is adjusted to a current value by discounting at a rate 'r'. The health profile of (prospective) patients over their expected future life span can be used to calculate the current value of their expected remaining QALYs and comparisons can then be made between different types of treatment on the costs per QALY gained, and, in theory, policy for determining the distribution of resources rationalised.

Banner (1992) has described QALYs as 'a proposal fraught with difficulties, not only moral but also technical or practical', and Potts (1992) more extremely as 'a killer'. The reasoning behind such descriptions is primarily the expression of quality of life per se in terms of numbers (Nord, 1992) and the resulting conclusion that some states of existence register as less than zero, that is they are states worse than death, particularly where life expectancy is low, as with older people and those in receipt of terminal care. In addition there is discomfort with the notion that the value assigned to life varies with the health state of a person, that all the emphasis is placed upon the size of any health improvement ignoring the starting point, and that the focus is on quality of life in life years rather than on quality of life in people

(Nord, 1992)², as well as problems with the assumptions underlying the calculation of QALYs and doubts about the quality of data used (Spiegelhalter et al, 1992). Further, what one does with such information raises both moral and ethical dilemmas.

From the mid-1970's, trials of clinical interventions began using quality of life as an outcome measure, in particular in the fields of oncology, rheumatology and psychiatry. In contrast to the plethora of current studies only 6% of clinical trials in the cancer field purported to measure quality of life outcomes between 1956 and 1976 (Bardelli and Saracci, 1978). In reviewing these trials, Bardelli and Saracci (1978) found that the majority of these studies used an inappropriate measure of quality of life; most commonly the Karnofsky performance Index (Karnofsky and Burchanel, 1949). This scale, which was developed as a measure of nursing workload, is completed by the physician and concerns only the physical functioning of patients. No assessment is made of other items thought to constitute quality of life and the scale takes no account of the subjective feelings of patients themselves (Ebbs et al, 1989).

Mosteller et al examined a sample of clinical trials in cancer and found 'the overwhelming majority of these studies reported outcome only in terms of survival or recurrence. Quality of life was mentioned but rarely measured' (Mosteller et al, 1980). Interestingly, Ebbs et al (1989) noted that few of these trials reported any clear difference between treatment groups when survival and recurrence were the only variables being assessed; if appropriate measures of quality of life had been included more useful data may have been generated.

² For a fuller discussion of the objections to QALYs see Potts (1992) and Nord (1992).

McPeck and McPeck reviewed 28 clinical trials of treatments for gastric cancer. Half of the trials reported nothing on quality of life, in five they found only a passing reference, seven reported the percentage of patients in various treatment groups suffering from distressing symptoms, but they included little or no discussion of the effects these had on patients' lives. Only two of the 28 papers offered a careful, systematic effort to examine the quality of patients' lives and report these findings as outcome measures (McPeck and McPeck, 1984).

In 1989, Ebbs et al described the 1980s as the 'peak of critical appraisal of the medical profession' in the United Kingdom³, highlighted by the Reith Lectures on BBC Radio, in which the legal and ethical issues facing the profession were scrutinised by Ian Kennedy (Kennedy, 1981). The, by now, increasing use of quality of life as an outcome measure in clinical trials has been described by Ebbs et al (1989) as the medical profession beginning to realise its responsibility for the welfare of the 'whole patient'. Similarly, Hunt (1997a) sceptically describes it as 'an extension of notions concerned with perceived health and a concern to include the views of patients in decision-making'.

The concept of quality of life has been slower to permeate surgery. O'Young and McPeck (1987) found that only 3% of trials reported in surgical journals mentioned quality of life. In the mid 1970s, Gilbert and colleagues reviewed a sample 107 papers evaluating surgical and anaesthetic treatment (Gilbert et al 1977a, McPeck et al, 1977; Gilbert et al, 1977b). They found that, while the quality of life following treatment frequently emerged as an important issue, the degree of long term follow up varied considerably. Although many surgical

³ Although in retrospect, from the viewpoint of the new millennium, we may have a different perspective on this.

investigators gathered and reported data on quality of life, many others had neglected this area.

More recently, quality of life measures have been applied to many aspects of health care from day-to-day clinical decisions, in setting priorities for allocating resources, in assessing the effectiveness of health services and in innovation (Ebrahim, 1987). As a result a profusion of papers published in medical and nursing journals have referred to the term quality of life but in a heterogeneous manner making comparison difficult (Ebbs et al, 1989). Indeed, where many papers refer to 'quality of life' what they are in fact referring to is some form of 'health-related quality of life', and not 'quality of life' itself (Farquhar, 1992) i.e. they are measuring just one domain of quality of life - health. Wade (1992) has expressed a similar sentiment in the field of neurological rehabilitation, where he describes most studies of quality of life as 'in fact measuring simple disability'.

Guyatt et al's (1989) survey of 75 randomised controlled trials found that 'although a number of investigators used quality-of-life instruments in a sophisticated manner, in only 10 of 55 trials in which measurement [of quality of life] had been judged to be crucial or important were instruments with established validity and responsiveness used'. Naeser (1992) describes, but unfortunately does not reference, a study of the treatment of patients with neuropathy in which 'a measure of how the patients slept during the night was claimed to reflect their quality of life'. Gill and Feinstein (1994) examined 75 randomly chosen articles that described the use of 'quality of life' instruments and found that very few even attempted to define what was meant by 'quality of life' or to justify the choice and content of measures

used. Similarly, Hunt (1997b) reviewed 26 clinical trials of anti-hypertensive drugs which included 'quality of life' outcome measures and concluded that none of the claims relating to quality of life could be upheld on scientific criteria relating to definition, rationale, measurement and interpretation of results. Naeser (1992) describes the confusion that exists in many clinical trials as to whether measures are clinical efficacy variables or quality of life variables: 'previous clinical endpoints, such as pain, performance status, body weight, or dryness in the mouth are in reality quality of life measurements today'. It is unclear from the paper if Naeser (1992) is condoning this activity.

In their review of measures of need and outcome in primary health care, Wilkin, Hallam and Doggett (1992) note the shift from measuring symptoms, function and disability to (positive) health, well-being and quality of life. In a similar sentiment to Schuessler and Fisher cited earlier (Schuessler and Fisher, 1985), they suggest that this 'shift' is merely cosmetic: 'the actual content of measures has changed rather less than might be suggested by their titles'.

They go on to state that:

'it might be argued that the changes in titles are more a reflection of prevailing political pressures than any real change in content. The titles of papers sometimes seem to owe more to the designated subject of the conference or book to which the authors are contributing, than to the content and conceptual foundations of the measures presented.' (Wilkin, Hallam and Doggett, 1992 (p15))

Hunt's (1997a) eloquent editorial on 'The Problem of Quality of Life' usefully summarises the growing concerns of such researchers, and specifically in relation to the definition of the concept, and its application and measurement in clinical settings and health economics: 'as a consequence there must be grave doubts about the wisdom of using "quality of life" as an

outcome which could influence the lives of patients'. She describes the 'state of disarray and dissent' as:

'...not being uncommon in the beginning of scientific investigation of an unclear phenomenon, where competing teams test hypotheses and build models, experiment with measuring techniques and refine theories. However, it is virtually unprecedented that a term which lacks clear definition, upon which there is no consensus in the research or the clinical community, which is measured by a motley array of questionnaires of doubtful appropriateness and dubious validity, is actually being applied in situations which will affect the decisions made about people who are ill. This is not only unwise it is clearly unethical.' (Hunt, 1997a (p205))

She describes two common and contradictory attitudes among some researchers and writers on the topic. First, the attitude exemplified by those who state categorically, but inaccurately, that there is 'general agreement' on the components that make up quality of life (see for example: Sullivan, 1992); and second, the attitude illustrated by those who justify a *laissez faire* use of measures by pointing out that there is 'no gold standard' for quality of life (Hunt, 1997a)⁴. The latter attitude has led to indicators of 'quality of life' ranging from purely physiological through functional capacity to complex series of questionnaires on social activities and psychological problems: 'too often, a particular questionnaire seems to have been administered simply because it was there or because it had been used before in a similar study' (Hunt, 1997a). Although it could be argued that this, at the very least, allows for some comparability between studies.

Fitzpatrick et al (1992a) state that the term quality of life 'misleadingly suggests an abstract and philosophical approach', and that most approaches used in medical contexts do not

⁴ Bech (1992) has noted that no rating scale has as yet been adopted by Index Medicus as a sub-heading under 'quality of life' (giving it the potential status of a gold standard) despite the acceptance of the heading in 1977.

attempt to include more general notions such as life satisfaction or living standards, and tend rather to concentrate on aspects of personal experience that might be related to health and health care. They go on to describe the synonyms for quality of life, specifically 'health related quality of life', 'subjective health status' and 'functional status', as 'more accurately' conveying the content and purpose of measures (Fitzpatrick et al, 1992a), although they do not question the validity of this. Faden and Leplege (1992) are more challenging, describing the term 'health-related quality of life' as an attempt to narrow the scope of the concept of quality of life to the impact of health states on it without reflecting a resolution of theoretical dilemmas about the nature or meaning of quality of life itself.

Hunt's (1997a) principal criticism appears to be of the lack of analytical work in the field: 'the paucity of intellectual debate on the topic, the absence of any theoretical development beyond a mere statement of position and the premature application of measurement...without a theoretical framework there is no means of linking what is actually and what is supposedly being measured'. However, she notes the lack of financial support for such work in contrast to the 'strong commercial backing for applied studies' (Hunt, 1997a).

Despite such concerns, quality of life remains high on the agenda of health and social research. Hunt (1997a) describes quality of life as the 'buzz word' or 'sound-bite' of health administrators, economist, some clinicians and pharmaceutical companies. There is mounting interest in the use of so-called 'quality of life measures' in the clinical setting beyond clinical trials, health services research and policy analysis i.e. in clinics and at the bedside (Faden and Leplege, 1992). Faden and Leplege (1992) have questioned the

legitimacy of this evolution presenting a useful summary of the arguments both for and against this extension of application of quality of life measures into clinical practice.

In 1977, 'quality of life' was accepted as a heading in Index Medicus. Hornberger and Lenert (1996) identified the more than 180% increase in the number of MEDLINE citations between 1985 and 1993 referring to 'quality of life' or 'health status' compared to only a 77% increase for all citations indexed by the term 'health'. At the beginning of 1998 Medline contained around 15,400 publications with 'quality of life' as a key phrase and 530 publications dealing with quality of life issues in clinical trials (Joyce, Acquadro and Haugh, 1998).

Muldoon et al (1998) suggested that over 1,000 new articles are indexed under 'quality of life' each year, however even this high rate has been exceeded: a MEDLINE search (using Silver Platter) for the MeSH heading 'quality of life' conducted for this thesis for 1997-1999 identified 6,707 publications, and an update of this search (using WEBSPIRS, conducted 25/11/02) for the year 2000 alone revealed 3,214. A search over the same time periods for the *key phrase* 'quality of life' identified 9,796 publications for 1997-1999 and 4,834 publications for the year 2000. A 'quality of life' MeSH heading search covering from 1966 (earliest available) to the end of 2000 identified 22,597 publications and a 'quality of life' key phrase search for the same period identified 32,012 publications (conducted 25/11/02).

Several topical reviews of quality of life research have been published in journals (see for example Land (1983) on social indicators, Larson (1978) on gerontology, Palys and Little (1980) on psychology, and Schuessler and Fisher (1985) on Canadian and American

sociology), and books purporting to review quality of life measures (e.g. Fallowfield 1990; Bowling 1995a & 1997a). Entire journals are now centred on the topic of quality of life (e.g. Quality of Life Research), institutions with research programmes focusing on ‘quality of life’ produce regular newsletters on the subject (e.g. the ‘Quality of Life Newsletter’ from the Mapi Research Institute⁵), and there are research centres and units devoted to ‘quality of life’ (e.g. the Health and Quality of Life Research Centre, University of Plymouth (<http://salmon.psy.plym.ac.uk/intro.htm>); The Quality of Life Research Unit, University of Toronto (<http://www.utoronto.ca/qol/>); and the independently run The Quality-of-Life Research Centre in Copenhagen (<http://home2.inet.tele.dk/fclk/>)).

Further, entire conferences, in addition to conference streams, are now devoted to the subject of quality of life and its measurement. For example, the 4th Annual Conference of the International Society for Quality of Life Research was held in Vienna in November 1997 attracting more than 600 delegates from 20 different countries and comprising 289 oral papers presented in 12 concurrent sessions, 153 poster presentations, six discussion forums and eight ‘meet the developers of instruments’ sessions. Oncology was the most heavily represented among the oral sessions followed by HIV/AIDS and other chronic diseases. Psychiatric disorders and substance abuse were the predominant topics in the poster presentations (Mazumdar, 1998). In his review of the conference Mazumdar (1998) suggests that quality of life conferences ‘seem to be getting into better shape’: whereas earlier conferences had focused on conceptual issues, and debated what was and what was not quality of life, this

⁵ The Mapi Research Institute describes itself as a ‘non-profit organisation whose objectives are to facilitate and advance the science and practice of HRQoL [health-related quality of life] evaluation and to support and promote collaborative research initiatives’ (Joyce, Acquadro and Haugh, 1998).

more recent conference discussed more methodological issues. However, judging by the lack of consensus that remains among the published literature, this apparent progress may be premature.

Defining quality of life

Any study of merit should define its terms of reference, aims and purpose. Consequently any proposal designed to measure or improve quality of life must define the concept in terms that are clear, precise, universally understood and acceptable (Denham, 1983). Therefore before quality of life can be evaluated, it is necessary to define those qualities that make both life and survival valuable (Bayles, 1980). However, it has been said that quality of life is a difficult concept to define (Frayers and Jones, 1983) and that attempts to do so become exercises in philosophy rather than precision achievements (Pirsig, 1974). There is little empirical research attempting to define those qualities which make life and survival valuable (Bowling, 1997a).

It is generally accepted that quality of life means different things to different people (George and Bearon, 1980; Bulpitt and Fletcher, 1990). It has been described as 'a maze which is surrounded by a marsh and shrouded in fog' (Huxley, 1986), as 'morally loaded' (Faden and Leplege, 1992), 'ambiguous and aggravating' (Edwards, 1985), and, perhaps more constructively, as a 'rubric' (Schipper and Clinch, 1988). It has been said that quality of life is a still evolving concept: 'to a certain extent it is popular ahead of its time, making it vulnerable to both abuse and discredit, particularly through over-simplification' (Schipper

and Clinch, 1988); a status alluded to by Todd in a book chapter subtitled ‘the emperor’s new clothes’ (Todd, 1995).

Published definitions of quality of life in medical and nursing journals are as numerous and inconsistent as the methods of assessing it. It is a problematic concept as different people value different things (see for example: McGee et al, 1991; O’Boyle et al, 1992, Browne et al, 1994). Closer inspection of papers that mention quality of life in their titles often reveals professionals’ limited or subject-focused perceptions of the concept. Many studies have either avoided defining what they purport to measure (see for example, Palmer et al, 1980, Bell et al, 1985) or have limited their definitions to what the investigators have seen as large components of the whole concept (Huxley, 1986; Ebbs et al 1989; Farquhar, 1992). To date there is no firm consensus about the meaning of the term (Denham, 1983; DeHaes and Van Knippenberg, 1985; Calman, 1984; Cribb, 1985; Edlund and Tancredi, 1985; Ferrans and Powers, 1985; Landesman, 1986) or its theoretical construct (Schipper and Clinch, 1988; Wade, 1992), although many determinants and indices have been suggested as standards for ‘life quality’ (Ferrans and Powers, 1985).

A proposed taxonomy of definitions:

The development of a classification or taxonomy of quality of life definitions for this thesis serves not only to demonstrate this lack of consensus, but also to organise existing definitions into a framework in order to identify common elements in definitions and factors influencing definitions. To this end the following taxonomy, based on that previously published by the

author during the preparation of this thesis (Farquhar, 1995b), is proposed.

Definitions of quality of life can be simply classified in terms of their origin: that is whether they are 'expert' (professionals') definitions i.e. those presented in the published academic literature (published conference abstracts, journal papers, and books), or whether they are lay definitions. This formed the first step in the development of the taxonomy, and the plethora of definitions in the 'expert' category compared with the 'lay' category was part of the justification for the empirical work. However the number and diversity of definitions within the 'expert' literature required further categorisation in order to identify a consensus, or at the very least, patterns within the definitions to enhance the literature's manageability, and further justify the empirical work. Thus the collection of definitions identified from the published literature for the purposes of this thesis were analysed qualitatively.

Just as a qualitative researcher might analyse a group of interviews by reading and re-reading their content, seeking out recurring themes, searching for deviant cases and refining and reorganising categories of themes and developing sub-themes as each new interview is incorporated into the analysis until theoretical saturation is reached, so the collected definitions were analysed. First the definitions were extracted from the published literature by photocopying them and isolating them from their original text, and labelling them with a reference number to identify their source. The definitions were then read, and re-read several times in order to gain familiarity with the total volume of material. This process led to the identification of different types of definition according to their complexity and nature: some were simple single sentences, some consisted of more than one sentence and others included

listings of possible components of the concept of quality of life.

It became apparent, however, that within this broad categorisation of the definitions in terms of their structure, there were clear variations in terms of the content of the definitions. Re-reading the definitions lead to the identification of key concepts within the structure of the definitions. For example, within the group of definitions that contained listings of possible components, there was variation in the quantity and type of components suggested; some definitions referred only to selected dimensions of quality of life (such as health and functional ability, or economic parameters of quality of life), whereas others considered a wider range of possible components. Thus the initial broader categories based on the structure of the definitions were enhanced by consideration of their content, and subcategories were developed and refined as further definitions were examined until theoretical saturation was reached i.e. new definitions fitted into the categories and subcategories that had been developed and no further refinements to the taxonomy were required.

I have suggested here that the process of analysing this qualitative material (i.e. the definitions) has parallels with the process of analysing empirical qualitative data but perhaps a more valid comparison, given that the definitions are not raw data, is with the emerging field of meta-ethnography. Meta-ethnography refers to the process of synthesising findings from individual qualitative studies using qualitative methodology (Campbell et al, 2003). Within this method, relevant empirical studies are selected for synthesis, read repeatedly and key concepts noted down; these key concepts become the raw data for the synthesis. Different types of synthesis exist depending on the way in which the selected papers relate to

each other (e.g. whether they are similar or conflict). Synthesis achieved through reciprocal translation entails the examination of key concepts in relation to others in the original study, and across studies, and is analogous to the method of constant comparison used in qualitative data analysis (Noblit and Hare, 1988). Campbell et al (2003) describe the translation of key concepts from one study to another, as idiomatic rather than a word-for-word translation, in order that concepts may be derived that encompass more than one of the studies being synthesised.

At its most simple level, this complex method bears comparison with that used for analysing the definitions reported within the 'expert' literature. That is, the definitions came from published sources, they were read repeatedly and key concepts (in terms of the structure and content of the definitions) noted down, the key concepts were examined within and across definitions, and translated in order that concepts could be derived encompassing all of the definitions being analysed. However meta-ethnography includes a formative evaluation of criteria for assessing the research to be synthesised which was not used in the development of this taxonomy. The taxonomy was to be as comprehensive as possible therefore no judgement for inclusion was made regarding the basis on which definitions were originally developed. Discounting definitions on the basis of their development might prevent their inclusion in the taxonomy and present a biased view of the definitions as they exist in the published literature. In addition, the aim of this analysis of definitions was not to synthesise the definitions in order to derive new concepts or theoretical insights, but to demonstrate consensus, or its lack, in the field.

As a result of this analysis, three major types of definition were identified within the ‘expert’ literature: first, definitions which are general or global (type I: global definitions); second, definitions which break the concept down into a series of component parts or dimensions (type II: component definitions); and third, those which focus on only one or two of the component parts recognised in the former type of definition (type III: focused definitions). Types II and III can be further subdivided according to their nature (for example, type II can be subdivided into type IIa and type IIb), as will be discussed later. Table 1.1, below, summarises the types and subtypes and a commentary follows to describe the types and subtypes in more detail.

Table 1.1: A Taxonomy of Quality of Life Definitions

(A) Expert/professional’s definitions	
Type:	Name for type:
I	Global definitions
II	Component definitions (type IIa: non-research-specific) (type IIb: research-specific)
III	Focused definitions (type IIIa: explicit) (type IIIb: implicit)
IV	Combination definitions
(B) Lay definitions	

(Farquhar, 1995b)

Type I: global definitions.

Global definitions appear to be the most common type of definition of the concept of quality of life. They are all encompassing, but because of their generality they tell us little about the possible components of quality of life or how the concept could be operationalised. They

usually incorporate ideas of satisfaction/dissatisfaction and happiness/unhappiness.

For example, Abrams (1973) defined quality of life as the degree of satisfaction or dissatisfaction felt by people with various aspects of their lives, and Andrews (1974) related it to the extent to which pleasure and satisfaction characterise human existence. Similarly, Dalkey and Rourke (1973) described it as ‘a person’s sense of well being, his [sic] satisfaction or dissatisfaction with life, or his happiness or unhappiness’ and Bunge (1975) equated it with well-being. However, Campbell et al (1976) argued that happiness and satisfaction are conceptually different, stating that ‘satisfaction implies a judgmental or cognitive experience, while happiness suggests an experience of feeling or affect’. Therefore, quality of life has also been defined more subjectively in terms of individuals’ own evaluations of their life experiences (Campbell et al, 1976; Andrews and Withey 1976). Similarly, Hanestad (1990) considers that quality of life concerns the individual person’s experience of his/her own life and life situation, with quality of life reflecting the individual’s well being.

Havighurst (1963) considered quality of life to comprise of ‘inner’ factors relating to what the subject thinks about his/her life, and ‘outer’ factors that measure behaviour such as social contact and activities. Similarly Campbell et al (1976) considered it to include both conditions of life and the experience of life, and Browne et al (1994) described it as a ‘dynamic interaction between the external conditions of an individual’s life and the internal perceptions of those conditions’. Shin and Johnson (1978) developed Campbell et al’s (1976) theme with the inclusion of self-evaluation through comparisons in their definition. They

described quality of life as ‘the possession of resources necessary for the satisfaction of individual needs, wants and desires, participation in activities enabling personal development and self actualisation and satisfactory comparison between oneself and others’ (Shin and Johnson, 1978). Other authors have included limiting factors in their definitions of quality of life, further suggesting the concept’s sensitivity to context. For example, Mendola and Pellegrini (1979) suggested that quality of life may be defined as ‘the individual’s achievement of a satisfactory social situation within the limits of perceived physical capacity’.

Within the category of global definitions are definitions, which consider the juxtaposition of quality of life and quantity of life. For example ‘the expression quality of life suggests the antonym quantity of life’ (Muhkerjee, 1989) and ‘one of the simplest descriptions of quality of life gives it only two dimensions: quality and quantity’ (Ware, 1987).

Type II: component definitions.

Component definitions are those definitions, which break quality of life down into a series of component parts or dimensions, or identify certain characteristics deemed essential to any evaluation of quality of life. All these dimensions could contribute to the type I definitions (global definitions). In this sense type II definitions are more useful for empirical work than type I definitions as they are a step closer to operationalising the concept. For example, Ferrans and Powers (1985) identified a series of dimensions included by authors in two or more studies they reviewed in the field of quality of life in renal disease: subject’s opinion of own quality of life or life satisfaction, socio-economic status (including occupation, education, income and/or financial status), physical health (including activity level/or

physical symptoms), affect, perceived stress, friendships (including social support), family (including children), marriage (including sex), achievement of life goals, satisfaction with housing and neighbourhood, satisfaction with city and nation, satisfaction with self (including self-esteem), depression, psychological defence mechanisms and coping. Table 1.2, below, summarises the dimensions and the studies in which they were represented.

Table 1.2: Quality of Life Dimensions (as identified by Ferrans and Powers (1985) in studies used to assess quality of life)

Dimensions	Representative studies
Subject's opinion of quality of life or life satisfaction	Andrews & Withey, 1976; Bortner & Hultsch 1970; Cantril 1965; Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Crandall & Putnam, 1980; Fry & Gosh, 1980; Johnson et al, 1982; Kazak & Linney, 1983; Kilpatrick & Cantril, 1960; Hatz & Powers, 1980; Jackle, 1974; Laborde & Powers, 1980; Levy & Wynbrandt, 1970; Neugarten et al, 1961; Padilla et al, 1983; Palmore & Kivett, 1977; Palmore & Luikart, 1972; Penckhofer & Holm, 1984; Soper, 1980; Sophie & Powers, 1979; Watts, 1981; Webb & Powers, 1982.
Socio-economic status (including occupation, education, income, and/or financial status)	Bonnet et al, 1978; Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Johnson et al, 1982; Kaplan De-Nour and Shanan, 1980; Levy & Wynbrandt, 1970; Padilla et al, 1983.
Physical health (including activity level and/or physical symptoms)	Bonney et al, 1978; Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Johnson et al, 1982; Kaplan De-Nour and Shanan, 1980; Levy & Wynbrandt, 1970; Padilla et al, 1983.
Affect	Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Conte & Salamon, 1982; Crandall & Putnam, 1980; Glenn & McLanahan, 1981; Johnson et al, 1982; Keon & McDonald, 1982; Levy & Wynbrandt, 1970; Neugarten et al, 1961.
Perceived stress	Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976.
Friendships (including social support)	Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Johnson et al, 1982; Levy & Wynbrandt, 1970.
Family (including children)	Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Johnson et al, 1982; Kaplan De-Nour and Shanan, 1980; Levy & Wynbrandt, 1970.

Marriage (including sex)	Bonney et al, 1978; Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Johnson et al, 1982; Kaplan De-Nour and Shanan, 1980; Levy & Wynbrandt, 1970; Padilla et al, 1983.
Achievement of life goals	Levy & Wynbrandt, 1970; Neugarten et al, 1961.
Satisfaction with housing and neighbourhood	Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976.
Satisfaction with city and nation	Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Cantril, 1965; Kilpatrick & Cantril, 1960.
Satisfaction with self (including self esteem)	Campbell, 1976 & 1981; Campbell & Converse, 1972; Campbell et al, 1976; Conte & Salamon, 1982; Kaplan De-Nour and Shanan, 1980; Neugarten et al, 1961.
Depression, psychological defence mechanisms, and coping	Bonney et al, 1978; Kaplan De-Nour and Shanan, 1980; Levy & Wynbrandt, 1970.

(Ferrans and Powers, 1985)

Fallowfield (1990) suggests that quality of life consists of four core domains: psychological (e.g. adjustment to illness, anxiety); social (e.g. personal and sexual relationships); occupational (e.g. ability and desire to carry out paid employment); and physical (e.g. pain, mobility). However, Rosenberg (1992) questions such a simplistic approach given that each of the components listed can be ‘subjected to standardised measurement’, thus rendering it ‘tempting to conclude that quality of life is but a higher-order factor with no minor surplus meaning’.

The World Health Organisation Quality of Life Group (WHOQOL Group, 1993) defined quality of life as ‘a broad ranging concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationships

to salient features of their environment'. Included within the WHOQOL definition is the recognition that individuals' quality of life is shaped by the culture and value systems in which they live (WHOQOL Group, 1993). Similarly, Bowling (1997a) describes quality of life (in relation to health) as 'a concept representing individual responses to the physical, mental and social effects of illness on daily living which influence the extent to which personal satisfaction with life circumstances can be achieved'.

Component definitions can be further subdivided into those component definitions that are not (type IIa) and those that are (type IIb) specific to the research topic. An example of a non-specific component definition is George and Bearon's (1980) definition of quality of life. They define quality of life in terms of four underlying dimensions, two of which are objective and two of which reflect the personal judgement of the individual. The objective dimensions are general health and functional status, and economic status. The dimensions reflecting the personal judgement of the individual, or subjective valuations, are life satisfaction and related measures, and self-esteem and related measures. They do not claim that these fully assess quality of life, but state that these are four central dimensions out of a potentially infinite number of aspects of quality of life.

Rescher, as illustrated in Table 1.3 below, outlined a series of quality of life domains under three broad headings: personal well-being, satisfaction from interpersonal relations, and environmental characteristics (Rescher, 1972).

Table 1.3: Rescher's Quality of Life Domains

Personal well-being	Basic aspects of: <ul style="list-style-type: none"> - health - wealth - security, contentment - self-esteem, self-respect etc. - self-development, education - status, success
Satisfaction from interpersonal relations	A. Based on reciprocity: <ul style="list-style-type: none"> - family relations - love, affection - sexual fulfilment - friendship, congeniality
	B. Self oriented: <ul style="list-style-type: none"> - self expression - leisure - activity, exercise, fun, recreation
	C. Other oriented: <ul style="list-style-type: none"> - social acceptance by others, social equality (esteem, respect) - social concern for others - positive impact upon others (leadership, power etc.)
Environmental characteristics	Satisfaction deriving from: <ul style="list-style-type: none"> - freedom and recognition of rights - respect of the individual and recognition of moral values - equality and the recognition of social values in general privacy - pleasing or aesthetic surroundings - satisfactory physical environment

(Rescher, 1972)

In a similar vein, Patterson (1975) described the key quality of life dimensions as health, function, comfort, emotional response and economics. Gough et al (1983) followed this line but conceded that one of the limitations of this approach was that the components 'may be as varied as personalities'.

Research-specific component definitions (type IIb) are useful in that authors have considered

the concept of quality of life in terms of the focus of their research question, and so have begun the process of operationalisation. However, where this occurs in the absence of a prior non-specific definition, some components of the concept of quality of life may be neglected where they are deemed irrelevant to the context of the research. This can be misleading. One example of a research-specific component definition can be found in Clark and Bowling's (1989) observational study of quality of life in nursing homes and long-stay wards for elderly people. They state that quality of life is 'not limited to functional ability, level of activity, mental state and longevity, but encompasses the concepts of privacy, freedom, respect for the individual, freedom of choice, emotional well-being and maintenance of dignity'. The latter factors are generally associated with the debate surrounding the prevention of institutionalisation; their definition of quality of life has therefore become research-specific.

Similarly, Edwards (1985) has noted that the concept of quality of life is more comprehensible, and its policy consequences clearer, within an institutional setting. The parameters of opportunities and freedom of action of people in institutions are much more tightly drawn and the environment within which they live more contained and controlled. In such circumstances, those actions that caring professions can take which will improve the quality of life of residents are more easily identifiable and easier to implement, if only because they are more constrained (Edwards, 1985). He goes on to suggest that definitions of quality of life for studies of social policy should concentrate on those factors that can be influenced by social policy. One could argue, however, that the scope of quality of life definition, research and subsequent policy should not be predetermined by its setting, as Edwards appears to suggest, if it is to be truly impartial and innovative.

Bulpitt and Fletcher (1990) used a research-specific definition expressed only in operational terms for their research into the effects of anti-hypertensive treatments on quality of life. That is, they chose to use just some of the components of quality of life and clearly stated those they were not looking at. Their definition of quality of life was given in terms of how the concept was measured, and the measures chosen were specific to the area of the research. They operationalised quality of life in terms of symptomatic (physical) well-being, psychological well-being, perception of the effects of anti-hypertensive treatment on lifestyle, and self-assessed cognitive function, and considered the first three of these to be the most important to the hypertensive patient. They did not include a measure of positive well-being, such as vitality or other areas of social participation, performance and satisfaction at work, and they make this explicit, although they do not state why they did not include these.

Type III: focused definitions.

Focused definitions are those definitions which refer to only one or a small number of the components of quality of life. The most common form of this type of definition refers only to components relating to health/functional ability. Focused definitions can be explicit (type IIIa) or implicit (type IIIb).

Explicit focused definitions (type IIIa) are found in papers that use terms such as 'health-related quality of life' or 'a micro-economic definition of quality of life' rather than the term 'quality of life' itself. For example, Naeser (1992) describes 'health-related quality of life' as 'the level of well-being and satisfaction associated with events or conditions in a person's life

as influenced by disease, accidents, or treatments’ and Bullinger et al (1993) describe it as focusing on the impact of a perceived health state on the ability to live a fulfilling life (Cheater (1998) cites this latter definition, but then goes on to state that in her paper ‘quality of life (QoL) will be taken to mean health-related QoL’: a practice which is misleading). More precisely, Patrick and Erickson (1993) define health-related quality of life as ‘the value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy’.

Gillingham and Reece (1979) describe a micro-economic definition of quality of life which assumes that the quality of life for the individual is the level of satisfaction one achieves as a result of the consumption of market goods, leisure, public goods, and other physical and social characteristics of the environment in which one is located.

Implicit focused definitions (type IIIb) occur where authors use the term ‘quality of life’ but define it in terms of one or two components of the whole concept: that is, they are focusing their definition on one or a small number of the components of quality of life, but do not make this explicit. In these circumstances it is difficult for the reader to assess how the authors fully interpret the term. Indeed, in some papers it appears that these rather limited definitions *are* the authors’ full interpretation of the term. Again these definitions are usually limited to components relating to health and functional status. One example of this type of definition was in a paper on the assessment of quality of life in clinical trials by Cox et al (1992). They did not define quality of life, but they operationalised it in terms of health and functional status measures; in such contexts it would be more suitable to use the term ‘health-

related quality of life' rather than 'quality of life' itself (Farquhar, 1992). Kuchler (1998) describes quality of life as 'more than a set of symptoms', criticising the 'common error' of defining a set of symptoms, usually those which the therapy under evaluation is targeting, as quality of life.

Similarly, Schipper and Clinch (1988) have described quality of life measures as representing the final common pathway of all interventions impinging upon the patient. They state that the point of departure for a definition of quality of life is the statement of the goals of medical therapy: 'the intent of medical therapy in this model is to return the patient to a day-to-day functional state no different from that before the onset of the disease. In other words, from a functional point of view the goal is to have day-to-day living unimpeded by either disease or its treatment'. They describe the quality of life construct that emerges from the contemporary literature as function-orientated and including four component parts: i) physical and occupational freedom; ii) psychological state; iii) social interaction; and iv) somatic sensation. In their definition, physical and occupational function refers to measures of daily activity; psychological state includes issues such as anxiety, depression, anger and fear; social interaction refers to the patient's ability to maintain useful social contact with family, friends, and work and community colleagues; and, somatic sensation refers to pain, nausea, vomiting and other physical sensations which one assumes impinge on a patient's ability to carry on with day-to-day activities (Schipper and Clinch, 1988).

Type IV: combination definitions.

There are other definitions of quality of life which appear in the 'expert' literature but which

do not neatly fit into the taxonomy described so far. These definitions overlap types I and II: that is they are global definitions, but they also specify components. They are combination definitions.

For example, Holmes and Dickerson (1987) looked at others' definitions (which were principally definition types I and II) and described quality of life as:

an 'abstract and complex term representing individual responses to the physical, mental and social factors which contribute to 'normal' daily living. It comprises many diverse areas, all of which contribute to the whole including: personal satisfaction, self esteem, performance ability, comparison with others, previous knowledge/experience, economic status, general health, and emotional status all as factors contributing to the overall quality of life'.

Somewhat confusingly, Holmes and Dickerson go on to re-define quality of life, later in the same paper, in terms of health. They state that 'quality of life was recognised to be a dynamic concept representing individual responses to the physical, mental and social effects of *illness* which influence the extent to which personal satisfaction with life circumstances can be achieved, and which allows favourable comparison with others according to the selected criteria' (Holmes and Dickerson, 1987). This later definition is still a type IV combination definition, but it is a research-specific type.

Similarly, Oleske et al's (1990) study of a diary as a means of understanding the quality of life of people with cancer, asks respondents to record the occurrence of *health* problems in the diary; the resulting data led them to conclude that the majority of reported problems were related to the physical dimension of quality of life. They did not, however, ask respondents to record the social problems that occurred, although they used a definition of quality of life that

included this dimension.

Thus, based on a qualitative analysis of definitions in the published literature, a taxonomy has been proposed that categorises 'expert' definitions into four types, two of which can be subdivided into two further subtypes. The existence of these varied types serves to identify areas of commonality within types but demonstrates a lack of overall consensus in the field.

Factors influencing 'expert' definitions:

Having identified a lack of consensus among quality of life definitions, it is worth considering what factors have led to this diversity. A primary factor has to be the multidisciplinary use of the term quality of life. This, as noted earlier, has led to a multitude of definitions reflecting the biases or interests of each discipline. For example, a health economist looking at quality of life outcomes in health care might focus on issues of cost per quantum benefit or QALYs (Schipper and Clinch, 1988), whereas geographers examining the quality of life in British cities have focused on crime levels, access to health care, pollution levels, cost of living and shopping facilities (Rogerson et al, 1989). However, as demonstrated by the taxonomy outlined earlier, diversity also exists within disciplines. Other factors are therefore involved. These include: the focus and scale of the evaluation or research; the cultural setting; the inappropriate use of operational definitions; the interchangeable use of the term with other concepts or components; and the weighting of dimensions. These will be discussed in more detail below.

As was seen in the taxonomy, the focus of the evaluation or research may influence the definition of quality of life, but so can its scale. For example, it has been suggested that one may examine quality of life issues within health care narrowly, in terms of an individual patient, or widely, to include his/her immediate family, or wider still to take account of the broader community. The focus on an individual patient could be said to come closest to the contemporary medical specialist point of view, and the broad community approach is similar to traditional public health approaches (Schipper and Clinch 1988). Each of these may employ different definitions of quality of life; definitions of a varying scale.

Schipper and Clinch (1988) have also suggested that the ambient cultural setting will be a major determinant of the definition of quality of life. For example, if quality of life is defined against some absolute external standard, such as number of hours worked, amount of medication taken, or culture-dependent population norms (such as for psychometric tests), it will be misleading to compare therapies across cultures, or even within ethnic communities in a given geographical area (Kleinman, 1986; Sartorius, 1987). For example, Scitovsky's discussion of quality of life across cultures concludes that quality of life is lower in America than in Western Europe, based on a variety of measures ranging from 'fresh fruit as a percent of all fruit consumed' to 'expenditures on flowers as a percent of national income' (Scitovsky, 1976). However, such differences may also be dependent on other variables such as gender, social class, age group or generation.

The use of operational definitions also influences our understanding of the term quality of life. Operational definitions assign meaning to a concept by describing the activities or

operations that are required to measure it. They have the virtues of clarity and precision (Callender, 1990), but they also have a number of disadvantages, particularly where they are used in isolation of conceptual definitions. Callender cites the example of Benson (1985), who in a poem entitled 'Ode to Propanolol' describes how his aesthetic sensibilities have been blunted by the drug, stating 'such an effect, which is important to the individual, may be entirely missed by a psychiatric rating scale' (Callender, 1985). The restrictiveness of operational definitions means that interpretation of results should be similarly circumscribed i.e. to say that an intervention has any given effect on 'quality of life' is meaningless without reference to the operational definitions used. Similarly absenteeism from work has been used as an index of impaired well-being (Alderman et al, 1981; Haynes et al, 1978), however 'if work is dirty, dangerous or otherwise uncongenial, then time off work may improve quality of life at least from the point of view of the patient' (Callender, 1990). Quality of life appears to be particularly vulnerable to this treatment i.e. it is defined by the indicators that have been selected, on whatever grounds, to identify it. Edwards (1985) describes this as definition by default, which usually occurs implicitly rather than explicitly.

The sometimes interchangeable use of the term quality of life with other concepts, such as 'sanctity of life', 'life quality', 'quality of survival', and 'quality of death', has influenced definition (Farquhar, 1995b), as has the use of domain-specific phrases such as 'the quality of urban life' and 'the quality of family life' (Schuessler and Fisher, 1985).

In addition, as was demonstrated earlier, quality of life is often blurred with one or a few of its components, most commonly health and functional status. For example, Howitt (1987)

refers only to health, symptoms and medications under the banner of quality of life. Similarly, Fitzpatrick et al (1992a) describe the purpose of quality of life measurement as ‘to provide...assessments of individuals’ or populations’ health and of the benefits and harm that may result from health care’, and Staniszewska (1998) equates quality of life with ‘subjective health status’. In addition, in a series of papers by Hyland (1992, 1992b, and 1993) health is frequently blurred with quality of life i.e. in the first paper he considers questionnaires describing ‘either functional limitations, negative mood states, or any other problem which could be attributed to poor health’ to be ‘one type of QOL [quality of life] assessment’ (Hyland, 1992a); in the second he states that ‘it is conventionally agreed that the term quality of life refers to the patient’s perspective of health, and that it can be measured through questionnaires’ (Hyland, 1992b); and in the third he uses the terms ‘quality of life’ and ‘health’ almost interchangeably in his paper on assessing the validity of health assessments (this use emerges in a section entitled ‘The Construct of Health’ e.g. (with my italics) ‘if the items in a *health* questionnaire tend to reflect the kinds of problem experienced by one disease but not the other, it will appear that patients with the former disease have a worse *quality of life* than the latter’) (Hyland, 1993). Similarly, Muldoon et al (1998) misleadingly state that:

‘quality of life research seeks essentially two kinds of information, the functional status of the individual and the patient’s appraisal of health as it affects his or her quality of life...ideally, subjective quality of life indices ideally [sic] should not be influenced by patient characteristics that are outside of the domain of disease and health care’.

Indeed the authors go as far as to suggest that ‘to protect against this...investigators should report correlations between quality of life indices and characteristics that are unrelated to

illness, and conduct statistical adjustments' (Muldoon et al, 1998).

The components of quality of life singled out in this way usually reflect the origin of the definition in terms of discipline. For example, it has been said that the phrase quality of life has almost supplanted the older words of happiness and welfare in contemporary social policy (Huxley, 1986). As Dalkey has said 'the phrase does have a fine ring to it and is somewhat less maudlin than happiness and somewhat less shop-worn than welfare. However there is some question as to whether the brave new phrase is any less vague' (Dalkey, 1968). Similarly then, in contemporary health care research, the phrase quality of life has almost supplanted the 'older' words of health and functional ability. The interchangeable use of the terms 'health', 'functional ability' and 'quality of life', far from clarifying the concept, only adds to the confusion (Farquhar, 1995b). Bowling (1997a) criticises recent trends 'to equate all non-clinical data with "quality of life"' as a likely source of conceptual confusion.

A further example of this is in a paper by Bech (1992). Bech (1992) describes the conceptual distinction between disability and handicap, as defined by the International Classification of Impairments, Disabilities and Handicaps (World Health Organisation, 1980), as equating the conceptual distinction between health-status measurement and quality of life. The definition of disability given is that disability reflects the consequences of impairment (biological abnormalities) in terms of physical performance, and handicap reflects purely subjective statements on the part of the patient (Bech, 1992 after World Health Organisation, 1980). One can only interpret Bech as therefore equating quality of life with the subjective expression of health status by patients. Indeed this is made explicit later in the paper: 'quality

of life is the patient's own experience of his or her own health' (Bech, 1992).

A further problem in defining quality of life is deciding what weight to give any particular component or dimension of the concept. Clearly if weights are not given to any of the dimensions then one is in fact using weighting by selection or rejection (Huxley, 1986), as in the case of the selection of health and functional ability at the expense of other components as described earlier. However, a fundamental dilemma here is not simply the question of what weighting should be applied to the various dimensions, but of who should decide on that weighting? Weighting systems that may appear fair or otherwise morally appropriate for the purpose of allocating societal resources may not be ethically appropriate when applied to individuals e.g. a panel of judges may rate being wheelchair-bound as worse than having some difficulty thinking, whereas a particular individual may not; however this individual's score on a weight-dependent quality of life measure might not therefore accurately reflect his/her quality of life as defined by his/her own values (Faden and Leplege, 1992).

Edwards (1985) has debated whether we should equate quality of life with needs or wants. He suggests that a great deal hinges around what we can sensibly say about the relationship between quality of life on the one hand and 'need' and 'want' on the other: 'is the quality of life to be equated with "need" or does it extend to "wants", either subjectively perceived or as generated through advertising or the market?' (Edwards, 1985). He suggests that quality of life in its common-sense meaning goes beyond what we normally consider as 'need' and can continue to be improved even when all need is met. Similarly, Schuessler and Fisher (1985) have noted that concern with quality of life intensifies proportionately as less time and energy

are required to meet the basic necessities of living. Edwards (1985) considers whether this means then that quality of life may be equated with needs plus wants.

‘Are those things that we want necessarily contributory to our quality of life? In so far as we equate wants with our own conception of our own good, and to the extent that quality of life is subjectively specified, the answer must be “yes”. Whether quality of life also consists of things we do not want (either really do not want or because it has never crossed our minds) depends upon whether its specification is subjectively or objectively made’ (Edwards, 1985).

In terms of subjective indicators, Edwards suggests that the components of quality of life (‘needs plus wants’) are self-defining. For objective indicators he suggests making some simple assumptions about what contributes to quality of life in Western market societies:

‘...possession of colour televisions, video processors, deep freezers, microwave ovens, boats, cars, velveteen telephone covers or whatever one fancies; access to, and resources to use cinemas, theatres, discos, opera, sports facilities, open space etc.’ (Edwards, 1985)

He suggests then that rather than an expert or a professional imposing meaning on the concept of quality of life we might attempt to discover the subjective meanings attached to such concepts by the population we are particularly concerned with (for example, in Edward’s case, personal social service clients). These subjective interpretations could then be used either to construct a variety of objective indicators using existing data or to describe a number of domains, which could be further investigated in terms of levels of satisfaction on the part of the population. He describes such subjective articulations as a way of ‘bypassing’ the problem of defining quality of life (Edwards, 1985), but it may be more constructive to look at these definitions as alternative or complementary definitions to the ‘expert’ definitions, particularly if we find a greater consensus among laymen (Farquhar, 1995b). This idea will be returned to in Chapter 4: The Case for Lay Definitions/Measures.

In summary then, Chapter 1 has set the context by describing the origins of ‘quality of life’ as a concept, charting its history from the end of World War II to the year 2000, focusing principally on its use within health-based disciplines. It discussed the definition of quality of life, organising the various published definitions into a taxonomy to demonstrate any consensus, or its lack, in the field. The various factors influencing definitions were then discussed.

Chapter 2: Quality of life in older people

Chapter 2 will review the literature relating to quality of life in older people. After a general introduction the review will present papers in relation to their setting, focusing first on institutional settings and then on the community setting. It will then describe the measurement of quality of life in later life as practised at the time of empirical data collection for this thesis. This will be by means of identifying commonly used domains/indicators of quality of life in later life, outlining issues of quality of life measurement in later life and issues relating to the survey method with older people. Much of the critical discussion of the literature on quality of life in older people will be contained within these latter two sections i.e. the sections on 'Issues of quality of life measurement in later life' and 'Issues relating to the survey method with older people'. By far the majority of studies described in the former sections (i.e. the sections relating to the quality of life of older people in institutional and community settings, and the commonly used domains/indicators of quality of life in later life) rely heavily on measures developed with and for younger adults, and upon the survey method. For clarity and to avoid repetition it was therefore deemed appropriate to first present these studies, and then critically appraise their method as one.

According to many authors, analysis of statistics from the industrialised nations indicate that people age 75 and older, and especially those age 85 and older, constitute the most rapidly growing proportion of the population (Grundy, 1983; Rosenwaike, 1985). Recent increases in the size of the 'oldest old' population have been greater than projected (Murphy, 1995).

From 2001, the numbers of people in the United Kingdom aged 60 years and over are now projected to rise by about 50%, reaching a peak in about 2036 (Office for National Statistics, 1999). The greatest rise in absolute number will be in the 65-74 year age group in 2036 (about 3 million), however the greatest proportional rise is in the oldest age group, 90 years and over, which is projected to double in number from about 400,000 in 2001 to 800,000 in 2036 (Office for National Statistics, 1999). In addition, forthcoming decades will see ‘the inclusion of the first wave of older baby boomers...[and] a substantial increase in the number of what has been referred to as “new age elderly” - a mix of pre-boomers and older baby boomers’ (Schiffman and Sherman, 1991).

Measuring the quality of life of older people is likely to be an increasingly urgent and worthwhile task for health service researchers because of the growing pressure on health, social and economic resources that this population group is going to generate in all advanced countries over the years to come. Grundy and Bowling (1999) define the issue as ‘how to extend the quality of increased life years in order to minimize dependency’. They describe one of the consequences of the hypothesized future compression of morbidity in older age into a shorter time period (Ebrahim, 1997) as the more positive perspective of healthy aging as normal, and a growing interest in the quality of life in advanced old age (Grundy and Bowling, 1999). In addition, Grundy and Bowling (1999) describe the international interest in the promotion of ‘successful aging’ (see below) due to higher expectations in older age as well as the policy interest in maintaining independence rather than fostering dependency.

To this end the empirical part of this thesis is focused on the quality of life of older people.

Examination of previous work on the quality of life of older people is therefore a prerequisite, however this review focuses principally on the literature of social gerontology, social indicators research and health services research relating to older people⁶. It is therefore not comprehensive.

Gerontologists involved in applied research have directed much of their attention to assessing the status and needs of older people and evaluating the impact of services and policies on older individuals. It has been suggested that much of this research implicitly aims to improve the quality of life of older people, or particular target groups of older people, and some research explicitly does so (Hausmann et al, 1974; George and Bearon, 1980).

In health services research, general health and functional status have traditionally been judged to be important dimensions of quality of life, particularly salient to older people with their higher rates of morbidity and mortality and their concern with health (Office of Population Census and Surveys, 1984). A person's inability to carry out activities of daily living, such as mobility, self-care, and household tasks can have important consequences for quality of life (Denham, 1983). As a result, much of the conceptual framework for quality of life measurement both in health services research in general and in health services research relating to older people has been derived from the World Health Organisation's definition of health as a state of complete physical, mental and social well-being (WHO, 1958). However this is usually operationalised within the medical model with consequently overly negative

⁶ The word limit restriction prevented the presentation of literature from a wider field although this was examined by the researcher during the preparation of the thesis.

connotations, particularly in reference to older people. For example, emphasis is commonly placed on disability, depression, loneliness, need for help and so on, at the expense of positive elements of old age.

Existing quality of life instruments for older people tend, therefore, to focus on deterioration in functioning according to a pre-determined model of life quality in old age (Browne et al, 1994). Browne et al (1994) consider that such an approach will underestimate the quality of life of an elderly person if it focuses exclusively on domains in which function is deteriorating rather than on those domains that the individual considers particularly relevant. However, from an economist's point of view, Williams (1977) explicitly recommends a broad definition of health as a proxy for measuring the quality of life of older people. He justifies this by stating that health is fundamentally important to quality of life, whereas 'income, wealth, better housing, cleaner air, more pleasant surroundings, are all instrumental' (p283). However, health is only one dimension of quality of life. Bowling found that adults of all ages rated relationships as the most important area of life, and although older people rated their health as most important this was not the only area of life rated as important (Bowling 1995b, 1995c, 1996).

Moreover the work of Browne et al (1994) has questioned the assumption that poorer or perceived poorer health status amongst older people increases the importance of health as a dimension of the quality of life of older people: Browne et al (1994), using the SEIQOL (described later), found that health status was not correlated with the perceived importance of health to quality of life amongst a sample of healthy elderly people living in the community,

and that there was no significant difference in the weight assigned to health between an older (mean age 73.7 years) and younger (mean age 28.8 years) adult sample.

Increasingly interest is being expressed in positive aspects of ageing, or “successful ageing”, partly due to the policy concern of how to maintain people in the community for as long as possible, and also due to the higher expectations of old age as standards of living, health and health care increase (Bowling, 1993). The introduction of the concept of successful ageing can be dated back to early work on life satisfaction by gerontologists in the USA (Neugarten et al, 1961; Havighurst, 1963; Williams and Wirths, 1965; Bradburn, 1969; Lawton, 1975; Andrews and Withey, 1976; Larson, 1978; Palmore, 1979). Its adoption has been slower in Europe, including the UK, and elsewhere due to its perception as “a further example of the western competitive mentality of success – and, by implication, failure – to an area of life which did not warrant it” (Coleman, 1992).

A number of definitions of positive or successful ageing exist, and these have been usefully described by Bowling (1993). For example, Rowe and Khan (1987) defined successful “agers” as people who maximise their life expectancy while controlling extrinsic factors, focusing their attention on biological functioning (physical and cognitive), autonomy, social support, bereavement and moving home, and the mortality risk associated with each of the latter two events. Fries (1990) defined successful ageing, from a public health perspective, as optimizing life expectancy while simultaneously minimizing physical, psychological and social morbidity, focusing on the physical plasticity in older people and the variability between people in old age. Baltes and Baltes’ (1990) review identified the key subjective and

objective characteristics of successful ageing in the literature to include length of life, biological health, mental health, cognitive efficacy, social competence and productivity, personal control and life satisfaction. They suggest that by using the adaptive strategies of selection, optimization and compensation, individuals can contribute to their own successful ageing (Baltes and Baltes, 1990).

Growing interest in the subject of successful ageing is said to reflect a new optimism in the field of gerontology, inviting participation ‘in the creation of ageing, instead of passively experiencing it as a given reality (Baltes and Baltes, 1990). Similarly, the increasing amount of literature on the quality of life of older people parallels the trajectory of the adoption of successful ageing in the western world (indeed the two terms are sometimes, confusingly, simultaneously used), but the concept of quality of life appears to have been more widely accepted, even if no better defined or understood.

The existing literature on the quality of life of older people can be broadly classified according to its setting i.e. whether it is based in an institutional setting or a community setting. These will now be examined in turn.

Quality of life of older people in institutional settings

Aspects of quality of life have been a key feature of much gerontological research focused on older people living in long-term care or other institutional settings. A report by The Royal College of Physicians (1992) on guidelines and audit measures for high quality long-term care

of elderly people states that:

‘the desired outcome in long-term care cannot be described in terms of disease rates as used in medical models. Ideally, the quality of such care should be judged by assessing the resultant “quality of life” of residents. Although “quality of life” is difficult to define and elusive to measure, particularly with physically and mentally frail residents, good quality of life should remain the goal of long term care’ (p5).

One of the difficulties of quality of life research in an institutional setting has been separating ‘quality of care’ and ‘quality of the environment’ from ‘quality of life’ (Ward, 1980; Davies and Knapp, 1981; Bond and Bond, 1987). In order to tease out the relationship between these concepts, Ward (1980) defined the quality of the environment in terms of the effect it has on quality of life in residential care: ‘standards or quality of the environment should be derived from information about the effects of particular environmental features, or combinations of these, on the life of those exposed to them’. Similarly, Davies and Knapp (1981) developed a model for the evaluation of institutional care in old people’s homes based on production relations. That is, quality of life was termed as an output and its determinants (resource and non resource contributions to the quality of care) as inputs.

For their observational study of quality of life in NHS nursing homes and long-stay care wards for older people, Clark and Bowling (1989) also considered the influence of quality of care on quality of life. They describe ‘process data’ (i.e. information about the way in which the service is provided) as being as valuable as ‘outcome data’ (i.e. the effects of the service on the patients’ mental and physical health, functional status and life satisfaction) in evaluative research. The study demonstrated how insightful qualitative data can be in comparison to quantitative data.

Faulk (1988) takes a different approach and locates his research into quality of life factors in homes for older people on a hierarchy of needs theoretical model derived from Maslow (1968). This has parallels in the discussion of the relationship of 'needs' and 'wants' to quality of life by Edwards (1985) described earlier. Maslow theorised that all human needs could be arranged in a hierarchy ranging from immediate and basic needs such as food, water and freedom from physical and psychological attack to more complex and long-term needs such as the need for affection, respect and self-fulfilment. Basic needs have to be satisfied before any attempt to meet those needs at a higher level, although greater value is thought to be placed on these higher level needs. Faulk states that Maslow's hierarchy provides a useful framework for identifying all human needs that is adaptable to include the special requirements of residents of homes for older people. He proposes that the characteristics that distinguishes these residents from other older people is not that they have different needs, but that they require some help in meeting their needs.

Faulk (1988) took pre selected variables, measured by objective and subjective indicators of need satisfaction, and placed them into one of two hierarchical categories adapted from Maslow's model: material resource needs and social integration needs. Material resource needs were objectively measured, using indicators such as the condition of the home or adequacy of the food, directly assessed by research staff. Social integration needs were subjectively measured using questions regarding the adequacy of privacy or feelings of closeness to other residents, and the degree to which their own needs had been met (Faulk, 1988). Faulk's results indicated that provision of material resource needs alone were

inadequate for the maintenance of a good quality of life in his subjects and that meeting their social integration needs was also required. The hierarchical nature of his findings led him to conclude that Maslow's hierarchy was a useful model for quality of life assessment in residential care.

Other studies of older people in institutional settings have focused on certain disease groups, or groups of people with particular levels of functioning or needs. For example, Osberg, McGinnis, DeJong and Seward (1987) conducted a study of life satisfaction and quality of life among disabled older adults: their sample comprised of people age 60 and older who were admitted to medical rehabilitation units. Of the 97 people interviewed, 43 had suffered strokes, 31 had hip fractures and/or hip replacements, and 23 had other diagnoses. Their measure of quality of life was based on just four variables: satisfaction with life today, self-rating of health, satisfaction with relationships with friends, and satisfaction with financial situation. They also included a measure of functioning although this was not explicitly part of their quality of life measure. The authors concluded that the resultant explanatory power of their model would most likely be enhanced by the inclusion of other variables such as the effect of environmental barriers and social support, including family involvement in particular (Osberg, McGinnis, DeJong and Seward, 1987).

It has been suggested that this focus on role functioning and activities of daily living stems from functionalism and the pathological model (Bowling, 1997b). The functionalist perspective focuses on interrelationships within the social system e.g. the ability to function in order to perform personal, social and economic roles and thus contribute to the

maintenance of society. For example, scales of physical functioning and ability, and their sub-domains in quality of life scales, focus on the performance of activities of daily living (e.g. personal care, domestic roles, mobility) and on role functioning (e.g. work, finance, family, friends, social) which are necessary for the maintenance of society as well as the individual (Bowling, 1997b). However it is questionable as to whether adherence to such a model truly reflects notions of quality of life held by the residents of institutional care for older people.

Quality of life of older people in the community

Although a considerable amount of work has been concerned with the quality of life of older people living in institutions (Fletcher, Dickinson and Philp, 1992), this group represents a relatively small proportion of the older population as a whole (Farquhar, 1994). The proportion varies (usually increasing) with age, but Blake (1981) has estimated that by far the majority of the older population (about three quarters) will never enter a nursing home. In addition, as patients are increasingly discharged back into or maintained in the community, community-based studies will become vital in assessing the impact of health and social service policy on quality of life (Farquhar, 1994). Institutionally based studies may have predominated due to the relative ease of identifying and approaching research subjects within institutions, as well as a concern for the quality of life of those no longer able to live independent, or relatively independent, lives within their own homes.

A number of community-based studies of older people have been conducted in contrasting

geographical areas and with different age groups of the older population (for example see: Bowling, Hoeckel and Leaver, 1988; Farquhar and Bowling, 1989; Bowling and Burkey, 1989). However few have been focused explicitly on the concept of quality of life. For example, Hunt (1978) assessed employment, income, housing, mobility, ability to look after oneself, and social activities to ensure the most efficient use of health and social services by older people at home. She found that ill health, loss of mobility, and decline in material circumstances were all age-related with those aged 75 and older most affected. Similarly Michalos (1982) found that satisfaction with housing contributed most to satisfaction with life as a whole for a sample of older people living in rural Ontario, while satisfaction with spouse and friends contributed most to general happiness.

Vetter, Jones and Victor (1988) conducted a survey to investigate the value of health and social services for older people in terms of their impact on quality of life. Respondents aged 70 and older were interviewed twice: once to discover their levels of satisfaction with various aspects of their lives and a second time, two years later, to discover changes in those levels. Quality of life was measured by a series of questions about the satisfaction a person feels with various aspects of life including their home, family, freedom, standard of living, education, leisure time, health, finances, and so on. Standard measures of health, anxiety and depression were also included as well as questions on social variables such as housing type, frequency of social contacts, and use of health and social services. Their findings led them to the conclusion that quality of life was meaningless as a unidimensional measure: disability had a profound effect on health and leisure activities, but little effect on satisfaction with family contacts. The importance of finances to quality of life declined over the two-year period

between interviews. Interestingly, those respondents who became more dependent over the two-year period had an increased level of satisfaction with their family relationships, confirming the central role of family ties in the care of older people (Vetter et al, 1988).

Carabellese et al (1993) conducted a community survey of 1,191 'elders' (aged 70-75 years) living at home in a town in northern Italy. Their aim was to determine the association between quality of life measures and sensory impairment in aged individuals living at home. For the purposes of the survey quality of life was defined as a multidimensional concept encompassing social, affective, cognitive, and physical domains. They concluded that the quality of life of community-dwelling older people was significantly linked to sensory impairment detectable through simple examination. Mood level and social relationships were particularly affected by visual impairment whereas self-sufficiency in daily living was more strongly related to hearing impairment.

Rickelman, Gallman and Parra (1994) attempted to determine the extent to which demographic variables and measures of attachment predicted quality of life in community-dwelling older men. A convenience sample of 100 men aged 58 to 84 (mean age 68.4) were asked to complete a demographic information form, the Adult Attachment Scale and the Life Situation Survey, the latter being used to measure 'subjectively perceived quality of life'. The Life Situation Survey (Chubon, 1987) is a 20 item self report instrument designed to measure a subject's level of agreement with statements that concern different aspects of their life situation. The findings suggested that perceived health status had a prominent role in 'influencing a subjective sense of life quality' and that there was a 'positive and significant

link between attachment and perceived quality of life’, although the authors later acknowledged that the predictors of quality of life in the study only accounted for 30% of the total variance (Rickelman, Gallman and Parra, 1994).

Ferrucci et al (1996) reported on the European Longitudinal Study on Aging (ELSA). ELSA began as a cross-national study on various aspects of life in older people in 1979-80 in ten European countries and in Kuwait, under the coordination of the WHO Regional Office for Europe. Eight countries were involved in a follow up between 1986 and 1991. Although not designed as a quality of life study at its inception, the principal investigators considered that the ELSA database could help in understanding the link between the aging process and the quality of life of the older people in different European countries. The editors of the resulting book acknowledged the difficulties in defining and measuring quality of life, and described the concept of health-related quality of life as ‘in some way easier to define’. They then opted to ask each individual ELSA centre to prepare a paper for the book ‘according to their own interest under the broad concept of Health-Related Quality of Life’, thus making comparison across countries difficult. Ferrucci et al (1996) state that each chapter ‘reflects the investigators ideological and cultural notions and also reflects the society in which they live’ and readers are invited to ‘approach these chapters with healthy scepticism’! A more systematic approach of agreeing on (at the very least) a European definition of health-related quality of life for application to each national dataset would have been more useful, even if that definition remained flawed.

One problem with many of these studies is that they purport to measure ‘subjective quality of

life' but are in fact measuring respondents' subjective responses to an often limited number of domains selected by others ('experts') to represent quality of life: to be truly subjective individuals need to select their own domains. In attempt to address this, Browne et al (1994) administered the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle et al, 1993) to a sample of 56 'healthy' older people, living independently in urban Dublin, at baseline (t1) and twelve months later (t2). The SEIQoL is an interesting departure from generic measures of quality of life in that it does not assume a relationship between a condition and the quality of life experience of it. Individuals are required to nominate, in a semi-structured interview, the five domains most relevant to their quality of life and then to assess current levels of functioning by rating each domain on a 0-100 vertical scale anchored at the two extremes by the terms 'best possible' and 'worst possible'. The anchors are designed to allow individuals to use their own criteria when assessing their quality of life in each domain. The relative importance of each domain for the quality of life of the individual is achieved through judgement analysis (Browne et al, 1994). Emphasis for the elderly group at t1 centred on family (mentioned by 89%), social and leisure activities (95%), health (91%), living conditions (80%) and religion (75%). A similar pattern emerged at t2 but with greater emphasis on finances (43%) and less on social and leisure activities (59%). This former finding contradicts that of Vetter, Jones and Victor (1988) described earlier, of a decline in the importance of finances over time (a two year period). Comparison with a younger sample (42 previously studied healthy adults of 28.8 years mean age (O'Boyle et al, 1992)) revealed a greater emphasis among the younger sample on relationships (86%), finances (60%), happiness (48%) and work (38%), in addition to 17 further domains that did not fit any of the labels used to categorise elderly people's concerns e.g. environmental issues, politics,

freedom/civil liberties and learning about life. Notably, quality of life was significantly higher for elderly people than for younger adults at t1. Browne et al (1994) carefully point out that their findings do not illustrate a list of domains for all elderly people, stating that ‘a “natural” set of concerns for all elderly people is unlikely to exist’.

The SEIQoL, as administered by Browne et al (1994), was not without its problems: 10% (n=7) of the responding sample could not comprehend the instrument. In addition, the sample included only ‘the healthy’ e.g. subjects were required to not be receiving prescribed medication, nor on a waiting list for medical treatment, nor suffering from a chronic or acute disorder requiring prescribed medication within the previous month (Browne et al, 1994). The relevance of this sample to older people living at home in general is therefore questionable.

Lamb (1996) conducted a cross-national study of quality of life factors associated with patterns of elderly disablement. Data were drawn from the World Health Organisation’s Health and Social Aspects of Ageing Project based in the Eastern Mediterranean and South East Asia, involving 10,416 non-institutionalised participants aged 60 and over. The only quality of life ‘covariates’ employed were: personal assessment of health as compared to others of similar age; the revised Philadelphia Geriatric Center morale scale (Lawton, 1975), as a measure of general well-being; and social support. She concluded that ‘cross-culturally, the examination of the quality of life covariates indicates a strong association with limitations such that functional and emotional limitations generally are correlated with a lower quality of life’. However the dearth of other variables precludes a greater understanding of the

relationship between disablement in older people and quality of life.

Bowling and Grundy (1999) re-analysed data from a longitudinal study of 630 people aged 85 and over living at home in Hackney, conducted in 1987 and 1990 and using structured interviews, with the aim of investigating quality of life in very old age. The analysis employed nine variables used to represent three major domains of quality of life: perceived 'wellbeing and autonomy', 'health and activity' and 'environment' selected on the basis of a literature review and focus group exercise. Socio-demographic variables, features of the respondents' lives, and mortality up to 30 months after baseline interview were included in the analysis. Almost half the sample achieved 'good' scores on at least five of the nine variables; few achieved 'good' or 'poor' on all nine. Changes in scores between baseline and follow-up interviews among surviving respondents were not substantial, but there was an association between the number of 'good' scores and mortality within 30 months of baseline interview (Grundy and Bowling, 1999). The policy implications of such findings are hard to imagine.

Bury and Holme's book *Life After Ninety* (1991) combines the community and residential setting. They attempted to interview a representative sample of 200 people aged 90 and older from eight areas in England. The study aimed to describe the quality of life of people aged 90 and older and to explore the meanings underlying the concept of quality of life in very old age, to inform the planning and implementing of policies. The definition of quality of life used for the study was that of George and Bearon (1980) described earlier. Among other things, Bury and Holme investigated respondents' state of health and material circumstances

(including where and with whom the older person was living), leisure activities, morale and well-being (including loneliness and boredom), the quality of relationships, and the kind of care and support being received. Their findings highlighted not only the diversity among people in this age group both in their circumstances and their evaluation, but also their shared sense of generation in the shape of their common experiences and attitudes. Bury and Holme's main conclusion was that life after age 90 can be compatible with a good quality of life and that improvement in longevity and the growth in numbers of the very old can therefore be regarded as a step forward for society as a whole. However, they added a cautionary note: they do not know whether people in their 70s or 80s have a better or worse quality of life than those in their 90s (Bury and Holme, 1991). Indeed, those in their 90s could be regarded as the survivors of their generation and are possibly quite different from the younger elderly (Farquhar, 1994).

Grimby and Wiklund (1994) also combined community and institutional settings in their study of 'health-related quality of life' among 565 Swedish urban citizens aged 76 years attending and outpatient clinic using the Nottingham Health Profile (Hunt, McEwen and McKenna, 1986), although most subjects (97%) lived at home. They acknowledged that their operational definition of quality of life was limited by the items on the Nottingham Health Profile, but found that impaired quality of life (as so defined) was correlated to observed and perceived illness, institutionalisation, widowhood, loneliness and financial discontent (Grimby and Wiklund, 1994).

Measuring quality of life in later life

Before discussing the issues surrounding the process of measuring quality of life in older people it is worth briefly considering the most commonly used domains or indicators of quality of life with this group. This is not to suggest that a pre-determined list of domains is a pre-requisite to the valid assessment of quality of life in older people, on the contrary it serves to illustrate the rather limited 'state-of-the-art' to date. Many of the lists are repetitive and fairly predictable, and lean towards the objective and (apparently) measurable.

Commonly used domains/indicators of quality of life in later life:

'Quality' can be observed and measured, but 'quality of life' cannot be observed directly. Other variables have therefore been used to serve as its indicators e.g. assets, health status and financial security (Gastil, 1970; Morgan and Smith, 1969). The objective indicators suggested by some authors have the advantage that they are not subject to observer error bias, but they are insensitive to the feelings of the subject (Denham, 1983) and whilst they may reflect accepted social norms these may not necessarily coincide with the norms and values of the individual being studied (Barry, Crosby and Bogg, 1993). In addition, concern has been expressed regarding the reliability of some social statistics: for example, crime rates, housing density (Briscoe, 1985) and incomes (Townsend and Gordon, 1992). Further, it is not always clear what is meant by objectivity in the context of quality of life (Simmons, 1994). Goodinson and Singleton (1989) note that objectivity sometimes refers to certain kinds of factual data (e.g. type of housing and living arrangements), whilst in other studies it refers to

information or reports gathered from sources other than the subject (e.g. relatives or the researchers themselves). The alternative, subjective measures, such as job satisfaction, and perceptions of health and morale, involve subjects being asked to make judgements about their lives; this is the strength of subjective measures. As Abrams (1976) stated 'people's perceptions, however uninformed they may be, are real and people act on the basis of them'.

Sherman and Schiffman's (1991) review of the quality of life of older people over the last thirty years, albeit for the purposes of marketing, focuses on a mix of objective and subjective indicators. They considered income, longevity, health, housing, gender, life satisfaction, cognitive age (Sherman and Schiffman's, 1991). In a paper presented at the British Association for the Advancement of Science annual meeting in 1991, Stout outlined what he believed to be the main factors for achieving a good quality of life in old age, whether the individual is living in the community or in residential care. His list included a reasonable income, adequate food, appropriate housing, good health, autonomy, warmth, and privacy. Hughes (1990) also suggest a multidimensional approach including objective elements such as functional capacity, physical, mental and social status of the individual, as well as subjective elements such as morale, life satisfaction and self-esteem.

Bowling (1997b) suggests that the greatest debate occurs in relation to the appropriate domains of emotional and social well-being which should be included. With regard to emotional domains for example, she notes that satisfaction with life has become a key variable in analyses of the emotional well-being of older, but not younger, people (Bowling 1995a, 1997a). Related concepts often included are happiness and morale, self-esteem and

control (Bowling, 1977b), for which measurement scales (mainly for use in gerontology) have been developed (see Bowling, 1997a). However their sensitivity in the measurement of *disease* outcomes in older or younger populations is relatively untested (Bowling, 1997b).

With regard to social well-being domains, Bowling (1997b) describes the availability of practical and emotional support that is perceived by the individual to be satisfying, as a key component. She cites Emerson and Hatton's (1994) observation that the analysis of social outcomes in relation to the role of social support has received increasing attention as health and social care increasingly shifts from hospital to community (Bowling, 1997b). The numerous measurement scales available tap a range of domains, but again there is little consensus over which are the most appropriate (Bowling, 1997b).

Denham (1983) and Bond and Bond (1987) have suggested that assessments of the quality of life of older people in residential care could include measures of survival, health, health perception, functioning, level of dependency, mental health, personal well-being/measures related to feeling, life satisfaction, type and level of activity (including social contacts), the quality of the physical and social environment, and the quality of working life for staff. A prescription of measures for the quality of life for older people living in the community may not be so very different from this list with the exception of the quality of working life for the staff, and the inclusion of more external factors such as financial circumstances, and aspects of the respondents' wider community (Farquhar, 1994), but to all intents and purposes it would be a prescribed list and not one generated by individuals themselves. As Rosenberg (1992) states, 'including components such as emotional status, social interaction, economic

status, self-perceived health status, and physical capacities pays respect to the multidimensionality of man but does not capture the subjectivity of man’.

Thus various authors have attempted to prescribe the domains or components of quality of life that should be measured in any assessment of the status of the concept among individuals or groups of individuals. Such lists have their uses in that they may give the researcher the misleadingly comforting or reassuring feeling that established scales of measurement exist for each domain (one can imagine physically ticking down such a list when considering how to operationalise the concept) but, at the same time, reading more than one of these lists leaves one with the rather more unsatisfactory feeling that they state the obvious, gain little over one another, and somehow lack the very element that makes the concept of quality of life so attractive as an outcome measure. They do not read as though they are truly measuring ‘life’ as lived by individuals with all their variations, uniqueness and complexities.

Issues of quality of life measurement in later life:

A large number of scales and tools have been devised to measure the components of quality of life suggested above. Several published reviews of these measures and the uses to which they can be put are now available (for example see: Fallowfield, 1993; George and Bearon, 1980; McDowell and Newell, 1987; Wilkin and Thompson, 1989; Fletcher et al 1992; Bowling 1995 and 1997a). Scales vary widely in concept, construction and content and therefore cannot always be compared directly with each other. Such diversity exists even within disease groups. For example, Hyland (1992b) examined the content and validity of

four questionnaires used for quality of life assessment in respiratory disease. He described differences in the content of the questionnaires, suggesting that this in part reflects differences in the source of the items i.e. 'authors who use health professionals as a source of information have included symptom items.... whereas those who restrict the source of items to comments between patients have not included symptoms, but have a greater emphasis on activities'. As with quality of life definition then, there is little agreement on what constitutes a quality of life measure. No instrument can ever be comprehensive enough for all uses.

Given this, the validity of a quality of life measure is difficult to establish - with what standard does one make comparisons? In addition, where scales have been tested for their reliability and validity, it is rare for the focus of such testing to be older people (recent rare exceptions include testing of the NHP and SF36 by Sharples et al, 2000). However the same could also be said when developing a quality of life measure - on whose standards should it be based? To date the majority of scales have been developed by professionals, and based on 'expert' definitions and standards of what gives a life quality. Further, where scale development has included the use of item gathering from laymen, these laymen are rarely drawn from the older population (Farquhar, 1994).

Grimley Evans (1992) has usefully summarised some specific characteristics of later life that present particular problems for the uncritical use of quality of life measures with older respondents, thus making the case for self-assessed quality of life all the more pertinent where older people are concerned (Farquhar, 1994). These characteristics include: the loss of biological adaptability associated with ageing (i.e. 'older people will be more disturbed, both

physiologically and psychologically, by inappropriate management than younger people’); the reduction in social adaptability due to the loss of wealth (and, therefore, choice and power it confers) and by social isolation due to the loss of family and friends (together with the personalised advocacy these can provide); cultural and generational gaps and unfamiliarities (i.e. ‘judgements made by younger people may reflect values alien to the generation in which older people grew up’); the ageist prejudices of Western societies with regard to the values and valuations of older people (e.g. ‘older people are necessarily less fit than younger people to make judgements’, or ‘the capacity to enjoy the pleasure of life inevitably diminishes as individuals grow older’); their increased susceptibility to environmental influences (i.e. due to reduced adaptability and acquiescence in their ‘lowly social status’); and the heterogeneity of older people (Grimley Evans, 1992).

This latter point in particular requires some further discussion. The older population does not constitute a homogenous category. The age at which ‘old age’ is classically regarded to begin in the western world is when an adult reaches 65 years of age; but some researchers, particularly in the United States, appear to regard old age as beginning at 60 years of age, or even 55 years. However an article or feature on a nonagenarian or even a centenarian in a local newspaper or on a regional news programme is no longer uncommon in modern Britain⁷ - the result being that the age range of older people can span over more than 35 years. At no other life stage are such disparate ages treated as homogenous (Farquhar, 1994). In fact, because both intrinsic and extrinsic ageing vary between individuals, the heterogeneity of older people is greater than that among younger people (Grimley Evans, 1992).

⁷ Ebrahim (2000) notes that Queen Elizabeth II sent out 3279 congratulations to British centenarians in 1999 compared with 255 in 1952.

Following the social gerontological literature, Sherman and Schiffman (1991), writing in the *Journal of Business and Psychology*, acknowledge this diversity in older people and distinguish 'cognitive age' from 'chronological age'. A measure of cognitive age might ask individuals to assess their age in specific 'chronological-like' age decades based on a series of personal age dimensions such as 'feel age', 'look age', 'do age', and 'interest age' (Sherman and Schiffman, 1991). Using such measures, a great many older people perceive themselves to be 10 or 15 years younger than their chronological age (Sherman and Schiffman, 1991). Increasingly, authors are now distinguishing between the 'younger' and the 'older' elderly and, although the age ranges included in this dichotomy vary, their use is as important in quality of life research as in descriptive or evaluative work (Farquhar, 1994).

Within the older population there are not only age differences, but also cohort differences (Kohout, 1992). Cohort effects arise from environmental factors that change over time and that produce marked cultural, social and psychological differences. Thus, in addition to the 'real' differences that exist between cohorts, the demands on their recall are quite different (Kohout, 1992). To illustrate this point, Kohout (1992) describes the contrasting experiences of two American cohorts:

'For example, a man born in 1905 would have entered the labor force in the early 1920s and would have retired around 1970 to 1975. People in this cohort are likely to have been born at home, perhaps with a midwife or family member attending, and their mothers probably had no prenatal physician care. Until late adulthood, when the health care system was more fully developed, they were unlikely to have seen a physician except when they were seriously ill. Many were foreign born or were recent immigrants. They were exposed to a number of epidemics during childhood and as teenagers were exposed to a worldwide influenza epidemic. A large proportion terminated their education with the eighth grade and few went on to college. Those who became factory workers probably worked long hours under sweatshop conditions.

By contrast, people born in 1925 are more likely to have been born in a hospital, and a physician is likely to have attended those born at home. A much higher proportion finished high school before entering the labor force, which was during World War II. The men are likely to have served in the armed forces, and more of the women entered the labor force than had done so previously. Those who worked in factories during and after the war were exposed to a new array of toxic substances, which resulted from advances in chemical technology.’ (Kohout, 1992)

As well as the potential impact on future health, cohort differences have a great impact on basic attitudes (Kohout, 1992). Attitudes are formed relatively early in life and are influenced by the prevailing norms at the time (Kohout, 1992). Thus, to cite Kohout (1992), ‘a person who entered the labor force during the depression of the 1930s is likely to have markedly different attitudes on economic and political issues from one who reached adulthood in the boom years of the 1920s. Those who came of age during World War II are likely to have yet another view’.

In addition to the particular age and cohort differences that are unique to older people, there are also gender, ethnicity and cultural differences within the older population just as there are among the younger population. This is not to say that the older population require any special treatment with regard to these variables (e.g. they do not need to be measured in a different way for older people), but they should be considered and not assumed irrelevant to this age group and may have particular relevance to quality of life. Variations in gender, ethnicity and culture exist for both younger and older people and require acknowledgement in terms of question wording, recording for the purposes of analysis, and recognition for the development of relevant conclusions and implications of findings; the same could be said for sexual orientation.

Issues relating to the survey method with older people:

The descriptive review of studies of the quality of life of older people presented earlier demonstrated that by far the most commonly used method of measuring quality of life in later life has been the survey. There are a number of issues related to the restrictions of the survey method that are particularly pertinent to older people and to quality of life research, as these will be presented here.

First, there are issues relating to the self-completion of quality of life questionnaires by older people. It has been suggested that older people may not process information as thoroughly or as systematically as younger persons (Reese and Rodeheaver, 1985). Information summaries (or instructions) may require a particular level of reading skill (Kendall, 1989) increasing the potential for misunderstanding by a group, such as older people, with fewer years of formal education (Atchley, 1985). In addition, sensory impairments may also interfere with both understanding (Kendall, 1989) and the physical ability to complete measures e.g. visual difficulties may make reading and writing more difficult. Herzog and Rodgers (1992) cite anecdotal evidence suggesting that because many older respondents do not see well enough or do not trust their competence, they tend to request that in face-to-face interviews the interviewers read the questions. Variation in the way that different interviewers present questions may be a source of bias e.g. their (unconscious) use of intonation when reading out a question. In a postal survey one can only speculate on who (if anyone) would provide assistance and the effects that that assistance might have on any responses given, particularly with such an individual and personal concept as quality of life. Presentation of postal

questionnaires must therefore be carefully considered: for example, fonts should be adequate (in terms of size and form), and figure-ground contrast must be strong (Herzog and Rodgers, 1992) for ease of reading. In addition, the quality of any printing or copying process should be closely monitored.

Arthritic hands, and other functionally related conditions, may make the process of writing slow and painful, and the resulting handwriting difficult to read. This may lead to difficulties for the researcher in translating responses, and shaky handwriting may be a source of embarrassment to respondents which may deter them from responding in the first place (e.g. where a questionnaire is administered postally) or lead them to seek help from others, with the inherent problems this may cause (as described above).

Although many of the types of questions involved in survey research may seem relatively innocuous, some may be troublesome for older people (Annas and Glantz, 1986). Colsher (1992) suggests that individuals may be upset by questions about illness and physical function limitations as they may highlight personal disabilities and losses; such questions are commonly incorporated into quality of life surveys of older people. Questions about relationships with offspring, other relatives, or friends, which again are commonly incorporated in quality of life surveys of older people, may also be disturbing. Those who expect close family relationships may be humiliated by what they view as their own failure to develop and maintain closeness (Colsher, 1992). Describing a network of friends that has been reduced because of death and institutionalisation may be upsetting and tests of cognitive function may be distressing to those with concerns about their own abilities (Colsher, 1992).

Other topics, such as sexual function, alcohol consumption and tobacco use may also present difficulties (Colsher, 1992).

These are concerns for any surveys involving older people, but have particular relevance in the field of quality of life research given the multi-dimensional nature of the concept. The resulting battery of instruments or items that subjects may be asked to respond to each has its own potential for distress or discomfort, but when taken as a whole the effect could be overwhelming. From a methodological point of view, this has the potential to produce socially acceptable, but invalid, results where respondents derive more comfort from appearing satisfied with the various aspects of their lives at a stage of life when their social (and economic) capital may be reduced thus reducing their opportunities to alter their lives. The employment of appropriately trained, highly skilled and mature interviewers, as well as strict adherence to research protocols, is therefore a prerequisite for both quality of life research and research with older people. Indeed, Bowling and Cartwright (1981) reported that elderly widowed people found interviews helpful at a time when others around them no longer wanted to talk about their bereavement. In addition, the support of interviewers themselves during the period of fieldwork (when they may have to cope with the emotions of respondents as well as their own emotions) is vital and requires skilful management and monitoring.

Special safety concerns may be raised where surveys use performance tests of physical function, such as repeatedly standing from a chair or walking a timed-course (Colsher, 1992). Even when respondents are given the opportunity to miss out those exercises they feel would

be unsafe, some may decide to try tests that might be risky for them in order to please the interviewer or to prove that they are physically fit (Colsher, 1992). The objectivity of physically testing respondents is an attractive option given the potential for respondents to misinterpret questions or elaborate on their abilities when asked to respond subjectively, however a balance needs to be struck between safety and validity.

Regardless of the nature of the questionnaire, participation in a survey itself may be stressful or tiring, especially where the interview is lengthy (Herzog et al, 1983; Herzog and Rodgers, 1992). Given the multidimensional nature of the concept of quality of life described earlier, the length of survey instruments used in this area of research is particularly problematic. In addition, because of the increased likelihood of communication difficulties with older people, the length of time to complete a survey instrument with this age group may be greater than with a younger adult sample. Adequate provision should therefore be made for respondents to take comfort breaks, or even for interviews to be conducted over split sessions (although the effects of this on responses should be monitored).

As well as the effects of surveys on older respondents, or potential respondents, there is also the potential for systematic bias in the results of surveys of quality of life of older people, some of which have been alluded to already. Herzog and Rodgers (1992) suggest several sources of errors in health surveys of older people, many of which may have relevance for quality of life research. These include: sampling, sponsorship and endorsement, incentives, proxy reporters, item-missing data, response errors, and the characteristics of survey questions. Where a study is epidemiological in nature, the recognition of such sources of

error is vital, they may still, nonetheless, be relevant and noteworthy in studies of quality of life of older people and will therefore be discussed in more detail below.

With regard to sampling, a study that has sampled older respondents solely from institutions or solely from the community, must do so explicitly as such samples may produce biased results about the entire population of older adults (Herzog and Rodgers, 1992). Institutionalised older people are distinctly different from the non-institutionalised, particularly among those aged 85 and over, in terms of sex, race, presence of hearing or visual impairment, and need for assistance in activities of daily living such as eating and walking (Rosenwaike, 1985). Each of these variables could have considerable influence on ratings and determinants of an individual's quality of life, and some could influence their ability to participate in the research independently.

Standard household sampling can be expensive, particularly when conducted face-to-face as the proportion of households containing individuals aged 60 and over decreases with increasing age. This leads to further difficulties in establishing valid denominators for calculating response rates where households cannot be screened (Herzog and Rodgers, 1992). As a result researchers have tended to rely on lists containing age information for sampling older people, for example FHSA lists. One of the inherent difficulties of using such lists for sampling older people is that they become outdated rapidly because of deaths and moves (Bowling, Hart and Silman, 1989; Herzog and Rodgers, 1992).

Sponsorship and endorsement of surveys is believed to be critical in attaining a high response

rate because it confers legitimacy, credibility and authority, yet there is little consensus on which type of sponsors are likely to be the most influential (Herzog and Rodgers, 1992). Studies in the US have used endorsements by local older persons' groups as well as national institutions such as the Census Bureau (Herzog and Rodgers, 1992). However some caution may need to be exercised here as it is possible that the source of endorsement or sponsorship may effect the importance placed on any one dimension of a potentially multidimensional concept such as 'quality of life' e.g. where the sponsor of a quality of life study is a health organisation respondents may consider (rightly or wrongly) that the researchers are most interested in that aspect of quality of life and focus their answers (consciously or unconsciously) accordingly. Such focusing may occur in relation to, or be compounded by, the professional background of the interviewers, where this is made known to respondents e.g. nurses, geographers, sociologists.

A proxy reporter is generally someone who knows the sampled individual well, such as a spouse, an offspring or a caregiver, and may be particularly important sources of information about the oldest old given their higher non response rates (Herzog and Rodgers, 1992). Here a trade-off presents itself: the notion of using proxy responses of any sort is contentious in quality of life research, however Herzog and Rodgers (1992) point out that proxies may have some use (admittedly in *health* surveys) in avoiding biasing data in favour of those able to respond at all.

Failure to answer a question within a survey can introduce bias on two counts. First, if those not answering the question differ systematically from those who do (Herzog and Rodgers,

1992), and second, if the respondent is attempting to complete a scale which requires a complete dataset in order to generate a quality of life 'score'. This source of bias appears to be potentially more serious for older people who give more frequent non-substantive responses e.g. 'don't know' (Ferber, 1966; Francis and Busch, 1975; Gergen and Back, 1966). The age-related increase in number of 'don't know' answers appears to be larger for questions that deal with attitudes, feelings and expectations than for those eliciting facts (Herzog and Rodgers, 1982); thus they may be a particular problem in quality of life surveys. Older adults are more likely to have difficulty understanding a question, organising their thoughts, and framing their answers, and are therefore more inclined to answer 'don't know' (Herzog and Rodgers, 1992). There is a difference between 'don't know' answers reflecting lack of knowledge and those reflecting unwillingness: thus procedures to reduce missing data resulting from either of these two sources should also be different (Herzog and Rodgers, 1992), however identifying which type of 'don't know' has been given can be difficult in a postal survey.

Response errors can occur for a variety of reasons: they can be motivational or cognitive. In this respect they may be compared with missing data as different symptoms of the same underlying problems e.g. bad question wording (Herzog and Rodgers, 1992). The assumption that the survey process is particularly challenging for older people has not always been upheld (Herzog and Rodgers, 1992), however Colsher and Wallace (1989) observed less consistency in the responses of the oldest-old than in young-old adults. These inconsistencies were accounted for in part by relatively poor memory performance (Colsher and Wallace, 1989). This may have particular significance for quality of life research. If an older person is unable

to recall how good or bad life was in the past (autobiographical memory), this may affect how they evaluate their quality of life at the present time. At present, however, there is a dearth of research on the processes involved in individual quality of life evaluation.

Differences in the meaning of questions for different age groups have been pointed out by gerontological researchers. For example, older people seem less comfortable with psychological self-descriptions appearing in personality and mental health scales (Herzog and Rodgers, 1992). Such instruments are frequently included in batteries of measures in quality of life surveys of older people, particularly where poor mental health is a measured exclusion criterion. It will be interesting to see in future years whether discomfort with psychological scales is a cohort or a biological age effect.

Closed questions in interviews and self-completed scales may reduce administration time, facilitate data entry and analysis (Kohout, 1992), however older people generally dislike the highly standardised format of typical survey questions and response categories (Herzog and Rodgers, 1992). Some may attempt to avoid direct responses by digressing from the question or rewording answers without using the provided categories (Jobe and Mingay, 1990; Kane and Kane, 1981), others may be frustrated by the fixed choices and wish to explain their answers (Kohout, 1992). Herzog and Rodgers (1992) describe anecdotal evidence that survey questions developed on younger adults can be too complex for older adults. They go on to state that gerontological researchers must be very careful about the wording of established and well-validated scales if the validation was conducted only on younger respondents (Herzog and Rodgers, 1992). One explanation for this is that older respondents are probably

less familiar with the closed format questions that younger respondents may have experienced in multiple-choice exams (Kohout, 1992). By far the majority of established 'quality of life' instruments use this format.

Moreover, older people have not learnt to think in terms of a Likert scale, from 'strongly agree' to 'strongly disagree', much less in terms of '1-to-10' rating scales (Kohout, 1992). Similarly, scales validated on community samples may not be valid for institutional samples, and vice versa. For example, a depression index developed for clinical patients and normally administered by a physician is likely to be received differently when a lay interviewer administers it in an older person's home (Kohout, 1992).

As described earlier, quality of life research with older people has most often employed the survey method thus this critique of the use of the survey method with older people, and for the measurement of quality of life, has been clearly warranted. The concerns raised are rarely addressed in published papers and so no judgement can be made on how these issues were treated, or indeed whether they were considered, by the researchers. This lack of acknowledgement may reflect attempts to conform to word limits for submitted manuscripts, but may equally demonstrate a lack of awareness of the potential effects of such research on older people and the subsequent effects on the validity of results.

The above discussion has centred on quantitative rather than qualitative enquiry. Murphy and Longino (1992) describe the key to the theoretical shift required by qualitative research is the idea that every aspect of social life is embedded in symbolism. With regard to studies of

quality of life with older people, we should be sensitive to the ways in which people interpret their lives, instead of focusing on empirical indicators: ‘only in this way can socially relevant research be conducted’ (Murphy and Longino, 1992).

Thus Chapter 2 reviewed the literature relating to quality of life in older people, presenting papers in relation to their setting, focusing first on institutional settings and then on the community setting. It described the measurement of quality of life in later life by identifying commonly used indicators of quality of life in later life, outlining issues of quality of life measurement in later life and issues relating to the survey method with older people. The review focused principally on the literature of social gerontology, social indicators research and health services research relating to older people, and is therefore not comprehensive.

Systematic reviewing is de rigour today, but this thesis was commenced earlier than this trend. Whilst a systematic review may offer advantages, the various reviews presented here are thorough (well over 500 references were examined) and cover the most pertinent issues in relation to the definition and measurement of quality of life with older people, particularly in relation to the state of the art just prior to the empirical data collection for this thesis. Literature from the period following this and up to the time of submission were also examined and included where relevant, however little was added to the taxonomy (presented in Chapter 1) beyond the mid 1990s given that this was published during the preparation of the thesis (Farquhar, 1995b).

Chapter 3: Measures used in the empirical study

Chapter 3 describes the search of the literature conducted to identify measures used in the empirical study. It then describes these measures in terms of their content, scoring, published tests of reliability and validity and use with older people. Finally, it considers the location of the measures within the taxonomy of definitions of quality of life presented in Chapter 1, and the implications of this for the valid measurement of quality life among older people.

For the empirical study described in this thesis, a search of the literature identified seven of the more commonly used scales for measuring ‘quality of life’, or its dimensions, among older people. The keywords ‘quality of life’ were used for a Medline search up to 1990⁸. This was supplemented with a hand search of key journals (e.g. Quality of Life Research) up to 1990. The criterion for selection of scales were that the scale should appear in the published literature before 1990 and be either i) described by its developers as a ‘quality of life’ instrument, or ii) have been subsequently used by others as a ‘quality of life’ instrument, or iii) been included in a review of ‘quality of life’ instruments, thereby suggesting its suitability or acceptance as a measure of quality of life.

Thus the seven scales identified were: the Nottingham Health Profile (Hunt, McEwen and McKenna, 1986), the Affect Balance Scale (Bradburn, 1969), the General Well-Being Schedule (Dupuy, 1978), the McMaster Health Index Questionnaire (Chambers et al, 1976),

⁸ Searches were conducted up to 1990 as the empirical study (to be described in more detail later) commenced in 1990.

the Self-Evaluation of Life Function Scale (Linn and Linn, 1984), the Dartmouth Co-operative Chart for 'Quality of Life' (Nelson et al, 1987), and The Faces Scale (Andrews and Withey, 1976). Each of these is described below.

Nottingham Health Profile

The Nottingham Health Profile (NHP) was developed in the UK. The conceptual basis of the NHP was that it should reflect lay, rather than professional, definitions of health. Its development followed 768 interviews with patients, suffering various acute and chronic ailments, on the effects of illness on behaviour. The NHP therefore relates to how people feel when they are experiencing various states of ill health. The 2,200 statements generated by the interviews led to the identification of relevant concepts. Scrutinisation of each statement for redundancy, ambiguity, understandability, clarity, ease of reading and reading age reduced the number to 138. These were further reduced and refined during a series of studies conducted in the late 1970's. The remaining statements (or items) were then classified into six 'areas': physical ability (8 items), pain (8 items), sleep (5 items), energy level (3 items), emotional reactions (9 items) and social isolation (5 items). The scale is divided into two parts: Part I and Part II.

Part I of the NHP measures perceived or subjective health status by asking for yes/no responses (scored 1 and 0 respectively) to 38 simple statements on the six areas listed above and relative weights are applied as the statements in each area vary in severity. The weights were derived using Thurstone's Method of Paired Comparisons using judgements obtained

from 1,200 outpatient interviews. A simpler non-weighted scoring system is also sometimes used in which the number of affirmative responses in each area is counted; indeed some authors are beginning to question the appropriateness of the weightings (see for example: Jenkinson, 1991; Jenkinson et al, 1991). After weighting, the resulting six area scores (the 'profile') range from 0 (no problems) to 100 (where all problems in the area are affirmed): thus the higher the score in each area, the greater the perceived health problems in that area. There is ongoing debate over the choice between reporting a total score and a profile. Hunt et al (1985) argue that an overall score is invalid whereas Kind and Carr-Hill (1987) state that if a profile is used then each area should measure different things, however the assignment of items to areas has been arbitrary. For comparative purposes, means can be computed on samples where $n > 20$; for smaller groups mean rank scores can be used. In the empirical study presented in this thesis the weighted scoring technique was used and a profile of mean scores presented.

Part II of the NHP asks about the effects of health on seven areas of daily life: work, looking after the home, social life, home life, sex life, interests and hobbies, and holidays. However, further developmental work with Part II is ongoing and the authors recommended that it should not be used until this is completed. Therefore the study presented in this thesis uses only Part I of the NHP.

The NHP was designed for self-completion (taking under ten minutes to complete), although the authors state that it is possible to read out the statements to those with sight or reading problems; presumably it is also possible to fill in the responses for those experiencing

difficulty with handwriting (due to visual or motor problems). It has been used for both groups of patients and for the general population, however it focuses on negative rather than positive experiences. Reference scores are available for healthy people (age and sex norms show higher scores for women and scores rising with age) and various categories of patients. Bowling (1991) describes it as a useful survey tool for assessing whether people have a severe health problem, but states that other data are required to indicate to the type of health problem(s) experienced. Jenkinson, Fitzpatrick and Argyle (1988) reported it to be sufficiently sensitive to successfully determine variations within and between illness groups, however the domains of mobility and pain, as measured by the NHP, were confounded.

Although the scale's authors do not consider it a measure of quality of life, it has misleadingly been adopted by much of the health services research community as just such a tool (see for example: O'Brien et al, 1988; Caine, Harrison, Sharples and Wallwork, 1991; Grimby and Wiklund, 1994; Visser et al, 1995; Lukkarinen and Hentinen, 1997; Staniszewska, 1998). Indeed Hunt (1988), one of the developers of the NHP, reports that 'the ambiguity of some health status measures is attested to by the fact that the same instrument may turn up under rather different rubrics, for example, the Nottingham Health Profile... has been referred to as an indicator of health status, a quality of life instrument and a measure of perceived distress' (p9). Wade (1992) cites the NHP in a list of quality of life measures suitable for use within neurological rehabilitation, but describes it as '[maybe] simply... recording mood rather than a more global concept of quality of life' (p247). However Bowling (1997a) states that the NHP would require supplementation if used as a measure of 'health-related quality of life'.

The scale's developers have published a book outlining its development, earlier studies of its reliability and validity, and a user manual (Hunt, McEwen and McKenna, 1986). The NHP has been tested for face, content and criterion validity and has been reported to be a satisfactory measure of subjective health status in the physical, social and emotional 'areas'. It has been shown to discriminate between: groups of 'well' and 'ill' people; levels of physiological fitness; high and low GP consulters; social classes; age groups; and sexes.

Mauskopf et al (1994) reported moderate to good correlations (of between 0.32-0.50) between the pain, energy and sleep dimensions of the NHP and pain reported by over 1,000 patients with zoster; the other NHP dimensions were weaker. Good results have been reported with the NHP and coronary patients (Caine et al, 1991; Permanyer-Miralda et al, 1991) and van Agt et al (1993) reported the ability of the NHP to discriminate between a normal population and those with a range of serious medical conditions. However, Alonso et al (1992) reported a variable performance in relation to respiratory disease and clinical measures of respiratory function, and Fitzpatrick et al (1992b) found it less stable in relation to rheumatology patients. Thus, the scale appears to be sensitive to changes following dramatic interventions, but its performance is less certain with more minor treatments (Hunt et al, 1984; Brazier et al, 1992).

Fairly high levels of reliability (for Part I) have been reported, although testing on this has been limited. Hunt et al (1981 and 1986) reported correlations of between 0.71 and 0.88 when the NHP was administered to 58 patients with osteo-arthritis and 93 with peripheral

vascular disease (PVD) at four and eight weeks respectively after baseline, with the exception of the items on home life (0.64), social life (0.59), interests and hobbies (0.44) for osteoarthritis patients; and social life (0.61), looking after the home (0.64) and work (0.55) for PVD patients.

Grimby and Wiklund (1994) administered the NHP at outpatients to 565 ambulant 76 year old patients. It was administered alongside measures of health and socio-demographic factors and found to be sensitive to differences in observed and perceived illness, institutionalisation, widowhood, loneliness and financial discontent.

The content of the scale is reportedly understood and acceptable to older people and is sensitive to change. However there has been vigorous debate about the NHP's floor effect, whereby healthy respondents or those with minor ailments, tend to show perfect scores and therefore have no scope for improvement (Hunt et al, 1985; McDowell and Newell, 1987). This effect probably results from its original design as an instrument for people seeking care, when it focused on people with disabilities and the concept of negative health; only later was it used on healthy populations (McDowell and Newell, 1987).

More recently, Sharples et al (2000) reported investigations of the reliability and validity of the NHP (Part 1) in an elderly population living at home (n=481). The Flesch reading formula (Todd and Bradley, 1994) rated the NHP as easy (RE=93.9%), indicating that it could be understood by around 88% of individuals aged 65 and over. No bias in test-retest reliability was found at one month and internal consistency was comparable with Cronbach's

alpha in the range of 0.61 to 0.85. Substantial ceiling effects (>20% cases) were found for all six NHP scales, but comparable scales exhibited significant and comparable relationships with actual physical performance and self reported ADL, morbidities, symptoms and the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) ($p < 0.01$ in all cases) (Sharples et al, 2000).

Affect Balance Scale

The Affect Balance Scale (ABS) was originally developed in the US by Bradburn and Caplowitz (1965) (12 items), and later revised by Bradburn (1969) (10 items). It is described as an indicator of happiness or general psychological well-being (Bradburn, 1969). The scale is based on the hypothesis that subjective well-being could be indicated by a person's position on two independent dimensions: positive and negative affect (Bradburn and Caplowitz, 1965). Well-being is expressed as the balance between these two, as positive factors (e.g. being complimented) can compensate for negative feelings to maintain the overall sense of well-being. However, the positive and negative affect are assumed to be independent; thus, a decline in positive feelings would not necessarily be accompanied by an increase in negative feelings.

Although the ABS was not designed as a quality of life measure, it is usually classified as a measure of morale (see, for example, Denham 1983 and Bowling 1997a). Denham (1983) describes morale as 'a measure of quality of life, particularly in the elderly' and goes on to cite the ABS, amongst other scales, as a suitable measure for this. The ABS is included in

George and Bearon's (1980) and Fletcher, Dickinson and Philp's (1992) reviews of quality of life instruments for use with older people, although the former list it under the heading 'life satisfaction and related concepts' and the latter under the heading 'unidimensional [measures of] subjective well-being'. Such variation in the location of instruments such as the ABS within reviews of this type is not uncommon and adds to the confusion surrounding the definition of quality of life and its dimensions; this is the responsibility of reviewers of instruments and not a failure on the part of the original authors of instruments.

The self-administered 10 item revised version of the ABS consists of five positive affect items and five negative affect items. The two sub-scales are independent, but both correlate with happiness (Bradburn, 1969). The 'balance' is the result of an additive process: it refers to the balance between positive and negative affect reflected by an individual's score on the scale. However, Cherlin and Reeder (1975) state that the scale is also confounded by items referring to activation or participation (e.g. item 1 'particularly excited or interested in something'), and Borgatta and Montgomery (1987) note that some of the items also appear to measure accomplishments; thus, for example, respondents who do not consider themselves actively engaged in a social setting may find difficulty in responding appropriately.

Response categories to each of the 10 items are dichotomous ('yes/no'). However scales of three, four or five points representing the frequency of experiencing the feelings (using an alternative stem question wording of: 'how often do you feel each of these ways?') have also been used.

Two alternative scoring methods have been described. A score of 1 is given for each 'yes' response and 0 for each 'no'; scores for each sub-scale (positive and negative) are then summed so that they range from 0-5. McDowell and Newell (1987) then describe the balance score as being calculated as the positive score minus the negative. Bowling (1997a), however, describes a more complex method where sub-scale scores are determined independently by summing scores for each of the five items in each sub-scale, and the two items in each sub-scale with the lowest frequencies are then combined so that sub-scales range from 0 to four. The negative affect score is then subtracted from the positive affect score and the resulting overall score is transformed to range from +1 to +9 by adding the constant +5. However the latter method was one used by Bradburn (1969) 'in order to have enough cases for meaningful analysis' (p.67); a point that Bowling (1997a) does not note. Bradburn (1969) describes the simpler method on page 59. Cherlin and Reeder (1975) have questioned the use of a summary statistic as it may entail loss of information compared with reporting positive and negative sub-scores separately. As Bradburn (1969) himself noted:

'it seems fairly clear that a person who scores 5 on the positive feelings index and 0 on the negative feelings index will have a high probability of being "very happy", it is not clear whether a person whose score is 5 on the positive feelings index and 4 on the negative feelings index will be more likely to be "very happy" than a person whose score is 1 on the positive feelings index and 0 on the negative feelings index... nor is it clear whether one would expect any differences between those who score 0 and those who score 3 on both indices' (Bradburn, 1969; p.65).

For the empirical study presented in this thesis the dichotomous 'yes/no' responses were used together with the stem question specifying the time referent 'past few weeks', and the simpler scoring method is used. In addition, positive and negative sub-scores are reported separately.

The ABS reportedly takes less than five minutes to complete (Fletcher, Dickinson and Philp, 1992). It has acceptable levels of validity and reliability, and is reportedly sensitive to change. With regard to validity, correlations with an 18 item version of Neugarten's Life Satisfaction Index A (LSIA) were around 0.66 (Bild and Havighurst, 1976) and a review of the scale by George and Bearon (1980) gives inter-scale correlations with other morale scales and the LSIA of between 0.61 and 0.64. Berkman (1971) used only eight of the ABS items and reported a correlation of 0.48 with a 20-item index of neurotic traits.

With regard to reliability, internal consistency (inter-item) correlations range from 0.47 to 0.73 for the positive and from 0.48 to 0.73 for the negative scale (Cherlin and Reeder, 1975; Warr, 1978). Warr (1978) also reported modest inter-scale correlations (0.24-0.26). Bradburn (1969) reported test-retest correlations of 0.76 three days apart, associations of more than 0.90 for nine items and 0.86 for the 'excited or interested' item.

George and Bearon (1980) consider the ABS to be applicable for use with older people, although not developed as a measure specifically for them. Gaitz and Scott (1972) administered the ABS to 1,441 non-institutionalised adults from Houston's three major ethnic groups (Anglo, Black and Mexican-American), aged 20 to 75+ years. They found the ABS had no significant relationship with age: the scores of the older respondents covered the full range (scored 0-10 in their study) with about two thirds of the scores falling in the 5 to 8 interval. George and Bearon (1980) describe the ABS as 'the best available measure of affect', however some critics regard it as too simplistic (Cherlin and Reeder, 1975).

General Well-Being Schedule

The General Well-Being Schedule (GWBS) is described as a concise multidimensional indicator of subjective feelings of well-being and distress, and was designed for use in the US Health and Nutrition Examination Survey (HANES I) (Dupuy, 1978). The scale assesses how the individual feels about his 'inner personal state' rather than about external conditions such as income, work environment or neighbourhood. A draft of the GWBS contained 68 items, however just 18 were used for HANES I, and these form the usual set of questions referred to as the GWBS. A 22-item version, known as the Psychological General Well-Being Index (PGWBI) is also available (Dupuy, 1984). Although not designed as quality of life instrument, the GWBS is described in Wenger et al's (1984) *Assessment of Quality of Life in Clinical Trials of Cardiovascular Therapies*.

As with the ABS, the GWBS reflects both positive and negative feelings. It covers six dimensions: anxiety, depression, general health, positive well-being, self-control and vitality. Each of the six dimensions is made up of between three to five items each. Each item has the time frame 'during the last month'. The first 14 questions use six-point response scales representing intensity or frequency (scored 1 to 6). The remaining four questions use 0 to 10 rating scale defined by adjectives at each end. Thus the GWBS appears to be a relatively complex instrument to complete, with a number of choices to make. It is designed to be self-administered, and takes about 12 minutes to complete (Bowling, 1997a).

In scoring replies, the polarity of certain questions is reversed so that a low score represents more severe distress. Subtracting 14 from the sum of scores gives a total score running from 0 to 110. Dupuy (1978) proposed cut-off points to represent three levels of disorder: thus, 0 to 60 represents 'severe distress', 61 to 72 'moderate distress' and 73 to 110 'positive well-being'. In addition, six sub-scores may be formed representing each of the six dimensions. The former method (total score) is generally considered the most useful (McDowell and Newell, 1987). The empirical study presented within this thesis uses both methods of score presentation (total score and sub-scores).

In terms of validity, Fazio (1977) reported that the GWBS correlated moderately (0.47) with interviewers' ratings of depression among 195 students and that the average correlation of the GWBS with six other depression scales was 0.69 and with three anxiety scales was 0.64. Edwards et al (1978) reported that psychiatric patients achieved different scores in comparison with US national population norms (provided by HANES I). The GWBS was also sensitive enough to detect the progress over three weeks of the 21 psychiatric day patients in their study. Kamman and Flett (1983) reported a correlation of 0.74 between the GWBS and the Affectometer 2 (Kamman and Flett's 96-item scale of general happiness and well-being). And, again using HANES I data, Wan and Livieratos (1977) and Dupuy (1978) reported factor analyses of the GWBS: three factors explained 51% of the variance (anxiety, tension and depression; health and energy; and positive well-being or life satisfaction).

In terms of reliability, Dupuy (1984) reviewed a wide range of studies and reported that internal consistency for the six sub-scales ranged between 0.72 and 0.88. Test-retest

reliability produced good results (0.50-0.86; median 0.66), with the exception of a lowered test-retest coefficient of 0.50 when the interval was extended from one week to one month. Monk (1981) reported test-retest coefficients of 0.68-0.85 for two samples within HANES I; Bowling (1997a) questions whether the lower correlations reflect the instability of the instrument or changes in individuals. Internal consistency coefficients of 0.93 were reported from the same dataset. Fazio (1977) reported internal consistency coefficients of 0.91 for men and 0.95 for women, together with correlations among sub-scores ranging from 0.16-0.72. Edwards et al (1978) reported an internal consistency coefficient of 0.69, whereas a review by Ware et al (1979) reported three studies giving coefficients of over 0.90.

McMaster Health Index Questionnaire

Developed at McMaster University, Ontario, Canada, the McMaster Health Index Questionnaire (MHIQ) is a measure of physical, social and emotional functioning designed to provide independent measurements of these separate areas (Chambers et al, 1976). It was conceived as a health status questionnaire suitable for use with a general population, which could be used to predict a health professional's clinical assessment of a person's health. Although not specifically designed for this, the MHIQ has since been described by its principal author as a 'general measure of quality of life' (Chambers, 1984: p 163; Chambers, 1988: p129) however he also, confusingly, uses the terms 'quality of life' and 'health status' interchangeably. A chapter on the MHIQ is included in Walker and Rosser's (1988) 'Quality of Life: assessment and application', and Wilkin, Hallam and Doggett (1992) have described it as a 'general measure of quality of life for use in health service evaluation' (p.147).

Subsequently, it has been used to measure quality of life in a number of studies (e.g. Chambers et al, 1982, Tugwell et al, 1990).

Using the WHO definition of health as a conceptual foundation, the content of the questionnaire was based on an initial pool of 172 items derived from three sources: existing measures (e.g. the Katz Activities of Daily Living Scale); external and internal multidisciplinary consultants; and, a review of the relevant literature (e.g. for the Social Function Index some questions were derived following a review of sociological studies of leisure and social participation). It does not, therefore, have an 'empirical foundation rooted in a representative sample of the public or patients' (Bowling, 1994: p5). However, an attempt was made to include positive as well as negative discriminators.

The questionnaire contains 24 physical function items (covering physical activities, mobility, self-care, and communication), 25 social function items (covering general well-being, work, social role performance, material welfare, family participation and friendships), and 25 emotional function items (covering self esteem, personal relationships, thoughts about the future, and critical life events); each section also includes a global assessment of function in that area. It comprises 59 items in total: some items cover both social and emotional functions. It is therefore lengthy.

All physical functioning items were designed to evaluate the patient's functional level on the day the MHIQ was administered, whereas the social function items are explicitly concerned with a specific time period (usually the present). Agree-disagree emotional function items do

not refer to a specific time period, but are phrased in the present tense; other emotional function items refer to the recent past as specifically defined (e.g. within the last year). Within the scale, emphasis is placed on performance rather than ability in order that information is elicited only on those activities that can actually be observed at the time the MHIQ is completed e.g. ‘*did* you dress yourself?’ rather than ‘*can* you dress yourself?’. In addition to being lengthy it is also, therefore, complex.

Scores for each section are calculated by converting all responses to dichotomies: a score of 1 is given to ‘good function’ responses and a score of 0 to ‘poor function’ responses for each item. In addition, questions not answered are scored to indicate poor function. This procedure produces what Wilkin, Hallam and Doggett (1992) describe as ‘some odd classifications’ e.g. watching television for between one and two hours per day scores 0 (poor social function), whilst watching less than one hour per day but more than three hours per week scores 1 (good social function). An index is then calculated for each of the three areas (physical, social and emotional) by summing the response scores and dividing this by the number of items within that area. Within the area of physical function some of the items are combined so that the original 24 items are reduced to 19 for scoring. The resulting function scores range from 0 (extremely poor function) to 1.0 (extremely good function). Alternative weighting schemes have also been developed, e.g. for chronic respiratory disease patients (Chambers et al, 1982). The empirical study presented in this thesis used the more commonly employed un-weighted method.

The self-completed version of the MHIQ takes about 20 minutes to complete. Some work

has been done comparing modes of administration (self-completion, telephone interview or face-to-face interview) and little or no effect was found: physical function score's sensitivity to change was reduced by modes other than self-completion whereas social and emotional scores were unaffected by administration mode (Chambers et al, 1987). This perhaps reflects the complexity of the questions and the choice of answers.

As far as it has been tested by its developers, the MHIQ reportedly correlates well with other relevant scales, however the values are unpublished: the physical-function item reportedly correlated well with rheumatologists' and occupational therapists' clinical assessments; and the emotional, physical and social function index reportedly correlated well with established measures of psychological well-being. The physical-function index also reportedly correlated with analogue pain scales and clinical and biological results (Chambers et al, 1982). Chambers et al (1982) described the MHIQ as sensitive to change based on changes in scores achieved by 96 physiotherapy patients between first visit and discharge; however, once again, the values were not published.

Reliability was assessed by asking 30 physiotherapy out-patients to complete the MHIQ on two occasions within a one-week period during which time their functional status was not expected to change (Chambers, 1984): the correlation between physical- and emotional-function values was 0.80; intra-class correlation coefficients ranged from 0.48-0.95 for the physical, emotional and social scores; and internal consistency coefficients between the physical-, emotional- and social-functional indices were 0.76, 0.67 and 0.51 respectively. Thus it has an acceptable level of reliability, although Wilkin, Hallam and Doggett (1992)

describe evidence of its validity as 'limited'. Bowling (1997a) suggests that more studies of its reliability and validity are needed.

The MHIQ has been used with a variety of patient populations including samples of older people in both acute inpatient and community settings, however Bowling (1997a) considers it to be of 'questionable applicability to the very elderly' because, for example, of the question on sports participation in the physical index. In addition, Wilkin, Hallam and Doggett (1992) point out that it has not been widely used by researchers other than its developers.

Self-Evaluation of Life Function Scale

The Self-Evaluation of Life Function Scale (SELF) is a 54-item, multidimensional, self-report scale developed in the US to measure physical, emotional and social function (Linn and Linn, 1984). It was derived from two studies of 826 people aged 60 and over, and is proposed as a measure for use specifically with older adults e.g. social adjustment is commonly assessed through role performance, however it is invalid to ask about job performance when most older people are retired, or to ask about marital function when many older people are widowed (Linn and Linn, 1984).

The content of the SELF was based on 130 items selected from eight existing scales, and modified for older people. The items were selected to 'represent function in multiple areas at one point in time, that might be expected to change as a result of treatment of the ageing process itself' (Linn and Linn, 1984: p604). Principle components method was used to

identify items with the highest loadings on a primary factor, thus reducing the 130 items to 70. These 70 were then entered into a second order factor analysis, further reducing them to 57 (three items are not used in the scoring). This produced seven factor solutions named: Physical Disability, Symptoms of Ageing, Self Esteem, Mobility, Depression, Social Satisfaction, and Personal Control. Items were then given consistent time frames and, where necessary, modified for self-report (Linn and Linn, 1984).

Factor scores can be used to weight each question in forming section scores (McDowell and Newell, 1987) however the simpler summing method is recommended by the offices of Margaret Linn⁹ (personal communication). Responses to each item (except for items 16 and 17) are scored from 1 to 4, with items 35, 40, 43, 44, 45, 50, 51 and 54 reversed scored. For item 16 the total number of medications indicated provides the item score, and for item 17 the total number of diagnoses indicated provides the item score. Higher scores indicate less favourable responses. Items are then summed under six factor scores: physical disability (13 items), symptoms of ageing (13 items), self esteem (7 items), social satisfaction (6 items), depression (11 items), and personal control (4 items). The simpler summing method (un-weighted) is used in the empirical study presented in this thesis.

The SELF has not been widely adopted but was included in this study as it was an instrument designed specifically for use with older people and has been used as a measure quality of life after surgery for aneurysm (Rohrer, Cutler and Wheeler, 1988). Tests conducted and reported by its developers indicate that: it can be completed by a large proportion of older adults in a

⁹ Margaret Linn is now retired: staff from her former offices provided the scoring not present in the original paper (Linn and Linn, 1984).

wide variety of settings; its factors are stable and reliable and can discriminate; it has good predictive ability for length of institutionalisation, physician visits and self-assessed health (Linn and Linn, 1984).

It has had only limited testing in terms of sensitivity to change (Linn and Linn, 1984). Browne et al (1994) used the Symptoms of Ageing factor from the SELF as a screening tool with 67 healthy respondents aged 65 and over, sampled from randomly selected general practices in the urban Dublin area who were: a) not currently receiving prescribed medication, b) not on a waiting list for medical treatment and c) not suffering a chronic or acute disorder requiring prescribed medication within the previous month. They reported a mean of 14.75 (s.d.=3.9) at t1 (baseline) and 16.62 (s.d.=5.0) at t2, 12 months later.

McDowell and Newell (1987) describe the validity of the SELF as 'weak', but its reliability as 'adequate'. In addition, the SELF has been adapted for telephone administration (16 item version) (Rohrer, Cutler and Wheeler, 1988).

Dartmouth Co-operative Chart 'Quality of Life'

The Dartmouth Co-operative Charts (Nelson et al, 1987) were developed in the US by a primary care research network, specifically for daily use in clinical practice. The aim of the charts is to provide clinicians in primary health care with an efficient system for screening, assessing, monitoring and maintaining patient function in routine office practice. They therefore needed to be quick and simple to administer, applicable to a wide range of

problems, possess face validity, be acceptable to both patients and clinicians, yield easily interpretable scores, and provide clinically useful information. The charts can also be used in surveys to assess need and to provide a measure of outcome in clinical research. Their content was based on the existing literature and instruments, consultations with health measurement experts and practising clinicians. In addition, development of the charts used data from over 3000 patients in a variety of settings.

The original instrument consists of nine charts (8.5" x 14") measuring function, general health status, and quality of life without reference to any specific disease. Each chart is a single item measure of a particular dimension of function or health status and eight of the nine are illustrated with cartoon figures. Respondents are asked to rate how they have felt over the past four weeks. A one-week version has also been used. The last of the nine charts deals with quality of life in terms of patients' perceptions. Each item is scored from one to five on a five point ordinal scale; higher scores representing unfavourable outcomes. Scores are not summed.

For routine clinical practice, only some of the charts are expected to be used for selected patients, however the authors do not suggest which charts would be most useful with which categories of patients. Thus in the study presented here, only the Quality of Life chart (DCCQoL) was used in order to test a global/single item measure of quality of life. This chart consists of an illustration of a cartoon figure holding a vertical five-rung ladder. Above this is the question 'How has the quality of your life been during the past 4 weeks? i.e. How have things been going for you?'. Each rung of the ladder is labelled with a response

category running from '1. Very well: could hardly be better' through to '5. Very bad: could hardly be worse'. The page is titled 'QUALITY OF LIFE'. No changes were made to the wording or illustration on the chart for its use in the empirical study presented in this thesis.

The chart(s) can be self-administered, or administered by a health care professional: in the latter case the professional shows the respondent the chart(s) and records the response. Each chart takes about 30-45 seconds to complete (Nelson et al, 1990) and all nine charts can be administered in three to five minutes (Wilkin, Hallam and Doggett, 1992). No problems have been reported in their use with older people (Wilkin, Hallam and Doggett, 1992), however in the only all-older samples with which the charts have been tested the quality of life chart was not used. For one of these studies (involving attendees at a Veterans Administration outpatient clinic) the DCCQoL had not yet been developed (Nelson et al, 1990) and the other opted to use just four of the nine charts and not include the quality of life chart (Meyboom-de Jong and Smith, 1990).

Since the empirical part of the empirical study presented in this thesis was conducted, the charts have undergone further development and the Quality of Life chart (together with the charts for pain and social support) is not included in the new instrument (van Weel and Scholten, 1992). Bowling (1997a) describes this 'deliberate omission' as 'regrettable, particularly in view of the current emphasis on including a specific self-assessment of quality of life in broader health-status measures'. Although this omission may be regrettable this latter comment is confusing given its implication that 'quality of life' is a component of 'health', rather than the other way round.

Testing for validity in the earlier version of the instrument (i.e. including the Quality of Life chart) was conducted initially on 1,400 patients with different groups of conditions from four medical centres in the USA (Nelson et al, 1987). The performance of the single charts is said to be less precise in detecting differences in functional status than multi-item health scales, although the full set of charts perform well together in comparison with Rand Medical Outcomes Study short-form measures (Meyboom-de Jong and Smith, 1990) and show higher levels of sensitivity than the NHP (Coates and Wilkin, 1992).

Low test-retest correlations for the original charts were reported by Meyboom-de Jong and Smith (1990): correlations of 0.67-0.82 were reported with a three-week interval (with a Kappa of 0.49-0.59), and 0.36-0.72 with a one-year interval (with a Kappa of 0.31-0.38). Further tests of validity and reliability have been conducted for the later version of the instrument but have not been cited here as the later version does not include the Quality of Life chart.

The charts have been found to be acceptable to both professionals and patients (Nelson et al, 1990). Perhaps more importantly, given the aim of the instrument, Landgraf et al (1990) reported that in 59% of 22 case studies, clinicians reported that the charts improved communication and 41% resulted in a modified physical plan. However, although they describe the results reported so far as 'encouraging', Wilkin, Hallam and Doggett (1992) suggest that there is considerable scope for further testing of the validity and reliability of the charts. Further, a review by Anderson et al (1993) considers the details of the research

design, on which the testing to date has been based, to be lacking.

The Faces Scale for Quality of Life

The Faces Scale is a visual approach to the measurement of feelings or global single items (e.g. life satisfaction). It has been used, along with other single-item indicators of well-being (e.g. the Delighted-Terrible Scale, Ladder Scale, and Circles Scales) to assess satisfaction with life in general or with more specific topics such as health, economic status, or housing. They are used to assess the affective component of quality of life rather than the physical and social conditions in which a person lives. Although no single author developed this method, it is usually attributed to Andrews and Withey (1976) who formally compared this and other single-item scales, testing them for validity (McDowell and Newell, 1987).

The Faces Scale usually consists of seven stylised faces, labelled A to G, depicting graded expressions from (A) 'delighted' (up turned, half circle smile) to (G) 'terrible' (down turned, half circle mouth), with a straight-mouthed 'neutral' face (D) in the middle. Unlike a 'real' face the eyes do not change on these stylised faces despite the changes in the mouths, which may give the impression that the smiles are not genuine; this was probably done for ease of depiction and consistency.

Respondents are required to select the faces that best represent their feelings in relation to a number of single items i.e. 'which face comes closest to expressing how you feel about....?'. Other researchers have used the same method to assess patient mood with 20 faces (Lorish

and Maisiak, 1986). In addition, according to the question wording, the scale may refer to the past, or may be used to express respondents' hopes for the future.

Interestingly, Andrews and Withey advise researchers to select study-specific items. The Faces Scale (seven faces) was used in both the baseline (1987-1989) and 1991 follow up studies (to be described later: see 'Samples' section) from which respondents were sampled for the empirical study presented in this thesis. For these studies The Faces Scale was used to measure respondents' feelings about various aspects of their lives e.g. 'accommodation', 'activities', 'independence or freedom' etc. In addition, for the empirical quality of life study presented here, a single item on 'quality of life' was added at the 1991 follow up for all respondents: 'which face comes closest to expressing how you feel about your quality of life?'. Thus the majority of respondents to the follow up study (not just those partaking in the quality of life study) completed this item.

The Faces Scale is easy to administer, quick to complete and the non-verbal approach may make the scale particularly suitable for use with respondents who have difficulty reading (Wilkin, Hallam and Doggett, 1992). Andrews and Withey (1976) reported satisfactory test-retest reliability over varying time periods, and Rodgers and Converse (1975) reported moderately high stability coefficients over a period of eight months. Bowling and Browne (1991) reported weak to moderate correlations (-0.24 to -0.65) with Neugarten's Life Satisfaction Index A when both were administered to samples of older people living at home in London and Essex. Bowling (1997a) describes further unpublished analyses of this dataset by Bowling and Browne showing reliability coefficients of around alpha 0.80 and weak to

moderate inter-item correlations of 0.30 to 0.59 between studies.

Wilkin, Hallam and Doggett (1992) note that the validity of single item measures such as The Faces Scale depends on the concept being measured and the phrasing employed. They go on to report that general questions concerning global health (Davies and Ware, 1981) or quality of life (Andrews and Crondall, 1976) have been shown to be valid, but state that care should be taken to define what is being measured. For methodological reasons the definition of the concept measured by The Faces Scale (i.e. 'quality of life') could not be done for the present study as 'professional' or 'expert' definition of the concept at this phase of the study (Stage Ia) might have influenced lay definitions gathered later i.e. at the Quality of Life Questions (Stage Ib) to be described later (see 'Methods' section). Similarly, in his study of stroke patients and their carers, Anderson (1988) did not present a definition of 'life satisfaction' when he used The Faces Scale 'so [that] the respondent can frame a response within her [sic] own interpretation of the meaning and constituents of the construct'.

The faces are scored from 1 ('delighted') to 7 ('terrible'). As the scale does not use descriptive terms it has stronger claims to interval level scaling than a question employing category labels (McDowell and Newell 1987; Wilkin, Hallam and Doggett, 1992), although this is questionable; this present study treats it as ordinal.

Apart from the original work by Andrews and Withey, few studies using the scale have been published. Of those that have, some have reported it to be fairly skewed with around a fifth to a quarter choosing 'terrible' faces whilst over half to two thirds chose 'delighted' faces

(Anderson, 1988; Bowling and Browne, 1991). However, both of these studies reported good acceptance of the scale by older respondents.

Thus none of the seven scales identified and described here were originally developed as quality of life measures. Their original designs were as measures of health (i.e. NHP), functioning (i.e. MHIQ, SELF), psychological well-being (i.e. ABS, GWBS), satisfaction (i.e. The Faces Scale) and for needs assessment (i.e. DCCQoL). They have all, however, been either used as quality of life measures for older people (e.g. NHP, MHIQ, SELF) or adopted under reviews of quality of life measures for older people (e.g. ABS, GWBS, DCCQoL, The Faces Scale) and to this extent represent the operationalisation of definitions of quality of life within the published literature up to 1990.

Given the focus of these measures on health and psychological well-being, these operationalised definitions can be firmly located within the type III focused definitions category of the taxonomy of quality of life definitions developed for this thesis and presented in Chapter 1. Whether they are type IIIa “explicit focused definitions” or type IIIb “implicit focused definitions” would depend on the context in which they were presented within the individual studies employing them. Of the two subtypes, an explicit focused definition (type IIIa) would be the less misleading.

Whichever subtype they were, they are clearly not based on a broad or all encompassing definition of quality of life, but on a definition that is focused on health. Given that these

were measures identified to assess quality of life in older people in particular, the predominance of health as the key indicator of quality of life is a concern because of the likelihood of poorer health amongst this age group, and the subsequent potential for a misleadingly poor judgement or rating of their quality of life. In addition, the increasing research and policy interest in the associated concepts of positive and successful ageing described earlier in Chapter 2 are at odds with the focus of these instruments.

Finally, all of these instruments essentially use the survey method of data collection, whether they are administered postally, by telephone or face-to-face. In addition some are lengthy and complex. Thus the inherent problems of the survey method when used both with older people and for studies of quality of life, as outlined in Chapter 2, will apply to these instruments. Thus they are far from ideal but represent the state-of-the-art of the measurement of quality of life among older people in the early 1990s.

Thus Chapter 3 described the search of the literature conducted in 1990 to identify the measures used in the empirical study. It then described these measures in terms of their content, scoring, published tests of reliability and validity and use with older people. In addition, it considered the location of the measures within the taxonomy of quality of life definitions presented in Chapter 1, and the implications of this for the valid and reliable measurement of quality of life among older people.

Chapter 4: The case for lay definitions/measures

Chapter 4 presents the case for lay definition and measurement of quality of life. It critiques some of the so-called 'self-assessed' quality of life studies and presents the arguments commonly levelled at lay definitions of quality of life. It then describes a small but growing body of literature reporting an absence of significant correlations between subjective and objective indicators of quality of life, and summarises the methodological literature on lay definition and measurement of the concept.

Calman (1984) has argued that quality of life can only be described and measured in individual terms. As the components constituting quality of life are personal, an approach where the subjects create their own definition may be a more appropriate starting point for a measure of the concept (Calman, 1984). Sullivan (1992) describes quality of life as intrinsically both subjective and situational, and states that it can therefore only be truly defined individually 'in the relative terms and in the historical perspective that refer to an individual's subjective experience of and overall satisfaction with life'¹⁰.

Skantze and Malm (1994) describe quality of life as influenced by the dynamic gap between personal aspirations, dreams, and hopes on the one hand, and perceived reality on the other: 'since individual preferences and aspirations, dreams and ambitions differ considerably depending on genetic factors, life experiences, and perceptions of reality, a person's quality of life can be judged only subjectively' (Skantze and Malm, 1994). Who else than the

¹⁰ However, disappointingly, in the same paper Sullivan (1992) later operationalises quality of life in terms of health status measures.

individual himself/herself is in a position to express his/her own experiences? According to Hanestad (1990) 'one must either say that the acquisition of this type of knowledge is impossible in principle or it must be accepted that the person wearing the shoe is the one who knows where it pinches and try, as far as possible, to correct the sources of error' (p32).

There is a vast body of literature on quality of life purporting to focus on the individual's (most often 'the patient's') assessments of their 'quality of life'. The resulting data are described as 'self-rated', 'subjective' or 'self-assessed'. However the majority of this work has simply asked patients to complete, by themselves, standardised questionnaires consisting principally of items over which they have no control beyond stating that they do (and possibly to what degree) or do not have some relevance to the individual. Rarely do individuals have any say over what items are actually included. Items may be missing that are important to a given individual and, equally, items may be included that bear no relevance to a given individual. This practice does not constitute self-assessed quality of life; it merely constitutes self-assessment on the items included. Further, content (or face) validity is rarely adequately tested: how often are individuals asked if the scale they have just completed was relevant to their quality of life? Most scales used in this field have titles that are meaningless to laymen. Many consist merely of initials or abbreviations, or relate to their centre of origin, whilst others do not contain the term 'quality of life' at all (usually because they are not, in fact, quality of life measures). True self-assessment must allow individuals more control; principally they must be allowed to give their own definitions of quality of life.

Bowling (1997b) usefully summarises such arguments under the rubric of 'hermeneutic

approaches' (as distinct from 'functionalist approaches'). She states that:

'phenomenologists would argue that health-related quality of life is dependent upon the interpretation and perceptions of the individual and that listing items in measurement scales is unsatisfactory because it is unknown whether all the domains pertinent and meaningful to each respondent are included. It is also argued that this method does not capture the subjectivity of human beings and the processes of interpretation' (Bowling, 1997b)

However, much criticism is directed to the validity of lay definitions of quality of life (Hanestad 1990). This is thought to be on account of the subjective nature of the concept. Hanestad (1990) has outlined four main criticisms commonly directed at quality of life data gathered from individuals: inadequate conceptualisation, the intimate nature of quality of life, the effects of confounding factors, and the transient nature of quality of life. These will each be discussed in more detail below.

First, critics believe that most people have not given adequate consideration to their conception of satisfaction and quality of life, or their feelings around these two subjects. However, Andrews (1974) found that when asking respondents about quality of life less than one percent chose the reply-type 'never thought about it'. Similarly Partridge, Johnston and Morris (1991) found that all of their 200 elderly respondents living at home were able to rate their perceptions of their quality of life on a scale from 1 (very good) to 5 (very poor). On the other hand, Fletcher et al (1992) noted that difficulties can arise where respondents have communication difficulties as a result of altered mental states, but that the point at which the severity of cognitive impairment excludes obtaining valid information from respondents about their quality of life is not known. For example, Jones et al (1986) conducted in-depth interviews lasting between one and three hours, incorporating some checklists, with 50 people

living in the community following long hospital admissions for psychiatric diagnoses and reported that few of the respondents were able to answer the questions asked. However, this finding contradicts those of Lehman (1983) and Huxley (1986) who have reported that people with long-standing mental ill-health are well able to discuss their quality of life and preferences in a meaningful way.

Second, critics believe that even if people can give a reply they will refuse to do so on matters, which they feel, are intimate and personal. However, Hanestad (1990) has administered questionnaires measuring quality of life in 248 diabetic patients, of whom only one withdrew because of unwillingness to reply to questions of this type.

A third criticism is that even if people are willing and able to reply, replies will be distorted by various confounding factors (Hanestad, 1990). Najman and Levine (1981) stated that self-assessments of life conditions are influenced by expectations, prior experiences and perceptions of current conditions, however one would imagine that these are very things one is trying to identify with a subjective method. Looked at from another angle, the *importance* of internal referents such as level of aspiration, comparison level and perceived control as mediators of subjective quality of life have been emphasised (Guter et al, 1983). Barry, Crosby and Bogg (1993) describe the 'normative approach' of objective measures as giving an indication of relative quality of life in comparison to socially accepted norms, while a subjective or individualistic approach gives an indication of the relative importance of different life areas for each individual. Within the context of the lives of long-stay psychiatric patients they state that 'it may be tempting to suggest that one should not give undue weight

to the client's own perspective for... reasons [such as] limited life experience, idiosyncratic frame of reference, and particular life problems, however in doing so, one runs the risk of imposing an external value system on the person, ignoring their own values and preferences' (Barry, Crosby and Bogg, 1993).

Fourth, critics state that the qualities experienced vary too quickly for them to be measured in a meaningful way: if this is so, then quality of life cannot be defined as a relatively enduring phenomenon (Hanestad, 1990). For example, Holmes (1989) suggests that subjective measures reify what is essentially a snapshot response to one part of a person's life at one point in time and that instead, life should be viewed as a process in which, for example, experiences which may be viewed negatively at one point in time may be seen differently later. Strack et al (1990) have cautioned that temporary influences such as mood and other transient influences at the time of judgement may influence assessments of subjective well-being. Similarly, Goodinson and Singleton (1989) have debated the suitability of including the concept of happiness in assessments of quality of life given that it is inherently unstable and may be temporary¹¹. However these are not arguments against lay definitions of assessments of quality of life, they are arguments against *any* assessment of quality of life: if a subjective measures take only a snapshot response, then so do more objective measures. If anything, subjective measures have greater potential to incorporate respondents longer term views than objective measures, because of their very subjectivity.

¹¹ Simmons (1994) states that satisfaction is often used as a more stable alternative. However, Naess (1989) argues that quality of life be assessed only by subjective reports of happiness and dismisses satisfaction as inappropriate: dissatisfaction (if not too severe) has a functional role motivating further achievement. Oleson (1990) advises inclusion of *both* satisfaction and happiness: satisfaction is a relatively stable indicator of the gap between goals and achievement, whilst happiness is a temporary response to a current situation.

In terms of health, during treatment, values certainly change (Clement-Jones, 1985). Morris et al (1986) describe how as changes in health occur so 'life takes on a new shape: it narrows, sometimes to a single room; work and running a household are no longer part of it. Friends and family are seen in a new way. Values change. What was once important may seem insignificant, while things once ignored have great weight' (Morris et al, 1986). Changes may also occur with time and political shift (Ebbs et al, 1989). Buttel, Wilkening and Martinson's (1977) study of 548 adult Americans (mean age of 44 years) demonstrated that social-psychological indicators of quality of life embodied a 'significant component of respondents' pre-existing ideological positions on U.S. society'. However, the debate here is whether these changes are changes in the *definition* of quality of life or in the assessed *level* of quality of life and/or variance in the *importance* of various component domains. One can also make the case that without the use of truly subjective measures, one would not be able to detect such valid changes: using objective measures where the choice of domains and relative importance of different domains does not change would produce misleading results. In addition, if there were no changes in a concept such as quality of life then there would be no call to measure it.

A confounding problem here is the repeated use of measures focusing on only some of the components of quality of life (as in the case of type II and type III quality of life definitions described for the taxonomy presented in Chapter 1). That is, an individual may 'improve' in relation to those components included but deteriorate in relation to those not included, with the result that the individual's 'quality of life' will have appeared to have improved when in fact it may not have overall; other (unmeasured) components have simply become more

important. Whether these two factors (definition and measurement) can be really separated in any attempt to get at lay definitions of quality of life is open to question (Farquhar 1995b). Various studies have tried to test variation in quality of life assessment over time but have produced contradictory findings. For example, Moum (1988) concludes that test-retest correlations for quality of life measures are not inordinately high, whereas Atkinson (1982) found strong evidence for the stability and validity of subjective measures overtime in a longitudinal study. All measures without exception were constant in unchanging situations and sensitive to change when it occurred (Atkinson, 1982). However, one of the inherent difficulties in comparing such studies is the different methodological approaches taken.

Feelings about one's life are intrinsic, subjective matters. If people are asked about these feelings most of them can and will talk about them (Andrews and Withey, 1976). On the other hand a few may lie outright (e.g. social desirability bias) or may colour their answers to some degree, and most will be influenced to some extent by the framework in which the questions are put and the format in which the answers are expected to be given (Andrews and Withey, 1976) (although one could argue that the latter can at least be standardised). A series of studies have demonstrated the differences between laymen's and professionals' assessments of quality of life. For example, having compared the correlation between scores obtained by professionals and patients themselves, Slevin et al (1988) concluded that if a reliable and consistent method of measuring quality of life in cancer patients is required, it must come from the patients themselves and not from nurses and doctors.

Certainly, many studies have reported an absence of significant correlations between

subjective and objective indicators of quality of life (Andrews and Withey, 1976; Campbell et al, 1976; Lehman, 1988, Skantze et al, 1990; Barry, Crosby and Bogg, 1993). For example, Barry, Crosby and Bogg's (1993) study of the quality of life of long-stay psychiatric patients produced an overall impression of a group of residents who rated low on quality of life as objectively measured (i.e. based on: living situation, frequency of social and family contacts, leisure activities, physical illness in last year, and contact with mental health professionals), yet evaluated their subjective life quality (using an adapted version of Lehman's Quality of Life Interview (Lehman, 1988)) in a positive manner. They suggested that coping with a major mental health problem over an extended period, together with the process of adapting to a dependent lifestyle in hospital, may have lowered levels of expectations and aspirations, thereby affecting appraisal of individuals' quality of life. This led the authors to question how objective conditions in different life areas are related to their subjective perception and evaluation. They posed the question: 'do states of well-being have a clear-cut objective counterpart?'. They highlighted the need for further examination of the appraisal process involved in making self-assessed judgements concerning quality of life, exploring social and cognitive mechanisms involved (e.g. standards of social comparison, subjective perceptual processes and internal states such as needs, knowledge, beliefs, values and attitudes) in order to arrive at a better understanding of the determinants of individual well-being (Barry, Crosby and Bogg, 1993; Barry and Crosby, 1994).

With regard to older people, Grimley Evans (1987) has shown that clinical descriptions illustrate profound differences in the way older people may rate their quality of life compared with professional carers. Further, in a study investigating whether perceived quality of life

was associated with preferences for life-sustaining treatment of older adults, Uhlman and Pearlman (1991) demonstrated that doctors rated older patients' global quality of life, physical comfort, mobility, depression, anxiety and family relationships significantly worse than did the patients themselves. Such findings have been reflected in other studies which have shown that older people put generally higher values than expected by younger investigators on life, even in states of ill-health (Grimley Evans 1992). Tests of validity in a study of the quality of the last year of life in older persons by Lawton, Moss and Glicksman (1990) indicated that it was probably the subjective component of quality of life that was the most vulnerable to misjudgement by others. The researchers interviewed the closest living relatives from a sample of deceased people (aged 65 and older at death), and a living comparison group of people aged 65 and older and their closest living relatives, and compared responses. Their results indicated that the highest levels of agreement were for observable or objective indicators of quality of life such as activities of daily living (81% agreement), and that the lowest levels of agreement were for the more subjective indicators such as depression (52% agreement), memory (60% agreement), pep and energy (62% agreement) and pain (68% agreement).

The implications of this for the wider context of health services research are that patients' feelings, views and preferences cannot be assumed (Bowling, 1995a). Without them we may produce research findings that provide information that researchers, practitioners, managers and policy makers want to know, but fail to address the concerns or questions that are important to patients. Thus health care decisions which do not take account of patients' views may not reflect concerns which are important to them, leading to dissatisfaction and the

potential failure to adhere to management plans (Cheater, 1998).

In an early attempt to identify lay definitions of quality of life, Hall (1976) reported the results of a survey involving 932 people aged 16 and over. The aim of this together with a series of other surveys, was to develop subjective indicators of quality of life. Respondents were asked what they thought of when they heard the words 'quality of life'. The largest single category referred to was the family, home life and marriage. A large number of respondents were unable to be specific and referred to being happy, contented or 'being satisfied inside yourself'. Health ranked quite highly and the longer the interval since the last visit to the doctor, the higher the rate of satisfaction. Money and prices was also an important category, as was standard of living or decent conditions (however these were expressed in terms of social values rather than material possessions). Factors which received least mention were 'pressures of life', consumer goods, equality and justice. Differences were found in relation to sex, age and social class as to which factors were the most important. For example: women were more likely to mention home life and health, whilst men mentioned living standards, work and freedom; younger people were more likely to mention money, living standards and work whilst older people referred more to values and to the past; and middle class people tended to think of social relationships, living standards, environment, freedom and leisure and to give a greater number of answers than working class people who were more likely to refer to money, or to give 'don't know' replies (Hall, 1976).

Andrews and Withey (1974) found that besides their jobs, health, consumption, and leisure, individuals attached particular importance to feelings of self-worth and 'success in coping

and accomplishing'. Similarly, a survey by Age Concern (1974) of the views of 2,700 people of pensionable age living in private households reported that health proved to be a vital part of quality of life: decline in health was associated with a decline in other activities, loneliness, and a greater reliance on others, such as for assistance with going shopping. With regard to retirement, over half the sample said they were happy to retire, many were just as busy after retirement as before, and only a few were disenchanted with their new lifestyle. Less than one in ten felt they had nothing to look forward to. Ward (1980) concludes from studies such as these that people are able to assess quality of life in terms of specific domains such as family life, work health and so on, and that they also use their internal feelings and values as referents.

A few measures have used individually generated content as the basis for quality of life assessment. Bernheim and Buyse (1983) described the Anamnestic Comparative Self-Assessment (ACSA) for measuring subjective overall quality of life that they used with cancer patients. Individuals were asked to make 'self-assessments of their well-being... [using] personal criteria from their unique life experiences'. Memories of the best and worst periods of life were used to define a personal scale of well-being, with a score of +5 assigned to the best and -5 assigned to the worst period. Initially, patients were then asked to estimate their average ACSA score at 4 points in time: i) during the period ending a year before their disease was manifest ('pre-morbid well-being'), ii) during the year preceding the manifestation of the disease ('early morbid well-being'), iii) at the time patients became aware of symptoms but had not yet sought medical advice, ('symptoms well-being') and iv) whilst undergoing diagnostic procedures ('diagnostic well-being'). Following this, every

time patients were routinely seen by the investigator during treatment or follow up they were asked to choose an average ACSA score that characterised the period since the last interview. Thus a 'profile' of patients' well-being emerges from which various scores can be derived. One limitation of this technique is the need for respondents to complete itemised scales of 'side effects and psychosocial variables' alongside it in order to identify the 'distinct variables determining quality of life'. In addition, as with a large number of 'quality of life' measures, assessments are made retrospectively.

Hufford and Shiffman (2000) describe a method for capturing 'real-time, real-world quality of life data' known as the Ecological Momentary Assessment (EMA). This method involves respondents carrying palmtop computer diaries that allow the researcher to 'administer flexible, programmable assessments and mark each record with a time and date stamp'. The diaries can be programmed to 'beep' patients randomly throughout the day to complete a report, or respondents can complete a report when they experience any number of predetermined events. The authors describe the advantages of the method as 'first, patients are studied in the environments they typically inhabit...[and] second, EMA depends on real-time data collection about momentary or near-immediate states'. What is not clear from their paper, however, is exactly what respondents are asked to assess, and how.

Browne et al (1994) have described other measures that allow individuals to describe their most important 'personal strivings' e.g. where respondents are asked to rate the current success and the relative importance of these strivings along a number of pre-determined dimensions (Emmons, 1986; Palys and Little, 1983; Rapkin et al, 1994). Similarly, Skantze

and Malm (1994) describe the QLS-100 inventory that lists 100 items arranged in 14 classes, from which (schizophrenic) patients are asked to identify which items they regard as currently unsatisfactory.

A more sophisticated method, without a pre-determined list from which to choose, known as the Patient Generated Index (PGI), was developed by Ruta et al (1994). For the PGI, patients are asked to nominate the five most important areas or activities in life that have been affected by their condition. These, plus a further area labelled 'all other areas' are then rated from worst to best possible and weighted in terms of relative importance. However, some difficulties with the index have been reported with less than two thirds of respondents completing it correctly, leading to response bias (Ruta et al, 1994; Macduff and Russell, 1998¹²).

Similarly, Guyatt et al (1987) developed a disease specific questionnaire, the Chronic Respiratory Disease Questionnaire (CRDQ) which asks patients to identify items (from both a pre-determined list of items likely to be important to patients with chronic airflow limitation and self-determined items) that were problems for them and to rate the importance of the problem items in order to attain the five most important problem items. Browne et al (1994) describe these measures as breaking from tradition with regard to the generic content of the quality of life concept (i.e. domains to be assessed, criteria to be used and weights to be placed on responses) but still assuming a generic structure for the construct of quality of life (e.g. number of domains to be assessed, method of combining scores).

¹² In the same study Macduff and Russell (1998) achieved 92-99% correct completion rates for dimensions of the SF36.

In an attempt to deal with these issues O'Boyle et al (1993) have developed the SEIQoL, as described earlier in Chapter 2, and Hunt and McKenna (1992) the QLDS, a scale for the measurement of quality of life in depression. Hunt (1997a) describes these measures (and one could add the PGI here) as representing 'significant advances in the field of quality of life research' in that their developers have attempted to base their measures on prior psychological and philosophical analysis. She points out, however, that both measures still make some untested assumptions i.e. having affirmed that quality of life will be conceptualised in a particular way, both sets of researchers moved onto applied measurement without first gathering data to test and redefine the model itself e.g. with the SEIQoL, the request for patients to cite the most important aspects of their condition assumes that these aspects will relate to quality of life (Hunt, 1997a), similarly with the PGI, patients are asked to list 'the five most important areas or activities of your life that have been affected by [condition x]'.

'Both the needs model [basis of the QLDS] and the SEIQoL illustrate an interesting, but alarming phenomenon in quality of life research, which is a rush to measurement quite at odds with usual scientific procedure. The material from which so-called 'quality of life' scores are derived is drawn from interviews with relatively small numbers of individual patients who have agreed to participate in the exercise. Normally, this would be a starting point for the testing of hypotheses about the theory underlying the models, the refining of concepts and re-testing. However, the primary purpose of the interviews appears not to be to develop an understanding of the possible relationship between illness, health, values and perceptions which might illuminate the concept of quality of life being applied, but rather to gather material for questionnaire content.... moreover, in the case of the needs model, the requirements of measurement and reliability/validity testing often remove a large number of items from the pool of potential items, thus, automatically omitting minority concerns from the questionnaire. In addition, validity testing is based not upon the issue of whether needs are related to quality of life but rather whether scores are related to the severity of the condition, or clinical progress, entirely different issues.' (Hunt, 1997a).

In essence, although they represent progress in the debate on quality of life, the models have never been supported by empirical work (Hunt, 1997a). This is not, however, a recent concern. A similar sentiment was expressed more than twenty years earlier, and perhaps more succinctly, by Bunge (1975) in the field of social indicators when he stated that ‘a better understanding and assessment of the quality of life calls for more intense theoretical and methodological work rather than an increase in the amount of social and environmental statistics... here as elsewhere data without ideas are sterile when not misleading’. He describes the process of selecting such indicators as using ‘our treacherous common sense to an extent that is uncommon in science’, stating that theoretical and methodological work ‘is of course well known in the natural sciences but is still largely ignored in the social sciences, where most indicators are proposed on an intuitive basis, without any theoretical discussion’ (Bunge, 1975). Hyland (1992b) and Wade (1992) have also noted the absence of a theoretical description of quality of life. Rosenberg (1992) refers to the discussion of the quality of life concept as being ‘limited to methodologically difficult but philosophically trivial reliability and validity questions of the various scales... and to debates of future measures to be included under the quality of life concept’. Brock’s (1993) examination of the medical ethics literature explicitly addressing the notion of quality of life identified few sustained analyses of the concept and its role in various medical and health care contexts. In addition, most of the empirical research that has been done to date has focused on people with ailments (Hunt, 1997a).

Overall this lack of theoretical and methodological study of the concept of quality of life, leads one to the conclusion that existing measures of ‘quality of life’, particularly those that

are not truly subjective (i.e. those with prescribed domains/items), have little basis on which to make their claims for validity. At the very least, measures should give respondents the opportunity to identify the components of life that they value i.e. those factors that give quality, or take the quality away. Measures which use items based predetermined domains will remain flawed: they may well be reliable and valid measures of those specific domains, but they may not reflect the values of the individual respondents in relation to quality of life, and therefore cannot be said to be reliably and validly measuring their quality of life. To date, only the SEIQoL and PGI come close to achieving any sort of validity; yet these instruments also have their limitations e.g. their focus on health, their limit on the number of domains that can be identified, and their relative complexity. Their development, and the growing debate in the literature on the measurement of quality of life, provides a platform from which lay definitions of quality of life (and other concepts, such as health) are increasingly being considered desirable. This should enable, in due course, the elaboration of the 'lay definitions' category of the taxonomy of quality of life definitions described in Chapter 1.

Rarely, then, has a study attempted to identify lay definitions of quality of life. Fewer still have attempted to compare such definitions with the more traditionally used quality of life measures (Farquhar, 1994). Recently, Bowling (1994) used the vehicle of the OPCS Omnibus Survey to obtain population norms of quality of life and health related quality of life, and the relative importance of the mentioned domains to people. The Omnibus Survey is a monthly survey of 2,000 randomly selected adults in Great Britain, which offers researchers the opportunity to buy into the survey with their own questions. Bowling's approach was based on questions developed for the SEIQoL and Guyatt et al's disease specific quality of

life questionnaires (i.e. CRDQ). In response to a generic question about the most important things in their lives (good or bad), respondents were most likely to select, in priority order, relationship with family or relatives, followed by their own health, the health of another (close) person, and finances/standard of living/housing. The survey also provided some useful data on the importance of context, question wording and mode of presentation of results. Results differed if respondents were asked instead to give ‘the most important effects on life of a longstanding illness or condition’ or if the result of questions were given in terms of the *first* most important thing in their lives (i.e. the first thing mentioned) or *the most* important thing (the most frequently mentioned thing across the five things listed). Further, analysis of the domains included in some of the most popularly used health status scales which are used to measure ‘health related quality of life’ revealed several domains ranked as important by the public to be missing (notably energy/tiredness, pain, finances, sexual functioning, education and religion) (Bowling, 1994).

Browne et al (1994) suggest there are idiosyncratic meanings behind domains nominated by each individual using such instruments as the SEIQoL, which are not revealed by the labels used to group them; these labels are not selected by the laymen themselves. For example, in Browne et al’s (1994) study, ‘health’ had many underlying themes for the healthy elderly including fear of illness in general, fear of death, fear of loss of independence, fear of pain, enjoyment of the possibilities that good health allows, worries over the cost of future health care and worries over the implications for others (e.g. a dependent spouse) of ill-health. In addition, most studies that do exist have been targeted on specified groups (i.e. those with a particular condition or those deemed ‘healthy’); few have used population-based samples.

The empirical work presented in Part Two of this thesis attempts to address some of these gaps in quality of life research. It is not an attempt to produce yet another ‘quality of life’ measure, nor even a list of prescribed domains to be included in future measures, but an attempt at what Hunt (1997a) describes as ‘pure research... to define, refine and understand the concept of “quality of life”, in order to ascertain if it could meaningfully be measured’ and, if so, how valid existing ‘measures’ are.

Faden and Leplege (1992) describe our obligation to respect the autonomy of individuals to define their own conceptions of a good life:

‘to set their own goals, and to plan their lives in accord with their own values, histories, and talents... the quality of any person’s life is in important respects unique and personal to that individual. The impact of any event or health state on a person’s quality of life is to a significant degree contingent on his or her personal projects, desires and history.’ (Faden and Leplege, 1992).

Similarly, Wade (1992) proposes three factors that probably contribute to quality of life:

1. The patient’s own wishes and expectations (and possibly those of family members). These can only be measured through direct questioning and might be difficult to establish reliably. Furthermore, each patient will attribute different degrees of importance to different expectations and there may be differences of opinion between different members of one family.
2. The limitations there are on a patient’s ability to achieve his or her wishes; these limitations arising either naturally (for example, being too short to enter the police force), or from the environment (for example, widespread unemployment or economic decline), or from a disease. (...)
3. The patient’s reaction to the limitations... This... includes both emotional reactions (for example, despair) and also other reactions, such as taking up a different career.’ (p. 94-95)

He goes on to conclude that ‘quality of life is, in other words, extraordinarily individualistic’ (Wade, 1992).

Thus, in Chapter 4 the case has been made for lay definition and measurement of quality of life. A critique of some of the so-called 'self-assessed' quality of life studies was presented together with the arguments commonly levelled at lay definitions of quality of life. A small but growing body of literature reporting an absence of significant correlations between subjective and objective indicators of quality of life was described, and the methodological literature on lay definition and measurement of the concept was summarised.

PART TWO: THE EMPIRICAL STUDY

In previous chapters I have established the importance of measuring quality of life, particularly among older people, and argued (through the development of a taxonomy of definitions) that there is a lack of consensus in the expert literature on the definition of the concept. In addition I have critically presented previous work in the field of quality of life definition and measurement in older people, and considered the various methods and issues relating to the measurement of quality of life amongst this group. One solution to the difficulties identified in these earlier chapters is the use of lay definitions and measurements of quality of life, and the preceding chapter presented the case for these. Thus part two of the thesis attempts to empirically address some of the gaps in quality of life research, focusing on older people.

Aims of the empirical study

The aims of the empirical study were:

- i) the identification of lay definitions of quality of life among people aged 65 and older living at home; and,
- ii) the examination of the relevance to older people of scales commonly used to measure quality of life.

Chapter 5: Samples and methods

Based on the arguments presented in the preceding chapters, I propose that some of the problems of defining and measuring quality of life can be addressed by asking people to describe the quality of their own lives, in their own words, using their own frames of reference (Farquhar, 1994). This chapter describes the methods used to investigate what older people say about quality of life when asked in this way.

Samples

The samples for the quality of life study were drawn from three existing samples of older people. The samples had been established for a series of surveys of the need for health and social services of older people living at home in south east England. The first survey (sample 1) was a census of 951 people aged 85 years and older living at home in City and Hackney, London in 1987 (630 subjects interviewed; 66% response rate), commissioned and funded by City and Hackney Health Authority and Social Service Department (Bowling, Hoeckel and Leaver, 1988). The second (sample 2) was a random sample of 691 people aged 65<85 years living at home in City and Hackney, London in 1989 (466 subjects interviewed; 67% response rate), commissioned and funded by City and Hackney Health Authority (Farquhar and Bowling, 1989). And the third (sample 3) was a random sample of 349 people aged 65<85 years living at home in the Braintree area, in Essex in 1989 (288 subjects interviewed; 83% response rate), commissioned and funded by Mid Essex Health Authority (Bowling and Burkey, 1989). On each occasion samples were drawn from Family Practitioner Committee

records and checked against electoral rolls. Further details regarding sampling have been reported elsewhere (Bowling, Hoeckel and Leaver, 1988; Bowling, Hart and Silman, 1989; Farquhar and Bowling, 1989; Bowling and Burkey, 1989). In total, the three samples yielded interview data on 1,384 older people living at home.

Analyses comparing responders with non-responders to these baseline studies revealed no significant differences with age and sex (Bowling and Farquhar, 1991). Further, local general practitioners provided information about non-responders aged 85+ in City and Hackney indicating no differences between responders and non-responders in relation to consultation patterns and the proportion who were reported to be housebound (Bowling, 1990).

Following these baseline studies, the three samples were re-contacted for a longitudinal survey aiming to identify factors associated with the successful survival of older people living a home, funded by the Joseph Rowntree Foundation (Farquhar, Bowling and Grundy, 1991a, 1991b, 1992). All responders to the 1987 (sample 1) and 1989 (samples 2 and 3) baseline surveys who were still alive and who were still living in the district in 1990 (sample 1) and 1991 (samples 2 and 3) were eligible for re-interview. Thus, 336 of the 1987 85+ years Hackney sample (sample 1), 399 of the 1989 65<85 years Hackney sample (sample 2) and 251 of the 1989 65<85 years Braintree sample (sample 3) were re-contacted, yielding follow up interview data on 787 elderly people living at home. The response rates achieved were: 256/336 (76%), 332/399 (83%) and 199/251 (79%) respectively. In tandem with this follow up study, data were gathered for the quality of life study presented in this thesis. Thus, the sampling frame chosen for the empirical work for this thesis was essentially opportunistic.

The researcher (MF) was employed to work on the parent study at the time of commencement of this thesis. Respondents were therefore not sampled from the general population, but from established samples.

Table 5.1 (below) summarises these sample histories and locates the various stages of the quality of life study presented in this thesis. The quality of life study, its various stages and sample sizes, will be described in more detail later in this chapter.

Table 5.1: Summary of Sample Histories

	<u>Year</u>	<u>Hackney</u>		<u>Braintree</u>
		<u>Sample 1</u>	<u>Sample 2</u>	<u>Sample 3</u>
<u>Baseline studies</u>	1987	85+ Baseline (n=630)		
	1988			
	1989		65<85 Baseline (n=466)	65<85 Baseline (n=288)
<u>Follow up studies</u>	1990	87+ Follow Up (n=256)		
		87+ QL Study: Stage I - a) Scales (n=53-162) - b) QLQs (n=74)		
	1991		67<87 Follow Up (n=332)	67<87 Follow Up (n=199)
			67<87 QL Study: Stage I - a) Scales (n=70-258) - b) QLQs (n=70)	67<87 QL Study: Stage I - a) Scales (n=46-183) - b) QLQs (n=70)
		67<87 QL Study: Stage II (n=17)	67<87 QL Study: Stage II (n=23)	

(QL=Quality of Life, QLQs=Quality of Life Questions)

Thus these established samples provided an opportunity to gather data not only from different age groups of the older population, but also from two contrasting locations. City and Hackney is an inner London borough, based in the East End of the city and has been identified as the second most deprived borough in England (after neighbouring Tower

Hamlets), on the basis of 1981 British Census data. This profile was confirmed by deprivation scores derived from the census data (Jarman, 1987). In contrast Braintree, is a semi-rural area in Essex comprising the market town of Braintree and surrounding villages. It is at the other end of the deprivation indices, having little overcrowding, few households lacking basic amenities, few residents in ethnic minority groups and fewer people receiving supplementary benefit (Bowling, Farquhar and Browne, 1991).

Braintree is among the oldest settlements in Britain. Its history lies in the pilgrim trade that was succeeded by a flourishing woollen industry in the middle ages. This declined at the end of the 18th Century but was followed by the rise a silk manufacturers (such as the Courtauld Company) which dominated the area for the whole of the 19th Century (Braintree and Bocking Heritage Trust, undated). In addition, other cottage industries thrived such as straw-plaiting and brush making. Today, the growth and prosperity of Braintree and its surrounding villages owes much to the engineering and metalwork firms established there at the end of the 19th Century and, unlike many towns, it has retained its textile industry: woollen cloth was replaced by silk, and this in turn by rayon and other man-made fabrics. Parts of the area are described as 'visually remarkable', containing former homes of cloth merchants from the 15th to early 19th Century; behind many Classical facades are the remains of properties dating back to the Middle Ages (Edwards, 1978).

Hackney comprises the three former metropolitan boroughs of Shoreditch, Stoke Newington and Hackney, each with a distinct history stretching back to the Middle Ages. However common themes link the three areas: urbanisation, industrial innovation, and ethnic diversity.

From 1200 to 1600, these were farming communities of the Middlesex countryside. The growth of London saw aristocrats and government officials building country houses in the area due to its proximity to the City and Westminster: only Sutton House (National Trust) remains today. As the area became increasingly built up, the aristocrats and businessmen moved to more fashionable areas, and the arrival of the railway in 1850 enabled the less well off to commute daily to the City. Thus Victorian villas and terraces were built, many of which remain today. During this period, Shoreditch became a centre for London's furniture industry attracting workers from many parts of Europe, and Hackney was home to paint, chemical and toy manufacturing. However, changing economic circumstances led to a number of firms moving out in the 1960s, 70s and 80s (London Borough of Hackney, 2000).

By the late 19th Century programmes of slum clearance were implemented with the building of large estates across the borough and amenities for local people, such as baths, libraries and day nurseries were created. Few of these amenities remain today and many of those that do are threatened with closure. This community has always been one of diverse ethnic, political and religious origin: for example, there has been a Jewish community in Hackney since 1684; the Afro-Caribbean community developed fully in the 1950s from its beginnings in 1630; and people from the Indian subcontinent came to Hackney in numbers after the Second World War. Thus today Hackney's population includes large communities of people from Africa and the West Indies, Turkey, Cyprus and the Indian subcontinent (London Borough of Hackney, 2000).

Despite the striking contrast between Hackney and Braintree in terms of their geographical

and social development, the three samples had strong temporal links. In terms of history, all sample members had experienced and survived a World War: in the case of the younger samples (samples 2 and 3) they would have been young adults, perhaps newly married or starting families; in the case of the older sample (sample 1) they would have been in their 40s. The impact of such an event on these cohorts requires some consideration: this subject will be returned to later.

It is worth noting here, that respondents who were confused or demented were not included in the baseline or follow up studies (or 'parent study') and therefore had no opportunity to be included in the quality of life study. Discounting such sectors of the population, although precluding generalisability, is not uncommon and has been justified by others such as Appleton:

'as this was a qualitative study in which the researcher was trying to explore and begin to understand the concept... in order to create meaning..., it was essential that the researcher select a sample who could articulate their thoughts and experiences and thus enhance the researcher's understanding of the concept'. (Appleton, 1995)

Again, because of the parent study, the empirical work was firmly located in the community: no attempt was made to access those living in institutions, however no claim was made otherwise. Further, the study was firmly located in the south east of England and any findings may be location dependent. Similarly, the findings will probably relate particularly to those living in the developed world yet in 1999 almost two thirds of people aged over 60 lived in developing countries, and this is likely to rise to 70% by 2025 (Randel, German and Ewing, 1999). However, Schuessler and Fisher (1985) have noted that an interest in quality of life is

a relative luxury for the developed world as 'concern with quality of life intensifies in proportion as less time and energy are required to meet the basic necessities of living'.

Methods

The quality of life study had two stages, Stage I and Stage II. Stage I consisted of two phases: the completion of 'quality of life' scales (Stage Ia) and the completion of the 'Quality of Life Questions' (Stage Ib).

Stage Ia: 'quality of life' scales:

The 1990/91 follow up study questionnaire schedule consisted of Neugarten's Life Satisfaction Index A (Neugarten et al, 1961), The Faces Scale (Andrews and Withey, 1976), the General Health Questionnaire (Goldberg, 1972), the Social Network Scale (Stokes, 1983), and an adapted¹³ and extended¹⁴ version of the Activities of Daily Living Scale (Townsend, 1979; Bowling and Salvage, 1984) as well as a number of individual items (e.g. demographics, health problems, service use, social contacts). Social class was based on respondents' self-report of their main job (or spouses' main job for married women) for most of their working life, and coded according to the Registrar General's Classification of Occupations (1980).

¹³ The levels of difficulty were increased from three ('no difficulty', 'has/would have difficulty', or 'cannot do at all') to six ('no difficulty', 'slight difficulty', 'moderate difficulty', 'severe difficulty', 'only with help', or 'cannot do at all').

¹⁴ The list of activities was extended from nine activities to 24, and some of the original nine were amended.

In addition, for the quality of life study, a thorough search of the literature identified seven of the more commonly used scales for measuring 'quality of life', or its dimensions, among older people (for inclusion criteria see Chapter 3 'Measures used in the empirical study'). The identified scales were: the Nottingham Health Profile (Part I) (Hunt, McEwen and McKenna, 1986), the Affect Balance Scale (Bradburn, 1969), the General Well-Being Schedule (Dupuy, 1978), the McMaster Health Index Questionnaire (Chambers et al, 1976), the Self-Evaluation of Life Function Scale (Linn and Linn, 1984), the Dartmouth Co-operative Chart for 'Quality of Life' (Nelson et al, 1987) and The Faces Scale (Andrews and Withey, 1976). Full descriptions of each scale were given earlier (see Chapter 3). The scales were used as published, with the exception of the SELF scale where a publishing error was detected and corrected (for a fuller description of this error and alteration see Chapter 7). No adjustments for older people were made to the content or layout of the various scales as it was felt important to use them in the format recommended for use, or previously used, with older people. Where appropriate the original authors were approached for permission to use the scales and this was granted. In addition, the baseline and follow up studies were given ethical clearance by the relevant Local Research Ethics Committees.

In Stage Ia of the quality of life study, every respondent to the 1990/91 follow up studies was asked to complete one of three randomly allocated pairs of these 'quality of life' scales. The team of six trained interviewers (including MF) conducting the 1990/91 follow up study interviews administered the scales. The interviewers were experienced interviewers who had worked for the follow up studies research team on studies involving older people before (e.g. all had worked on the baseline studies). In addition, they included OPCS interviewers and

social science (under)graduates. They ranged in age from their mid twenties to late forties, and all were female.

The interviewers were trained by the researcher (MF) in the techniques for presenting and administering the scales. Their training consisted of reading through the content of the scales as a group, then role playing in pairs (roles were reversed half way through the exercise), and discussing issues raised (e.g. question wording, response categories etc). The interviewers had also been trained by the researcher (MF) for the baseline and follow up studies themselves, and so had had specific training and experience of the issues that may arise when interviewing older people in their own homes and the safety of the interviewers themselves. These issues were reaffirmed for the quality of life study training and special emphasis was given to the potential for emotional upset of respondents given the content and complexity of some of the scales. Ways in which interviews could handle this were discussed and interviewers were encouraged to report back any concerns (including their own emotional reactions to interviews) immediately after interviews. In addition regular debriefing sessions were conducted prior to interviewers being given their next caseload of interviews. The researcher (MF), who was also an interviewer, was supported by her supervisor.

Interviewers carried with them copies of the most recent Age Concern Handbook containing contact numbers of agencies that may have been useful to respondents, and the department had links with GPs within each of the geographical areas; in addition the local police and Age Concern themselves were informed of the dates that the study was taking place in each area (for the safety of both the respondents and interviewers).

Wherever possible the scales were self-completed; interviewers provided assistance only where the respondent was obviously visually impaired or requested assistance. In these cases the questionnaires would be read out as written and a note to this effect written on the top of the questionnaire. Interviewers were asked to note any problems with the administration of the scales and they were reported back to the researcher (MF) at regular debriefing sessions throughout the data collection period. The results of these sessions are reported anecdotally in the 'Results' section.

The scales were administered (randomly) in pairs, as it was judged too onerous for older respondents to complete all seven of the scales; it was felt that this would have been unethical, particularly given the critique presented in Chapter 2 on the potential problems of the survey method with older people. In addition, completion of so many scales at one sitting may have invalidated responses to the later scales due to respondent fatigue.

The pairings were as follows: the Nottingham Health Profile and the Affect Balance Scale (printed on pale pink paper); the General Well-Being Schedule and the Dartmouth Co-operative Chart 'Quality of Life' (printed on pale yellow paper); the McMaster Health Index Questionnaire and the Self-Evaluation of Life Function Scale (printed on pale blue paper). These pairings were chosen simply because of the length of the various scales e.g. the 38-item Nottingham Health Profile was paired with the much shorter 10 item Affect Balance Scale. This decision was made on ethical grounds, purely to avoid making the task of completing some of the scale pairings more cumbersome or lengthy than other pairings e.g. if they were

paired on the basis of either similar or divergent conceptual content then two long questionnaires may have been paired and administered to one group of respondents whereas another group may have received two shorter ones. The pairings were printed on matching coloured paper to ease the task of administration for interviewers. Randomising the pairings, or the order of their presentation within the pairings, might have permitted examination of order effects, however testing for the effects of these variations would have required larger sample sizes.

In addition, a single quality of life item was added to The Faces Scale used in the follow up studies, and all respondents were asked to complete this. Copies of the scales, as used in this study (with the exception of the paper colour), are given in Appendix 1.

Available data relating to the psychometric properties of these instruments was presented in the literature review. Consideration was given to adding to this body of data by testing the properties of these instruments when completed for the purposes of the present empirical study, and in relation to data gathered by other means for this study (i.e. responses to the brief set of 'Quality of Life Questions'). However the resulting sample sizes would have been too small to permit analysis, and restrictions on word counts for this thesis imposed limits on what could and could not be included. In addition, Rosenberg has questioned the legitimacy of such actions suggesting that too much attention has been paid to the psychometric properties of scales at the expense of meaning to individuals: 'Is it ethically justifiable to pretend that such an essential aspect of human life as quality of life can be captured through the operationalisation procedure of psychometrics?' (Rosenberg, 1992).

Quantitative analysis of scales.

Non-parametric statistics are used throughout these analyses as the data are unlikely to be normally distributed. Kruskal-Wallis one-way analysis of variance was used to compare the three independent samples within this study. In addition mean scores (and standard deviations) are presented rather than medians, for clarity. All quantitative analyses were conducted using SPSS (Norusis, 1993) and Confidence Interval Analysis (CIA) software (Gardner et al, 1992).

Stage Ib: The 'Quality of Life Questions':

In order to establish the ability of older people to talk about the concept of 'quality of life' and to gather their thoughts on what the concept meant to them, sub samples of one in four respondents from each of the three samples (n=214 in total: 74 respondents from the older Hackney sample (sample 1); and 70 from each of the two younger samples (samples 2 and 3)) were asked the following brief set of unprompted open ended questions about the quality of their lives:

1. How would you describe the quality of your life?
Why do you say that?
2. What things give your life quality?
3. What things take the quality away from your life?

4. What would make the quality of your life better?
5. What would make the quality of your life worse?

A copy of the form containing the questions is given in Appendix 2. All of the sub sample members were interviewed by the researcher only (MF). Answers were written down verbatim by the researcher (MF), and any difficulties with concept were recorded in written notes. Answers were later open coded by the researcher (MF). The researcher (MF) was alert to the potential for emotional upset among respondents, particularly given that this issue was raised in the critique of the literature on the use of the survey method with older people in Chapter 2. The interviewer (MF) always carried a packet of tissues, allowed adequate time for the establishment of rapport and scheduled interviews so that interviews could be completed without respondents feeling as though they were being rushed. Where respondents were upset this was always acknowledged by the interviewer, and respondents were given an appropriate period of time to compose themselves and always reminded that they could withdraw from the interview at any time.

Certain factors were borne in mind when designing the questions. Most importantly the questions had to encourage the respondents to describe the quality of their lives using their own words, so an open question format was chosen throughout and the question wording was kept simple and avoided jargon (Oppenheim, 1992). The first question, ‘how would you describe the quality of your life?’ was designed to establish whether respondents could describe and talk about the quality of their lives. The follow up question ‘why do you say that?’ was included in order to establish why respondents described their lives in the ways

that they had, and to encourage them to talk about the concept. This would help identify a lay definition of quality of life. Ratings of quality of life are meaningless unless the factors that influence those ratings can be identified.

The next pair of questions ‘what things give your life quality?’ and ‘what things take the quality away from your life?’ were designed to encourage respondents to think about their life quality in both positive and negative terms. This was felt to be important where the initial description of the quality of their lives was very positive or very negative and the resulting response to the follow up question (‘why do you say that?’) referred only to positive or negative aspects of their lives accordingly.

The final pair of questions, ‘what would make the quality of your life better/worse?’, were included for similar reasons to the pair above, but also to examine how changeable or flexible the respondents regarded the concept of quality of their lives to be, within the context of their own lives. In addition, it was hoped that these latter questions would establish some order of priority to the factors they had mentioned.

Coding of Quality of Life Questions.

Responses were categorised as positive or negative or open coded, depending on the nature of the question, on the basis of the explicit content of the utterances. Thus, responses to the first question, ‘how would you describe the quality of your life?’ were coded according to whether they gave a very positive (e.g. ‘very good’), positive (e.g. ‘quite good’), neutral (e.g. ‘well,

it's OK' or 'I mustn't grumble'), negative (e.g. 'not very good'), or very negative (e.g. 'terrible') response. Responses to the rest of the questions were open coded, the categories for the coding being generated by the answers given.

A decision was made to code only the first three responses of each respondent to the Quality of Life Questions. One could argue that some data could have been lost to analysis by this decision, but very few respondents gave more than three answers. This finding was similar to that of Bowling who reported that 'few mentioned more than 3 items' in response to an open ended question about the most important things in respondents lives for her national survey (Bowling, 1994).

It was not possible to analyse responses to the Quality of Life Questions by gender because of the smaller proportion of men surviving to each age group within these relatively small samples.

Stage II: In-depth Interviews:

In Stage II of the study, the intention was to conduct in-depth interviews with 40 respondents from the two younger elderly samples i.e. 20 of the respondents from Hackney (sample 2) and 20 of the respondents from Braintree (sample 3) in order to gather qualitative data about quality of life in terms of its meaning and self assessment. One in three potential interviewees were randomly approached from those respondents interviewed by MF at Stage I and verbally asked if they would like to take part in the quality of life interviews. The

purpose and aims of the study were explained (including the fact that this was a piece of research for a higher degree) and their anonymity was assured.

In order to ensure that respondents had fully consented to take part in this stage of the study, and to give them an opportunity to 'opt out' if they had changed their minds subsequent to the researcher's (MF) earlier visit, each of the verbally consenting respondents was written to. It was agreed that the researcher would contact respondents nearer the time of the interview by telephone to arrange an appointment for the visit. Only one respondent had no access to a telephone, so it was agreed that the appointment would be made in writing, by post. Following each of the subsequent telephone calls, the researcher (MF) again wrote to each respondent to confirm the date and time of the appointment.

The 40 interviews (23 from Braintree and 17 from Hackney) were all conducted by the researcher (MF) after the completion of Stage I, between mid May 1991 and mid January 1992. However the majority of the interviews were conducted during the autumn/winter of 1991 (i.e. 12 interviews were conducted in October and a further 13 in November 1991; mean date 16/10/91, median date 30/10/91; median month October; modal month November). The maximum number of interviews conducted in one day was two. All were conducted in respondents' own homes, at their convenience and audio-taped with respondents' permission.

A qualitative approach was chosen for this stage of the study, as this was essentially exploratory, given the dearth of data on lay definitions of quality of life. Qualitative methods are particularly useful for studying phenomenon or events about which little is known (Field

and Morse, 1985). This approach focuses on individuals' experiences and can provide rich and detailed descriptions of previously unexplored phenomena (Morse, 1991). Further, it allows the data to act as a 'catalyst for conceptualisation' (Knafl and Howard, 1984).

Flick (1998) states that a precondition for successfully conducting qualitative interviews 'is to explain the specific character of the interview situation to the interviewee' (p. 104). Thus at the start of the interviews it was explained to respondents that there were no set questions written down for them to answer, and there were no right or wrong answers. The researcher was interested in their views. They were informed that the researcher may write a few notes during the interview, but these would simply be reminders or prompts to the researcher to further questions.

The interviews themselves were a combination of narrative and episodic interviews (Flick, 1998). They contained elements of both narrative and episodic interviews. They contained narrative elements in terms of their structure¹⁵, and episodic elements in terms of their central style or content. Classically, a narrative interview structure would consist of a generative narrative question, a stage of narrative enquiries, and a balancing phase (Flick, 1998). In an episodic interview the underlying assumption is that:

'respondents' experiences of a certain domain are stored and remembered in forms of narrative-episodic and semantic knowledge. Whereas episodic knowledge is organized closer to experiences and linked to concrete situations and circumstances, semantic knowledge is based on assumptions and relations which are abstracted from these and generalized' (Flick, 1998).

¹⁵ In-depth interviews are often described as "unstructured" however this is a misnomer as no interview is devoid of structure. Whyte (1982) describes all interviews as "structured" in terms of the research problem.

Thus, broadly speaking, each Stage II interview consisted of three phases. They began with a generative narrative question (Reimann and Schutze, 1987) and moved into a middle phase where both the various components of quality of life and its temporal variation were discussed (the stage of narrative enquiry), followed by a closing phase. A generative narrative question refers to the topic of study and is intended to stimulate the respondents' main narrative (Flick, 1998). In this study respondents were typically asked:

'What I want to talk about, if we can, is the phrase "quality of life" and what "quality of life" means to you. So probably the best way to start is if you tell me what you think the words "quality of life" mean. What does it mean to you?' [Source: interview 3316]

The middle, narrative phase comprised the majority of the interview. Here, both the various components of quality of life and its temporal variation were discussed. Respondents would typically begin by describing a series of components of quality of life, would provide some evaluation of their own situation with regard to each and then discuss the relative contribution each of these made to the quality of their lives overall. This process frequently included a temporal element. Respondents were encouraged not only to consider the quality of their own lives in comparison to those of their contemporaries, but also in comparison to the lives of their parents, their children and their grandchildren: looking at the past, present and future.

Interviews were generally drawn to a close using techniques such as 'mirroring what has been said' (i.e. summarising, feedback and interpretation by the interviewer) and by questions of comprehension (Flick, 1998). This differs from the classic 'balancing phase' of a narrative interview in that the latter aims at determining theoretical accounts at the end of the interview, whereas theoretical discussions tended to occur throughout the middle phase of the

interviews described here, as each new component of 'quality of life' emerged. In these theoretical discussions, each respondent was taken 'as an expert and theoretician of himself or herself' (Schutze, 1983, cited in Flick, 1998) because of the importance of determining *lay* definitions of quality of life.

The central element or style of an episodic interview is the periodical invitation to present narratives of situations, or chains of situations, and predictions (narrative-episodic knowledge) together with questions asking for respondents' subjective definitions and abstractive relations (semantic knowledge) (Flick, 1998). The interviews conducted for this study contained elements of both of these types of knowledge.

In addition, because an episodic interview allows 'a more concrete approach' than does the narrative of life history, the interviewer has more opportunities to intervene in the course of the interview (Flick, 1998). The interviewer can ask key questions concerning situations to be recounted and concepts to be defined, allowing 'routines and normal everyday phenomena' to be analysed (Flick, 1998). Thus,

'the extremely one-sided and artificial situation given in the narrative interview here is replaced by a more open dialogue, in which narratives are used as only one form of data. By linking narratives and question-answer sequences this method realizes the triangulation of different approaches as the basis of data collection.' (Flick, 1998, p.111)

The degree of structure in an interview is likely to alter as a study progresses, with earlier interviews tending to be the least structured (May, 1991). This occurs as a result of the reflexive nature of qualitative methods whereby informal analyses and interpretations occur

from the very first field contact. Thus, as observed by Rose (1994), interviews become ‘more structured by the interviewer, but not to the extent of inhibiting informants’ freedom to express themselves or introduce new themes’. This was certainly the case for this study.

Following these in-depth interviews, all forty respondents gave their permission to be contacted again should the research require it; indeed many offered this access spontaneously and were keen to be kept informed of the progress of the research. In the event, further follow up did not occur.

Tapes were professionally transcribed with the respondents’ permission and names changed to assure anonymity. Flick (1998) notes that a standard for transcription has not yet been established, thus a set of conventions for transcription were agreed between the researcher (MF) and the transcriber. For example methods for annotating inaudible material, audible interruptions, pauses and broken off words were agreed together with the labelling and layout of the transcript, and labelling of the speakers. MF then corrected transcripts against the original recordings for accuracy and the inclusion of additional non-verbal detail (e.g. laughter, respondents’ physical actions, interruptions, and any relevant data from fieldwork journal). Prior to any formal coding or analysis, an indexing system (Whyte, 1982) was set up whereby interviews were categorised first by area and then chronologically, in the order that they occurred. Each corrected indexed transcript was then read several times in conjunction with the relevant entries in the fieldwork journal, to gain familiarity with the data and ‘learn nuances of [the] research participants’ language and meanings’ (Charmaz, 1995).

A fieldwork journal was maintained throughout the data collection period, and beyond, which contained accounts of the impressions from interviews (annotated by serial number only), quotations from unrecorded conversations, memos and notes about analyses and interpretations (which started immediately after field contacts), together with ‘experiences, ideas, fears, mistakes, confusions, breakthroughs and problems’ (Spradley, 1980, p71). This form of documentation not only provides additional knowledge, but also serves in the reflection on the research process (Flick, 1998).

Alternative methods that could have been employed include the use of focus groups¹⁶, however Hufford and Shiffman (2000) suggest that studying people ‘in the environments they typically inhabit...maximize[s] ecological validity and real-world generalization’. Ecological validity refers to the degree that patients’ data accurately reflects real-world influences (Hufford and Shiffman, 2000). Focus groups, unless conducted within established groups such as at day centres or within old people’s clubs, are not naturally occurring typically inhabited settings. Thus interviewing respondents in their own homes was justified in the first instance. Follow up work using focus groups might have further enhanced the dataset.

Coding of in-depth interviews and analysis of qualitative data.

Data from episodic interviews should be analysed with the methods of thematic or theoretic coding (Flick, 1998). Thematic coding is usually employed for comparative studies in which

¹⁶ Some focus groups were conducted for the parent study in relation to the concept of ‘successful ageing’, both with established specially convened groups. The time and resources required to set up these groups was considerable.

the groups that are studied are derived from the research question and thus defined a priori e.g. through theoretical sampling. The collection of data is correspondingly conducted with a method seeking to guarantee comparability by defining topics but remaining open to views related to them (Flick, 1998). This was not considered suitable for a study aiming to identify lay definitions of quality of life. By contrast, theoretic coding is the procedure for analysing data collected in order to develop grounded theory, as introduced by Glaser and Strauss (1967) and further elaborated by Glaser (1978), Strauss (1987) and Strauss and Corbin (1990). Thus, in this instance the theoretical method was chosen.

Strauss and Corbin (1990) have outlined the detailed process of interpretation for theoretical coding. This involves a complex process of ‘open coding’, ‘axial coding’ and ‘selective coding’ until theoretical saturation is reached. Flick (1998) describes some of the limitations of this method, including: the hazy distinction between ‘method and art’; the potential for endless option for coding and comparisons; and the lack of clarity regarding what criteria the end of coding should be based on.

Charmaz (1995) offers an alternative view of the procedure involving initial line-by-line open coding, followed by exploration of some of the resulting codes in greater depth. The latter step is known as focused coding (Charmaz, 1995). The initial line-by-line open coding aims at expressing the data in the form of concepts attached to units of meaning (e.g. sentences), together with annotations. The concepts and annotations then developed through focused coding can then lead to the formulation of categories (Flick, 1998). This process of category development is then elaborated through memo writing, before the writing up of the analysis

can commence (Charmaz, 1995). Charmaz's method was the method adopted for the study presented here.

Thus this method lead to the identification of a broad index of the components of quality of life mentioned at each interview, together with comparative data of a temporal and geographical nature. For example, temporal data included discussions within interviews of present, past and potential future circumstances as well as generational differences; geographical data included discussions within and analysis between interviews regarding the geographical location of various events and experiences. It was therefore possible to identify at least conceptual (in terms of the components of quality of life), if not theoretical, saturation within the sample of 40 interviews. Flick (1998) critiques theoretical saturation in that the criterion 'leaves it to the theory developed up to that moment, and thus the researcher, to make such decisions of selection and ending' (p187). This is particularly relevant in an area such as quality of life where there is a dearth of developed theory. Thus, in summary, analysis of these data followed standard approaches of qualitative data organisation using a grounded theory approach, through coding, category development and testing, including scrutiny of deviant cases.

NUD*IST software (version 4) was used throughout the qualitative analysis (Qualitative Solutions and Research Pty Ltd., 1997). Tesch (1990) argued that qualitative researchers gain substantial benefits in terms of time, efficiency and more thorough analysis by adopting qualitative data analysis software. Fielding and Lee (1998) conducted a series of focus groups with users of such programmes and found that those users who, for various reasons,

were uncomfortable with existing manual methods generally found the systematicity of computer based methods helpful and even liberating. Their grasp of the data was enhanced as software facilitated repeated passes through the data making it harder to produce glib summaries. The ability to locate material quickly gave a momentum to the analysis that enhanced its completion, or encouraged flexibility preventing premature analytic closure. Other researchers, however, felt computers delivered data management benefits rather than transforming their analytic practice. They found packages difficult to learn and the features too complex (Fielding and Lee, 1998). However, Lee and Esterhuizen (2000) suggest that qualitative data analysis software has become socially acceptable among qualitative researchers, as demonstrated by the increasing number of conferences, user groups, electronic bulletin boards and literature on the subject; ability to use a qualitative data analysis package is increasingly seen as a marketable skill in applied research (Fielding and Lee, 1998). Thus for this study, it was felt that the potential advantages of the computer method outweighed its disadvantages in terms of enhanced data management and the opportunity to develop new research skills.

Smith (1995) considers it possible to include in a write up of qualitative data some indication of the prevalence of themes identified within the dataset (if appropriate), after the analysis is complete. Thus it was possible, for example, to provide some data on the frequency with which respondents mentioned various components of quality of life across the sample. However, as Smith points out (1995): “meaning is central and the aim is to try to understand the content and complexity of those meanings rather than take some measure of frequency” (p18).

Management of validity and reliability within the qualitative data.

Slevin and Sines (1999) note that some researchers consider the words validity and reliability to be ‘semantically incompatible with qualitative research’. The words ‘truthfulness’ and ‘consistency’ respectively are often used to replace them. A number of methods can be utilised to enhance truthfulness and consistency (see for example Slevin and Sines, 1999), and some were employed in the empirical study reported here.

Use was made of the constant comparative method whereby emerging data allowed for verification of findings from previous data (Glasser and Strauss, 1967; Strauss and Corbin, 1990) i.e. between the Quality of Life Questions and the in-depth interviews and within each method. Thus the themes and categories that emerged over and over again were considered to have high levels of both truth and consistency. Those that were not verified by subsequent data were considered to be lacking in truth and consistency and were not included in the list of emergent dimensions (Slevin and Sines, 1999). Thus consistency between the qualitative methods (convergent truthfulness or triangulated convergence), and within each qualitative method, was verified. Given the inconsistencies identified in the literature on quality of life throughout the development of the taxonomy described earlier, it was not considered relevant to test for convergent truthfulness between the qualitative data and the known literature.

For internal consistency (i.e. within each respondent’s set of Quality of Life Questions or interview) a similar approach was used. Responses were looked for that confirmed earlier responses, and inconsistent responses were identified: Brink (1991) describes this as checking

for 'equivalence'. This could occur either at the time of data collection or during analysis. The advantage of the former method is that respondents can be asked to clarify their answers, particularly with regard to what Strauss (1987) terms 'red flag' statements. The word 'never' is an example of a red flag in that there are very few phenomena in life to which the word 'never' applies (Slevin and Sines, 1999). When such a word was used in an interview, respondents were gently challenged to confirm that they really meant 'never' (e.g. in relation to feelings of loneliness or boredom several respondents used the word 'never').

The use of a tape recorder and subsequent verbatim typing of interviews into transcripts by experienced transcribers, which were then checked and corrected by the researcher, assured consistent and accurate recording of data (Slevin and Sines, 1999). Subsequent to this every effort was made not to select only the most interesting quotes, but a range of quotes was sought for each exemplar both in terms of their content and source (geographical area, gender and, in the case of the Quality of Life Questions responses, age group). However word limits have precluded the provision of more copious narrative exemplars not only within this thesis, but in published papers.

For both the Quality of Life Questions (Stage Ib) and the in-depth interviews (Stage II) it was not possible to test for repeatability. Although events may have caused respondents' quality of life to change by the time of second administration of the Quality of Life Questions or a second interview, it would have been interesting to see if the themes or dimensions that were important to them remained the same. The timing of a second visit would require some consideration. For those respondents who took part in both methods, however, there was a

reassuring consistency in the overall themes that were identified, although this was not tested at individual respondent level.

It would have been useful to include inter-rater or inter-coder reliability testing for both the Quality of Life Questions and the in-depth interviews. This was not possible as there were no resources to allow for a second coder on the transcripts at the time of the empirical work, but this would not preclude such testing in the future. This would enable discussion of theme headings and content (e.g. was 'control' the appropriate label for that group of responses?), and may have resolved or clarified issues such as overlapping themes and linkage of themes. Given that the system of coding was essentially a theory-free conceptual system there was no theoretical basis on which to address such issues. If the timing of the thesis had been more contained, it would have been useful to involve the respondents themselves by seeking their views on the honesty and consistency of the findings (Slevin and Sines, 1999): this could have taken the form of a focus group exercise which could, in itself, have generated further data.

Thus, Chapter 5 has described the three established samples of older people on which the study was based. It described and critiqued the methods and rationale of data collection, training of interviewers, coding and analysis within each the stages of data collection (Stage Ia, 'quality of life' scales; Stage Ib, The 'Quality of Life Questions'; and Stage II, In-depth Interviews) and the management of validity and reliability within the qualitative data.

Chapter 6: Results I: Response Rates and Demography

Chapter 6 describes the response rates to each of the stages of the study: the ‘quality of life’ scales (Stage Ia), Quality of Life Questions (Stage Ib) and In-depth Interviews (Stage II). It then describes the demography of the samples.

Response Rates

As described earlier, these are the respondents to follow up studies of people who were aged 85 years and over and 65<85 years two years earlier. Thus the respondents in each sample are aged 87 years and over (older Hackney sample: sample 1) and 67<87 years (younger Hackney and Braintree samples: samples 2 and 3), and the columns are so labelled in the relevant tables.

Response rates to ‘quality of life’ scales (Stage Ia):

Table 6.1, below, shows the number and percentage of respondents who completed the ‘quality of life’ scales in each of the three samples at Stage Ia.

Table 6.1: Response rates to scales at Stage Ia

Sample	Hackney		Braintree	Total
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
Scale				
Nottingham Health Profile	75 (65/87)	67 (85/126)	83 (60/72)	74 (210/285)
General Well-Being Schedule	73 (63/86)	69 (84/121)	83 (60/72)	74 (207/279)
Affect-Balance Scale	75 (65/87)	68 (84/124)	83 (60/72)	74 (209/283)
McMaster Health Index Q'aire	66 (55/83)	64 (71/111)	78 (46/59)	68 (172/253)
Self-Evaluation of Life Function Scale	66 (53/80)	64 (70/109)	79 (46/58)	68 (169/247)
Dartmouth Co-op Chart for Quality of Life	80 (70/87)	99 (92/93)	100 (60/60)	93 (222/240)
The Faces Scale for Quality of Life	63 (162/256)	78 (258/332)	92 (183/199)	78 (603/787)

n.b. numbers in parenthesis indicate 'successfully completed scales/attempted administered scales'

Thus Table 6.1 shows that overall, the MHIQ and SELF consistently had the lowest response rates. The DCCQoL was the instrument with the highest response rate across the three samples, achieving a 99% completion rate with the younger Hackney sample (aged 67<87: sample 2) and 100% with the Braintree sample (sample 3). With the exception of the two single item instruments (DCCQoL and The Faces Scale for Quality of Life), the younger Hackney sample (aged 67<87: sample 2) had the lowest response rates for the scales (i.e. NHP, GWBS, ABS, MHIQ and SELF). The Braintree sample consistently had the highest response rates for all of the scales. The older Hackney sample (aged 87+: sample 1) had the lowest response rate for the two single item instruments, but interestingly were most likely to

complete the single item DCCQoL and least likely to complete The Faces Scale for Quality of Life out of all of the scales. The reasons for the latter finding are unclear, but may reflect a lack of comprehension of the format of the scale or the interviewers' presentation or explanation of the format of the scale.

Response rates to Quality of Life Questions (Stage Ib):

A sub-sample of 214 respondents completed the Quality of Life Questions (Stage Ib). Seventy four respondents were from the older Hackney sample (sample 1) and 70 from each of the two younger samples in Hackney and Braintree (samples 2 and 3).

Response rates to the in-depth interviews (Stage II):

Forty-three people were recruited to the in-depth interview study (Stage II): 20 from Hackney and 23 from Braintree. Only one person refused when asked; this was a member of the Braintree sample who explained that she had been too unwell recently to commit herself to any further research.

One respondent from the Hackney sample withdrew after recruitment due to a sudden and serious decline in the health of her husband. She reported having wished to take part because she felt the subject of the study was both interesting and important and said she would contact the researcher (MF) if her husband's condition improved, however no further contact was made. One Hackney respondent was later lost from the sample as there was no answer at the

door on three occasions even though agreed appointments had been made, and one further Hackney respondent withdrew due to foot surgery. Therefore 17 of the 20 respondents (85%) from Hackney were successfully interviewed. All 23 respondents (100%) from Braintree were successfully interviewed.

These high response rates using an established sample within a study consisting of a series of stages or phases are similar to those reported by Appleton (1995) who found that all respondents to an earlier stage of her study agreed to participate at the interview stage. In this present study these rates may have resulted from the effects of altruism (e.g. respondents wanting help a researcher with her work towards her higher degree), knowledge of the researcher (i.e. the researcher was no longer a complete stranger), a need for contact (e.g. some respondents would follow the closure of the interviews with offers of further cups of tea or an invitation to call in if the researcher was ever passing), or an interest in the topic (i.e. 'quality of life'). Alternatively, it may be a particular feature of interviewing older people that these in-depth interviews worked so well. Ford and Sinclair (1987), working with older women in particular, noted:

'Most of them [...] have time and enjoy visits and additional company. Undoubtedly some felt flattered, or at least pleased to be the centre of attention, particularly where they felt strongly that older people were undervalued by society' (p 11).

For some of these respondents this was the third meeting with the researcher: once for their baseline interview for the parent study, once for the follow interview for the parent study (including the Quality of Life Questions) and once for the in-depth interview for the present study. Indeed, Finch's finding that 'some variation on the comment "I've really enjoyed

having someone to talk to” was made at the end of many interviews’ (Finch, 1984) was echoed in the empirical work reported here.

Demography of the samples

Table 6.2, below, describes the demography of the three samples at Stage Ia in terms of their age group, sex and social class distributions.

Table 6.2: Age, sex and social class of respondents at Stage Ia

Sample	Hackney		Braintree	Significance test
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
Age				
67<77	- (-)	37 (124)	49 (97)	
77<87	- (-)	55 (182)	45 (89)	
87+	100 (256)	8 (26)	6 (13)	samples 2/3 only: U=29296.0 p=0.014 ^a H= 6.004 df=1 p=0.014 ^b
Sex				
Male	16 (40)	40 (198)	31 (61)	
Female	84 (210)	60 (133)	69 (138)	$\chi^2=39.712$ df=2 p<0.001 ^c
Social class				
I	* (1)	1 (3)	3 (5)	
II	15 (37)	11 (36)	21 (42)	
III _{nm}	14 (34)	11 (38)	12 (24)	
III _m	45 (112)	56 (186)	45 (90)	
IV	15 (38)	10 (32)	15 (29)	
V	9 (21)	8 (26)	4 (9)	
Armed Forces	- (-)	2 (6)	- (-)	
Other	2 (6)	1 (5)	- (-)	$\chi^2=38.313$ df=14 p<0.001 ^c
No. respondents	(249-256)	(331-332)	(199)	

(*=<1%) (^a Mann Whitney, ^b Kruskal Wallis, ^c Chi Square)

The table shows that within the two '67<87' year old samples, a small number of respondents had actually reached aged 87 years by the time of their follow up interview in 1991. The younger Hackney sample (sample 2) contains slightly more respondents aged 77 years and over than the Braintree sample (sample 3) ($p=0.014$). The data on age were collected in terms of membership of a series of age groups rather than actual age.

As would be expected in samples of older people, the table shows that the majority of respondents were female, particularly in the very elderly group (sample 1) ($\chi^2=39.712$, $df=2$, $p<0.001$). Social class differences were found for both age group and area. More of those living in Hackney (samples 1 and 2) were from a lower social class than those living in Braintree sample (sample 3); more of those in the older age group (sample 1) were from a lower social class than those in the younger age groups (samples 2 and 3) (all 3 samples: $\chi^2=38.313$, $df=14$, $p<0.001$; samples 1/2: $\chi^2=29.923$, $df=7$, $p<0.001$; samples 2/3: $\chi^2=31.782$, $df=7$, $p<0.001$).

Table 6.3a, below, isolates the demography of the three sub-samples to the Quality of Life Questions at Stage Ib, in terms of their age group, sex and social class distributions.

Table 6.3a: Age, sex and social class of sub-sample respondents completing the Quality of Life Questions at Stage Ib

Sample	Hackney		Braintree	Significance test
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
Age				
67<77	- (-)	36 (25)	46 (32)	
77<87	- (-)	57 (39)	48 (33)	
87+	100 (74)	7 (5)	6 (4)	samples 2/3 only: U=2134.5 p=0.238 ^a H=1.394 df=1 p=0.238 ^b
Sex				
Male	11 (8)	38 (26)	33 (23)	
Female	89 (66)	62 (42)	67 (46)	$\chi^2=15.594$ df=2 p<0.001 ^c
Social class				
I	- (-)	1 (1)	4 (3)	
II	20 (15)	6 (4)	20 (14)	
III _{nm}	10 (7)	7 (5)	16 (11)	
III _m	46 (34)	58 (40)	45 (31)	
IV	14 (10)	7 (5)	12 (8)	
V	8 (6)	15 (10)	3 (2)	
Armed Forces	- (-)	4 (3)	- (-)	
Other	3 (2)	1 (1)	- (-)	$\chi^2=28.927$ df=14 p=0.011 ^c
No. of respondents	(74)	(68-69)	(69)	

(^a Mann Whitney, ^b Kruskal Wallis, ^c Chi Square)

As with Table 6.2, Table 6.3a shows that within the '67<87' year old samples a small number of respondents who had actually reached age 87 years by the time of their follow up interview in 1991. Unlike Table 6.2, Table 6.3a shows no statistically significant differences between the two younger samples (samples 2 and 3) in terms of age group (p=0.238). However again, as would be expected in samples of older people, the table shows that the majority of

respondents were female, particularly in the very elderly group ($\chi^2=15.594$, $df=2$, $p<0.001$). Social class differences were again found by area: those living in Hackney (samples 1 and 2) had a lower social class than those living in Braintree sample (sample 3). However no statistically significant differences in social class were found between the age groups when comparing the two Hackney samples (samples 1 and 2) (all 3 samples: $\chi^2=28.927$, $df=14$, $p=0.011$; samples 1/2: $\chi^2=14.031$, $df=7$, $p=0.051$; samples 2/3: $\chi^2=19.972$, $df=7$, $p=0.006$).

Table 6.3b, below, shows no significant differences in terms of demographic variables between those who completed the Quality of Life Questions (i.e. members of the sub-samples) and those who did not (i.e. the non sub-sample members) at Stage Ia, for the three samples together, or for each individual sample. This suggests that the sub-samples were representative of the samples as a whole.

Table 6.3b: Comparison of sub-sample (Stage Ib) and non sub-sample members' demographic variables

Sample	Hackney				Braintree		Total	
	Age 87+ (sample 1)		Age 67<87 (sample 2)		Age 67<87 (sample 3)			
	Sub-sample	Non sub-sample	Sub-sample	Non sub-sample	Sub-sample	Non sub-sample	Sub-sample	Non sub-sample
	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)
Age								
67<77	- (-)	- (-)	36 (25)	38 (99)	46 (32)	50 (65)	27 (57)	29 (164)
77<87	- (-)	- (-)	57 (39)	54 (143)	48 (33)	43 (56)	34 (72)	35 (199)
87+	100 (74)	100 (176)	7 (5)	8 (21)	6 (4)	7 (9)	39 (83)	36 (206)
Chi-square Test:		N/A		$\chi^2=0.113$ df=2 p=0.945		$\chi^2=0.436$ df=2 p=0.804		$\chi^2=0.613$ df=2 p=0.736
Sex								
Male	11 (8)	18 (32)	38 (26)	41 (107)	33 (23)	29 (38)	27 (57)	31 (177)
Female	89 (66)	82 (144)	62 (42)	59 (156)	67 (46)	71 (92)	73 (154)	69 (392)
Fisher's Exact Test (2-tailed):		p=0.186		p=0.782		p=0.628		p=0.292
Social class								
I	- (-)	1 (1)	1 (1)	1 (2)	4 (3)	2 (2)	2 (4)	1 (5)
II	20 (15)	13 (22)	6 (4)	12 (32)	20 (14)	22 (28)	16 (33)	14 (82)
III _{nm}	9 (7)	15 (27)	7 (5)	13 (33)	16 (11)	10 (13)	11 (23)	13 (73)
III _m	46 (34)	44 (78)	58 (40)	55 (146)	45 (31)	45 (59)	50 (105)	50 (283)
IV	14 (10)	16 (28)	7 (5)	10 (27)	12 (8)	16 (21)	11 (23)	13 (76)
V	8 (6)	9 (15)	15 (10)	6 (16)	3 (2)	5 (7)	8 (18)	7 (38)
Armed Forces	- (-)	- (-)	5 (3)	1 (3)	- (-)	- (-)	1 (3)	1 (3)
Other	3 (2)	2 (4)	1 (1)	2 (4)	- (-)	- (-)	1 (3)	1 (8)
Chi-square Test:		$\chi^2=4.138$ df=6 p=0.658		$\chi^2=12.29$ df=7 p=0.091		$\chi^2=4.030$ df=5 p=0.545		$\chi^2=5.050$ df=7 p=0.654
No. of resp.	(74)	(175-176)	(68-69)	(263)	(69)	(130)	(211-212)	(568-569)

Chapter 6 has described the response rates to each of the stages of the study: the ‘quality of life’ scales (Stage Ia), Quality of Life Questions (Stage Ib) and In-depth Interviews (Stage II). The data presented shows that the samples appear to be representative of the older population. Thus it should be possible to generalise the findings presented in the following chapters to other populations of older people living in the community in inner city and semi-rural areas of England.

Chapter 7: Results II: ‘Quality of Life Scales’

In this chapter the percentage of respondents who required help with completing the ‘quality of life’ scales will be reported, together with respondents’ views of, and scores attained on each of the scales (Stage Ia), thereby considering the relevance to older people of scales commonly used to measure quality of life.

Assistance with ‘quality of life’ scales

There was anecdotal evidence from interviewer feedback (including the researcher, MF) that some respondents found the completion of scales tiring following the interview for the follow up study. Table 7.1, below, shows the percentage of respondents requiring help with completing scales by sample. The number of respondents who appear to have completed individual scales on this table is greater than the number on Tables 7.2 through 7.8, as incomplete data for some scales (e.g. through missed items or unreadable responses) reduced the total number of respondents once total or sub-scale scores were computed.

Table 7.1: Interviewers' assistance given with scale completion at Stage Ia.

Sample	Hackney		Braintree	Significance test	Total
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)		
Assistance given with scale?					
NHP					
Yes	41 (127)	15 (13)	10 (6)		21 (46)
No	59 (39)	85 (75)	90 (55)	$\chi^2=22.085$ df=2 p<0.001	79 (169)
GWBS					
Yes	48 (31)	19 (17)	8 (5)		25 (53)
No	52 (34)	81 (74)	92 (55)	$\chi^2=29.015$ df=2 p<0.001	75 (163)
ABS					
Yes	35 (28)	14 (12)	7 (4)		18 (39)
No	65 (43)	86 (76)	93 (57)	$\chi^2=19.122$ df=2 p<0.001	82 (176)
MHIQ					
Yes	43 (26)	18 (15)	12 (6)		25 (47)
No	57 (34)	82 (67)	88 (44)	$\chi^2=17.447$ df=2 p<0.001	75 (145)
SELF					
Yes	51 (30)	21 (17)	12 (6)		28 (53)
No	49 (29)	79 (64)	88 (45)	$\chi^2=24.047$ df=2 p<0.001	72 (138)
DCCQoL					
Yes	28 (18)	13 (12)	5 (3)		15 (33)
No	72 (51)	87 (80)	95 (57)	$\chi^2=11.677$ df=2 p=0.003	85 (188)
No. of respondents	(59-69)	(81-92)	(50-61)		(191-221)

Table 7.1 shows that there were significant differences between the three samples with regard to interviewers' assistance given on each scale. As the table shows, the very elderly sample in Hackney were the most likely to require assistance with completing the scales, followed by the younger Hackney sample. The younger Braintree sample was the least likely to require assistance with completing scales.

Most interestingly the SELF scale, which was the only scale specifically designed for use by older people, was the scale that the respondents (from any of the samples) were most likely to request help with; more than half of the very elderly sample were given assistance with this scale. This was followed by the MHIQ and GWBS, both of which were described in the review in Chapter 3 as fairly complex and lengthy. The DCCQoL, the single item measure, required the least help although, notably, more than a quarter of the very elderly sample (28%) still required help with this.

Help was usually required in the form of reading the scales (reportedly because of visual difficulties), or recording responses (reportedly because of arthritic hands or, again, visual difficulties). This finding was reflected in self-reported data from the 1990/91 follow up studies: 53% (n=132) of the very elderly Hackney sample reported problems with their eyesight (not corrected by glasses) compared with 31% (n=102) and 28% (n=56) of the two younger samples respectively ($\chi^2=40.531$, $df=2$, $p<0.001$); and 54% (n=138) of the very elderly Hackney sample selected the categories 'only with help/unable to do at all' regarding their ability to fill in forms and write, compared with 35% (n=90) and 11% (n=27) of the two younger samples respectively ($\chi^2=157.181$, $df=8$, $p<0.001$) (the percentages reporting being

unable to do this activity at all were: 32% (n=79), 14% (n=46) and 7% (n=14) respectively ($\chi^2=158.269$, $df=10$, $p<0.001$)).

Views of, and scores attained on, the 'quality of life' scales

The views of and scores attained by the three samples on the various 'quality of life' scales used will be described in turn.

Nottingham Health Profile (NHP):

At the debriefing sessions the interviewers (including MF) reported that, on the whole, the NHP was well received by respondents. Some commented that the print was too small, however this was the responsibility of the researcher (MF) rather than the scale's developers. Respondents reportedly asked for clarification of, or assistance with, the following items:

- i) 'I'm finding it hard to make contact with people' (part I, social scale) – respondents were unclear whether this referred to a primary physical contact (i.e. in terms of being able to get out and about), a secondary physical contact (i.e. telephone or written contact) or contact on an emotional level (i.e. understanding or getting through to one another); and
- ii) 'I feel as if I am losing control' (part I, emotional scale) – respondents were unclear if this related to their thoughts, their behaviour or their ability to look after themselves.

Table 7.2, below, shows the mean scores for each of the six ‘areas’ (scales) of Part I of the NHP, by sample.

Table 7.2: Responses (mean scores) to the Nottingham Health Profile

Sample	Hackney		Braintree	Kruskal Wallis Test: <i>H</i>	Total Mean (s.d.)
	Age 87+ (sample 1) Mean (s.d.)	Age 67<87 (sample 2) Mean (s.d.)	Age 67<87 (sample 3) Mean (s.d.)		
Scales					
Energy Levels	28.94 (37.19)	24.84 (33.18)	17.22 (30.20)	<i>H</i> =4.22 df=2 p=0.121	23.99 (33.87)
Pain	17.87 (28.91)	16.33 (25.69)	18.81 (26.64)	<i>H</i> =1.09 df=2 p=0.579	17.51 (26.90)
Emotional Reactions	17.19 (25.24)	11.92 (18.22)	9.08 (20.47)	<i>H</i> =6.23 df=2 p=0.044	12.79 (21.43)
Sleep	25.69 (30.56)	26.68 (30.50)	26.97 (31.51)	<i>H</i> =0.14 df=2 p=0.933	26.45 (30.67)
Social Isolation	18.52 (22.93)	9.39 (16.86)	8.11 (15.85)	<i>H</i> =12.10 df=2 p=0.002	11.92 (19.20)
Physical Mobility	38.01 (27.39)	21.66 (24.76)	20.28 (25.15)	<i>H</i> =18.23 df=2 p<0.001	26.37 (26.78)
No. of respondents	(67-68)	(85-88)	(60-61)		(213-217)

(n.b. higher scores indicate a higher level of problems, lower scores indicate a lower level of problems)

The table shows that there were no differences between the samples in terms of their scores on the Energy Level (*H*=4.22, df=2, p=0.121), Pain (*H*=1.09, df=2, p=0.579) or Sleep (*H*=0.14, df=2, p=0.933) scales, however there were statistically significant differences for the Emotional Reactions (*H*=6.23, df=2, p=0.044), Social Isolation (*H*=12.10, df=2, p=0.002)

and Physical Mobility ($H=18.23$, $df=2$, $p<0.001$) scales (Kruskal-Wallis Tests). For each of these sub-scales the very elderly sample in Hackney (sample 1) scored the highest (indicating a higher level of problems) and the younger sample in Braintree (sample 3) scored the lowest (indicating a lower level of problems).

Affect Balance Scale (ABS):

As with the NHP, the interviewers reported that the ABS was well received by respondents, although a few reportedly found it repetitive. It consisted of just 10 items and was presented on half a side of A4 paper in a larger font size than the NHP. Some interviewers commented that the line spacing between the questions was too small, meaning that respondents sometimes missed out one or two questions or placed responses to one item in response boxes for subsequent items. However this was again the responsibility of the researcher (MF) rather than the scale's developers. Respondents reportedly asked for clarification of, or assistance with, the following questions:

- i) B: 'Did you ever feel so restless that you couldn't sit long in a chair?' - respondents who had severe problems with mobility found this a problematic question as they could feel restless but have no option than to spend much of their day in a chair;
- ii) C: 'Did you ever feel proud because someone complimented you on something you had done?' - respondents sometimes hesitated at this question reporting that they had experienced pride but no longer received praise or compliments of this sort (particularly when living alone), and for some it was a patronising question; and

- iii) I: ‘Did you ever feel that things were going your way?’ - respondents had difficulty understanding what was meant by this question.

In addition, where they were required to read out questions, interviewers frequently reported having to remind respondents of the temporal context of the questions i.e. ‘during the past few weeks’, before they recorded their final replies. Within the ABS the temporal context is given only in the introduction to the questions, and not given at each individual question as in the GWBS. It is not known how often this misunderstanding occurred for those who completed the scale unaided.

In Table 7.3a, below, the Affect-Balance Scale scores for the three samples are shown.

Table 7.3a: Responses to the Affect-Balance Scale

Sample	Hackney		Braintree	Total
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
Balance scores				
-5	- (-)	1 (1)	- (-)	1 (1)
-4	2 (1)	1 (1)	- (-)	1 (2)
-3	8 (5)	1 (1)	3 (2)	4 (8)
-2	9 (6)	5 (4)	2 (1)	5 (11)
-1	9 (6)	7 (6)	8 (5)	8 (17)
0	19 (12)	20 (17)	13 (8)	18 (37)
1	8 (5)	15 (13)	10 (6)	11 (24)
2	15 (10)	23 (19)	18 (11)	19 (40)
3	15 (10)	7 (6)	17 (10)	12 (26)
4	9 (6)	10 (8)	12 (7)	10 (21)
5	6 (4)	10 (8)	17 (10)	11 (22)
No. of respondents	(65)	(84)	(60)	(209)

(Kruskal-Wallis Test: $H=6.969$, $df=2$, $p=0.031$)

(n.b. lower scores on the ABS indicate poorer psychological well-being)

The table shows that taking the three samples together, the majority of respondents scored at the positive end of the scale, with 81% of respondents achieving a score of 0 or more (within a score range of -5 to +5), and 60% of scores falling in the 0 to +3 interval. The table also shows that there were significant differences between the three samples on the ABS (Kruskal-Wallis Test: $H=6.969$, $df=2$, $p=0.031$), with the very elderly Hackney sample (sample 1) scoring lowest, followed by the younger Hackney sample (sample 2), then the younger Braintree sample (sample 3). Lower scores on the ABS indicate poorer psychological well-being.

Table 7.3b and 7.3c, below, show the Positive and Negative Affect sub-scores respectively for the three samples.

Table 7.3b: Responses to the Positive Affect sub-scores on the Affect-Balance Scale

Sample	Hackney		Braintree	Total % (n)
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
Positive Affect sub-scores				
0	19 (12)	20 (17)	10 (6)	17 (35)
1	19 (12)	17 (15)	13 (8)	17 (35)
2	20 (13)	24 (21)	25 (15)	23 (49)
3	17 (11)	16 (14)	22 (13)	18 (38)
4	13 (9)	11 (9)	10 (6)	11 (24)
5	12 (8)	12 (10)	20 (12)	14 (30)
No. of respondents	(65)	(86)	(60)	(211)

(Kruskal-Wallis Test: $H=4.020$, $df=2$, $p=0.134$)

Table 7.3c: Responses to the Negative Affect sub-scores on the Affect-Balance Scale

Sample	Hackney		Braintree	Total
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
Negative Affect sub-scores				
0	38 (25)	63 (55)	69 (42)	57 (122)
1	24 (16)	14 (12)	13 (8)	17 (36)
2	17 (11)	9 (8)	5 (3)	10 (22)
3	12 (8)	8 (7)	9 (6)	10 (21)
4	8 (5)	4 (3)	2 (1)	4 (9)
5	1 (1)	2 (2)	2 (1)	2 (4)
No. of respondents	(66)	(87)	(61)	(214)

(Kruskal-Wallis Test: $H=12.908$, $df=2$, $p=0.002$)

Table 7.3b showed that there were no significant differences on the Positive Affect sub-score (Kruskal-Wallis Test: $H=4.020$, $df=2$, $p=0.134$), however there were significant differences on the Negative Affect sub-score as was shown in Table 7.3c (Kruskal-Wallis Test: $H=12.908$, $df=2$, $p=0.002$). The older Hackney sample (sample 1) achieved lower scores than the two younger samples (samples 2 and 3) indicating poorer Negative Affect.

The Positive Affect sub-scores appear fairly evenly distributed across the range of possible scores (Table 7.3b), whereas the Negative Affect sub-scores were skewed towards the lower end of the scale representing fewer 'yes' responses to negative items (Table 7.3c).

Table 7.3d, below, shows the means calculated for the total sample and the three samples separately, on the Positive Affect sub-scores, Negative Affect sub-scores and ABS.

Table 7.3d: Mean scores on the Positive and Negative Affect sub-scales and the Affect-Balance Scale

Sample	Hackney		Braintree Age 67<87 (sample 3) Mean (s.d.)	Kruskal- Wallis Test: <i>H</i>	Total Mean (s.d.)
	Age 87+ (sample 1) Mean (s.d.)	Age 67<87 (sample 2) Mean (s.d.)			
Scales					
Positive Affect sub-scale	2.26 (1.65)	2.15 (1.61)	2.68 (1.59)	<i>H</i> =4.020 df=2 p=0.134	2.34 (1.63)
Negative Affect sub-scale	1.32 (1.37)	0.82 (1.31)	0.67 (1.21)	<i>H</i> =12.908 df=2 p=0.002	0.93 (1.32)
Affect-Balance Scale	0.95 (2.38)	1.37 (2.16)	2.05 (2.17)	<i>H</i> =6.969 df=2 p=0.031	1.44 (2.26)
No. of respondents	(65-66)	(84-87)	(60-61)		(209-214)

Thus Table 7.3d showed a similar picture to Tables 7.3a-7.3c, with no significant differences for the Positive Affect sub-score, but statistically significant differences for both the Negative Affect sub-score (sample 1 had the highest mean indicating a poorer Negative Affect followed by sample 2, then 3) and the ABS (sample 1 had the lowest mean, indicating a poorer ABS score, followed by sample 2 and then 3).

Andrews and Withey (1976) reported mean scores for respondents aged 65 and over to their 1972 US national survey (November Form 2) of 1,072 American adults: Positive Affect mean sub-score 2.8; Negative Affect mean sub-score 1.3; and ABS mean score 1.4. Moriwaki (1974) administered the ABS to two samples of people aged 60+ years: one (n=8) from Los Angeles County mental health clinics and the other (n=19) from church ‘judged to be

mentally healthy by an informant'. The mean for the normal sample was 8.27 (with ABS scored 0-10) and for the psychiatric sample was 4.25: the mean score for the present study based on a 0-10 scoring was 6.4354 (s.d. 2.2611) (n=209).

General Well-Being Schedule (GWBS):

The interviewers reported that although most respondents had found the individual questions of the GWBS relatively short, simple and easy to understand, some had commented that the overall length of the schedule was too great and its content repetitive. Respondents reportedly asked for clarification of, or assistance with the following individual questions:

- i) q10: respondents were unsure what was meant by 'bodily disorder';
- ii) q12: respondents commented that 'blue' was an unusual word to use; and
- iii) q17: respondents were unsure what was meant by 'pep' or 'vitality'.

In addition, interviewers reported that respondents found difficulty with the anchored visual analogue scales used in questions 15 through 18. These scales ranged from 0 to 10. Most respondents appeared to understand that '0' represented, for example, 'very depressed' and '10' 'very cheerful' (q18), however some did not then understand what the numbers 1 through 9 represented.

The finding that respondents reportedly found the 18 items of GWBS too long was surprising given that comments on length were less frequently made about the 38-item NHP. The items

included in the NHP are, however, shorter in terms of words and, perhaps more importantly, the response categories in the NHP are simpler: questions 1 to 14 of the GWBS have 6 response categories to choose from, and questions 15 to 18 have 11, compared with just two response categories throughout the NHP. In addition, the wording of the response categories varies throughout the GWBS, as does the polarity of the categories, whereas both category wording and polarity remain constant (i.e. ‘yes’/ ‘no’) throughout the NHP. Together these differences may have made the GWBS harder work to complete (and harder for interviewers to read out and possibly repeat) than the NHP, suggesting that the time taken to complete it, rather than its physical length, was perhaps longer.

Table 7.4a, below, shows the total scores for each of the three samples presented according to Dupuy’s (1978) proposed cut-offs.

Table 7.4a: Responses to the General Well-Being Schedule (total scores)

Sample	Hackney		Braintree	Total
	Age 87+ (sample 1)	Age 67<87 (sample 2)	Age 67<87 (sample 3)	
	% (n)	% (n)	% (n)	% (n)
Total scores				
0-60: ‘severe distress’	32 (20)	11 (9)	7 (4)	16 (33)
61-72: ‘moderate distress’	18 (11)	14 (12)	15 (9)	16 (32)
73-110: ‘positive well-being’	51 (32)	75 (63)	78 (47)	69 (142)
No. of respondents	(63)	(84)	(60)	(207)

(Kruskal-Wallis Test: $H=16.300$, $df=2$, $p<0.001$)

The table shows that there were significant differences between the three samples (Kruskal-Wallis Test: $H=16.300$, $df=2$, $p<0.001$). Three quarters or more of the two younger samples

(samples 2 and 3) achieved a score between 73-110, representing ‘positive well-being’, compared with just over half of the very elderly sample in Hackney (sample 1). Looking at the three samples together the results compare well with US national reference standards derived from HANES I data: 71% of respondents (6,913 non-institutionalised adults, aged 25 to 74 years) fell into the ‘positive well-being’ category, 15.5% showed ‘moderate distress’, and 13.5% ‘severe distress’ (compared with 69%, 16% and 16%).

Table 7.4b, below, shows the six sub-score means for each of the three samples.

Table 7.4b: Responses to the General Well-Being Schedule mean sub-scores

Sample	Hackney		Braintree	Kruskal-Wallis Test: <i>H</i>	Total Mean (s.d.)
	Age 87+ (sample 1) Mean (s.d.)	Age 67<87 (sample 2) Mean (s.d.)	Age 67<87 (sample 3) Mean (s.d.)		
Sub-scores					
Anxiety	20.67 (6.70)	23.71 (5.52)	23.62 (4.25)	<i>H</i> =10.300 df=2 p=0.004	22.75 (5.74)
Depression	14.86 (5.36)	17.34 (4.53)	17.98 (3.38)	<i>H</i> =13.422 df=2 p=0.001	16.76 (4.68)
Positive Well-Being	10.62 (3.63)	12.01 (3.43)	13.27 (2.43)	<i>H</i> =19.914 df=2 p<0.001	11.95 (3.38)
Self-Control	15.30 (2.99)	15.82 (3.34)	16.52 (1.41)	<i>H</i> =5.341 df=2 p=0.069	15.86 (2.82)
Vitality	12.06 (5.28)	14.27 (4.55)	14.57 (4.39)	<i>H</i> =8.857 df=2 p=0.012	13.69 (4.84)
General Health	10.08 (5.33)	12.26 (3.96)	11.70 (3.61)	<i>H</i> =6.211 df=2 p=0.045	11.77 (6.48)
No. respondents	(63-65)	(84-87)	(60)		207-214

(n.b. high sub-scores represent positive states i.e. a high Anxiety sub-score represents a low level of anxiety whereas a high Vitality sub-score represents a high level of vitality)

The table shows that there were statistically significant differences between the three samples for every sub-score of the GWBS except the Self-Control sub-score (Kruskal-Wallis Test: $H=5.341$, $df=2$, $p=0.069$). Anxiety, Depression, Positive Well-Being, Vitality and General Health sub-scores were lower for the older Hackney sample (sample 1) than the two younger samples (sample 2 and 3) (Kruskal-Wallis Tests: Anxiety ($H=10.300$, $df=2$, $p=0.004$); Depression ($H=13.422$, $df=2$, $p=0.001$); Positive Well-Being ($H=19.914$, $df=2$, $p<0.001$); Vitality ($H=8.857$, $df=2$, $p=0.012$); and General Health ($H=6.211$, $df=2$, $p=0.045$)). High sub-scores represent positive states i.e. a high Anxiety sub-score represents a low level of anxiety whereas a high Vitality sub-score represents a high level of vitality. Thus the sub-scores achieved by the samples shown on the table indicate higher levels of anxiety and depression, and lower levels of positive well-being, vitality and general health for the older sample (sample 1) than the two younger samples (samples 2 and 3).

McMaster Health Index Questionnaire (MHIQ):

As with the GWBS, many respondents described the MHIQ as 'long'. It consists of 59 items in total. Interviewers reported clarifying, or giving assistance with, the following items in section A:

- i) q2b: 'today, do you have any physical difficulty at all with climbing up 2 flights of stairs?' – respondents who had little experience of more than one flight of stairs said they were guessing their answer; and
- ii) q2j: 'today, do you have any physical difficulty at all with cleaning floors?' – a few

respondents commented that they could carry out light hoovering or sweeping, but would have greater difficulty scrubbing a floor on their hands and knees.

In section A, the examples given for question 3 (relating to respondents' ability to take part in sports) were not always relevant to older respondents e.g. 'hockey' and 'swimming' are first examples listed and none of respondents in any of the samples were actively participating in such sports although the other examples of 'bowling' and 'golf' did have relevance for a few respondents in Braintree only. Such 'examples' are meant to be just that, but some respondents took them quite literally, believing that questions were irrelevant to them if they did not carry out the activities cited. For those who completed the questionnaire unaided it is unknown whether this question posed problems for them or not, and whether this affected their responses. In addition, respondents reportedly found the filter questions difficult to follow.

Interviewers reported that a number of respondents found section B (the emotional functioning items) of the MHIQ 'confusing' because of the content of the questions rather than their format. One interviewer notated section B (emotional functioning items) of a series of questionnaires in Braintree as follows:

- i) 3357 (item 11) - *'had to stop at this point, he was totally confused and becoming very upset'*;
- ii) 3213 (item 13) - *'could not cope with this, found it very confusing even when I tried to explain he could not remember what the question was'*; and

- iii) 3021 (item 14) - *'stopped at this point – she did not like this part and would not do any more'*.

It was unclear whether the difficulties described by this interviewer were the result of her own difficulties with the scale, or the difficulties of the individual respondents. The latter three questionnaires were not included in the analyses presented here. As described above, section B consists of a 5 point anchored visual analogue scale, however the anchors are only given at the top of the section and are not repeated at the top of the second page of the section. As a result, interviewers commented that respondents were more likely to ask for assistance with this section, or were continually referring back a page to check the polarity of the anchors, which they found confusing. Interviewers were reportedly required to clarify, or give assistance with, the following items in section B:

- i) item 11: 'everyone should have someone in his life whose happiness means as much to him as his own' - some respondents who were widowed found this item difficult;
- ii) item 15: 'in a society where almost everyone is out for himself, people soon come to distrust each other' – many respondents hesitated at this item, finding it difficult to interpret; and
- iii) item 19: 'most people don't realize [sic] how much their lives are controlled by plots hatched in secret by others' – many respondents found this item bizarre, and several noted the American spelling of 'realise'.

As with section A, in section C the examples given for question 23 (relating to 'social

functioning’) were not always relevant to older respondents; ‘work’ is the first example listed and very few of any of the samples were actively participating in paid employment although a very small number (mainly in Braintree) were involved in voluntary work e.g. 1990/91 follow up data from the parent study indicated that of those who completed the MHIQ, 2% (n=1) of the very elderly in Hackney (sample 1), 9% (n=7) of the younger elderly in Hackney (sample 2) and 16% (n=8) of the younger elderly in Braintree (sample 3) reported participating in paid or voluntary work. In addition, one interviewer felt the line spacing between the response categories of section C was inadequate. Interviewers reportedly provided clarification of, or assistance with, the following questions in section C:

- i) q34: respondents commented on the American vocabulary in the response category ‘on vacation’;
- ii) q37d: respondents asked for clarification on what was meant by a ‘social agency representative’;
- iii) q42a: ‘During the last year, have any of the following problems happened to you: separation from your spouse?’ – one respondent asked if this included separation as a result of hospitalisation, and another (who was married) asked what a ‘spouse’ was; and
- iv) q42f: ‘...some other problem or change in your life?’ - respondents asked what sort of problems this referred to.

Thus, similarly to the GWBS, the MHIQ uses several different types of response category i.e. section A is in the form of a 5 point anchored visual analogue scale (i.e. anchored by ‘strongly

agree' and 'strongly disagree') and section B is in the form of a Likert scale varying between 3 and 5 response sets in length. The wording and polarity of the anchored visual analogue scales is constant with each item, but the Likert scale wording varies with the subject of the question. Thus completing the Likert scale items may have been harder work for respondents (and interviewers).

Table 7.5, below, shows the mean scores and standard deviations for each of the function indices of the MHIQ, by sample.

Table 7.5: Responses (mean scores) to the McMaster Health Index Questionnaire

Sample	Hackney		Braintree Age 67<87 (sample 3) Mean (s.d.)	Kruskal- Wallis Test: <i>H</i>	Total Mean (s.d.)
	Age 87+ (sample 1) Mean (s.d.)	Age 67<87 (sample 2) Mean (s.d.)			
Function Indices					
Physical Function Index	0.33 (0.20)	0.64 (0.21)	0.71 (0.18)	<i>H</i> =68.792 df=2 p<0.001	0.56 (0.25)
Social Function Index	0.62 (0.074)	0.66 (0.066)	0.69 (0.056)	<i>H</i> =26.998 df=2 p<0.001	0.66 (0.071)
Emotional Function Index	0.63 (0.13)	0.67 (0.14)	0.70 (0.13)	<i>H</i> =9.538 df=2 p=0.008	0.67 (0.13)
No. of respondents	(59)	(79)	(49)		(187)

(n.b. a lower score indicates a lower level of functioning)

The table shows that there were statistically significant differences between the three samples on each of the function indices, with the very elderly Hackney sample (sample 1) scoring

lowest on all three, and particularly low on the Physical Function Index (Kruskal-Wallis Tests: Physical Function Index $H=68.792$, $df=2$, $p<0.001$; Social Function Index $H=26.998$, $df=2$, $p<0.001$; Emotional Function Index $H=9.538$, $df=2$, $p=0.008$). The Braintree sample (sample 3) scored the highest scores of the three samples on all three functioning indices.

Self-Evaluation of Life Function Scale (SELF):

Interviewers reported that the SELF was generally well received, although respondents had commented on its length (54 items). Its generally positive reception may have been because it was only instrument included in the study that was designed specifically for use with an older population however, as was noted earlier, it was the instrument respondents were most likely to request help with completing. It may well be that the content of the instrument is more appropriate for older people, but the structure or format still requires some improvement.

The responses categories to questions 1 through 15 are in the form of four fixed choice answers, questions 16 and 17 are medication and symptom checklists, and questions 18 through 54 are Likert scales. In this study, Likert scales appear to have been more acceptable to respondents than visual analogue scales, even when the latter were anchored.

Questions 1 through 15 presented little difficulty to respondents. However interviewers did report clarifying, or giving assistance with, the following questions:

- i) question 6: respondents commented that they could do some of the ‘chores’ exemplified but not others;
- ii) question 7: respondents noted the American spelling of ‘cheque’ (‘check’), and a number in Hackney commented that they did not write cheques as they did not have cheque accounts; and
- iii) question 11: where interviewers had to read this item out they found the use of the word ‘travel’ inappropriate (again perhaps too American) and suggested that the word ‘get’ would be better. However this was rarely commented on by the respondents themselves.

Question 16, the medication checklist, presented difficulties for respondents who were unclear what their various medications were for (particularly where a number of different medications were being taken); it was also unclear whether this list referred to prescribed medications only, as respondents could be taking over-the-counter preparations either in isolation or in addition to prescribed medicines. Once this problem was identified within this study, interviewers were advised to request that respondents list all medications, whatever their source. In questions 22 to 54, interviewers reported that respondents asked for clarification, or assistance with, the following items:

- iv) item 29: ‘Feeling blue’ – respondents asked for clarification of meaning;
- v) item 42: ‘Life has meaning to me’ – again respondents asked what was meant by this statement;
- vi) item 47: ‘I have enough work activities or chores to do during the day’ – respondents

commented that they did not go to work any more; and

- vii) item 48: 'I get a sense of satisfaction out of work activities or chores that I do' – again respondents commented that they no longer worked.

There was also an important typing error in the scale developers' original publication (Linn and Linn, 1984) that was unknowingly transferred to the questionnaire as used in the study. Several respondents noted that item 44 read 'This is the *deariest* [sic] time of my life', and were unclear whether this should read *dearest* or *dreariest*? Consequently the meaning of this item could have been changed entirely. The item should read: 'This is the dreariest time of my life'. As soon as this problem was identified, the interviewers were notified and asked to clarify this for respondents. It is not known, however, how the first respondents, who had not commented on the mistake and therefore raised interviewers' awareness of it, had interpreted the item.

In addition, where they were required to read out questions, interviewers reported having to remind respondents of the temporal context of questions 22 to 34, i.e. 'in the past month'. As with the ABS the temporal context is given only in the introduction to the questions and not given at each individual question. Questions 1 to 21, however, did have a temporal context at each question. Again, as with the ABS, it is not known how often this misunderstanding occurred for those who completed the scale unaided.

Table 7.6, below, shows the mean scores and standard deviations for each of the six factors on the SELF, by sample.

Table 7.6: Responses to the Self Evaluation of Life Function Scale

Sample	Hackney		Braintree	Kruskal-Wallis Test: <i>H</i>	Total Mean (s.d.)
	Age 87+ (sample 1) Mean (s.d.)	Age 67<87 (sample 2) Mean (s.d.)	Age 67<87 (sample 3) Mean (s.d.)		
Six Factor Scores					
Physical Disability	24.18 (5.67)	16.15 (2.87)	16.15 (3.35)	<i>H</i> =71.628 df=2 p<0.001	18.51 (5.42)
Symptoms of Ageing	29.81 (8.26)	27.35 (8.69)	24.08 (6.50)	<i>H</i> =16.108 df=2 p<0.001	27.24 (8.28)
Self-Esteem	12.64 (3.90)	13.40 (2.98)	12.52 (2.76)	<i>H</i> =2.314 df=2 p=0.314	12.92 (3.26)
Social Satisfaction	14.10 (2.80)	11.22 (2.47)	10.28 (1.88)	<i>H</i> =45.436 df=2 p<0.001	11.83 (2.87)
Depression	22.24 (5.56)	21.69 (4.34)	20.14 (3.58)	<i>H</i> =6.793 df=2 p=0.033	21.47 (4.63)
Personal Control	8.88 (1.89)	10.19 (1.76)	9.72 (1.89)	<i>H</i> =12.242 df=2 p=0.002	9.65 (1.90)
No. of respondents	(51-58)	(70-80)	(44-50)		(168-188)

(n.b. a higher score indicates a problem, or a lower level of functioning)

The table shows that there were statistically significant differences between the three samples on all of the factors except Self-Esteem (Kruskal-Wallis Test: $H=2.314$, $df=2$, $p=0.314$). The very elderly sample in Hackney (sample 1) achieved the highest Physical Disability (Kruskal-Wallis Test: $H=71.628$, $df=2$, $p<0.001$), Symptoms of Ageing (Kruskal-Wallis Test: $H=16.108$, $df=2$, $p<0.001$), Social Satisfaction (Kruskal-Wallis Test: $H=45.436$, $df=2$,

$p < 0.001$) and Depression factor scores (Kruskal-Wallis Test: $H=6.793$, $df=2$, $p=0.033$) indicating that they had greater problems with these areas, and the younger Braintree sample (sample 3) had the lowest scores (indicating that they had the least problems with these areas). However the table also shows that the very elderly sample in Hackney (sample 1) achieved the lowest score for the Personal Control factor, followed by the younger Braintree sample (sample 3), then the younger Hackney sample (sample 2) (Kruskal-Wallis Test: $H=12.242$, $df=2$, $p=0.002$), suggesting that the very elderly in Hackney had the highest level of functioning on Personal Control.

Linn and Linn (1984) reported means on the six factors for 115 U.S. respondents aged 60 or over, sampled from public housing, private homes and mobile homes: Physical Disability 16.2; Symptoms of Ageing 24.3; Self-Esteem 11.3; Social Satisfaction 12.1; Depression 20.7; and Personal Control 8.8.

The 95% confidence intervals of the difference between Browne et al's (as described earlier) means on the Symptoms of Ageing factor at t1 and t2 (Browne et al, 1994) compared with this present study were 10.4-14.6 and 8.5-12.7 respectively (SE of difference=1.05 and 1.08 respectively, $df=253$, $t=1.97$). Some differences between these two samples are to be expected as the present study included respondents with varying levels of health, in contrast to Browne et al's sample who were all 'healthy' (Browne et al, 1994).

Dartmouth Co-operative Chart for Quality of Life (DCCQoL):

The DCCQoL was perhaps the simplest of the questionnaires administered in the pairings, consisting of only one item. It also appeared to be the most visually pleasing: the line spacing and font size were the largest of all the questionnaires used and, perhaps because of its cartoon imagery, it was the questionnaire most likely to bring a smile to the faces of respondents (however some interviewers were concerned that some respondents may have found the chart's style patronising). Its content was also reportedly the least likely to be questioned. However, perhaps because of its simplicity, respondents tended to respond 'openly' rather than select one of the fixed choice answers and interviewers were frequently required to remind respondents of the choices printed on the sheet. Interviewers reported that some respondents had asked what the cartoon ladder was meant to be (they found it hard to take in visually) and what its purpose was (conceptually). One respondent asked if the cartoon figure was a man or a woman: the figure is unclothed and has no genitalia.

Table 7.7, below, shows the scores for respondents completing the DCCQoL, by sample.

Table 7.7: Responses to the Dartmouth Co-operative Chart for Quality of Life

Sample	Hackney		Braintree	Total
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
Very well: could hardly be better	16 (11)	17 (16)	22 (13)	18 (40)
Pretty good	37 (26)	47 (43)	53 (32)	46 (101)
Good and bad parts about equal	34 (22)	33 (30)	25 (15)	30 (67)
Pretty bad	11 (8)	2 (2)	- (-)	5 (10)
Very bad: could hardly be worse	4 (3)	1 (1)	- (-)	2 (4)
No. of respondents	(70)	(92)	(60)	(222)

(Kruskal-Wallis Test: $H=7.699$, $df=2$, $p=0.021$)

The table shows that the majority of respondents in all three samples selected positive response categories (85% of 87+ Hackney sample (sample 1), 97% of 67<87 Hackney sample (sample 2), and 100% of 67<87 Braintree sample (sample 3)). The cartoon figure featured in the scale has a smiley face: it may be possible that this positive expression deterred some respondents from selecting a more neutral or negative response. Also, although the naked figure is genderless, it appears more male than female, and given that by far the majority of respondents to the study were female, the option of giving respondents a more female cartoon figure might have increased the chart's acceptability still further. The influence of illustrations in increasing sensitivity, particularly in different cultural settings, is uncertain (McHorney et al, 1992).

However Table 7.7 also illustrates that the very elderly sample in Hackney (sample 1) were

the least positive about the quality of their lives, followed by the younger elderly in Hackney (sample 2) and then the younger elderly in Braintree (sample 3) (Kruskal-Wallis Test: $H=7.669$, $df=2$, $p=0.021$). It is notable that three of the very elderly respondents in Hackney chose the response type 'very bad: could hardly be worse'.

The Faces Scale for Quality of Life:

Interviewers reported that most respondents found The Faces Scale enjoyable to complete. No particular problems were reported with the quality of life item. Where interviewers gave assistance they were usually required to read out the question whilst respondents indicated the face representing their answer, either by naming the letter printed under the face or pointing to the face itself. Unfortunately, no systematic record of assistance was maintained for this scale. It was printed in the main schedule of the parent study and the item on quality of life followed a series of other items for the parent study that used The Faces Scale's response categories, thus interviewers (other than MF) tended to regard it as part of the parent study.

Table 7.8, below, shows the scores for respondents completing The Faces Scale for Quality of Life (and not the other items used with the scale for the parent study), by sample.

Table 7.8: Responses to The Faces Scale for Quality of Life

Sample	Hackney		Braintree	Total
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)	
A (delighted)	25 (41)	20 (52)	20 (36)	21 (129)
B	25 (41)	28 (72)	35 (64)	29 (177)
C	22 (36)	30 (78)	29 (53)	28 (167)
D (neutral)	14 (23)	11 (29)	10 (18)	12 (70)
E	5 (8)	5 (12)	4 (7)	5 (27)
F	6 (9)	3 (7)	2 (4)	3 (20)
G (terrible)	3 (4)	3 (8)	* (1)	2 (13)
No. of respondents	(162)	(258)	(183)	(603)

(*=<1%) (Kruskal-Wallis Test: $H=1.555$, $df=2$, $p=0.46$)

This table illustrates that, using this method, the three samples were broadly similar in their views of the quality of their lives with 72-84% of respondents selecting ‘delighted’ faces (A-C), 10-14% selecting the ‘neutral’ face (D), and 7-13% selecting ‘terrible’ faces (E-G). There were no statistically significant differences between the samples when tested across the seven-point scale (Kruskal-Wallis Test: $H=1.555$, $df=2$, $p=0.46$). However when the scale was collapsed to a trichotomy (‘delighted’ A-C, ‘neutral’ D and ‘terrible’ E-G) a significant difference was found between the three samples with very elderly Hackney sample (sample 1) generally scoring worst followed by the younger Hackney sample (sample 2) then the Braintree sample (sample 3): ‘delighted’ scores of 72%, 78% and 84% respectively; ‘neutral’ scores of 14%, 11% and 10% respectively; and ‘terrible’ scores of 14%, 11% and 6% respectively; Kruskal-Wallis Test: $H=6.149$, $df=2$, $p=0.046$.

Table 7.8 also demonstrates the skewness of the scale as described by Anderson (1988) and

Bowling and Browne (1991), with over three quarters of respondents selecting a ‘delighted’ face compared with just a tenth who selected a ‘terrible’ face.

Although the broadly similar responses of the three samples to this scale may appear to be in contrast to the results of other scales that indicated differences between the three samples, the conceptual content of the question may be important here. The single item question asked respondents to indicate how they *felt* about the quality of their lives, not how they would *assess, rate* or *describe* the quality of their lives. That is, it is an assessment of affect and not experience. Their responses to this scale may therefore have indicated a broadly similar level of *acceptance* of their self-rated quality of life.

Thus Chapter 7 has reported the percentage of respondents who required help with completing each of the ‘quality of life’ scales, together with respondents’ views of, and scores attained on each of the scales (Stage 1a). Administering the scales was not straightforward: members of all three samples experienced some degree of difficulty in completing each of them. Significant differences were found between the samples regarding their need for assistance, with the older respondents from Hackney being the most likely to ask for help and the younger respondents from Braintree being the least likely. In addition significant differences were found between the scales with regard to their ease. The more complex and lengthy scales appeared to require more help (e.g. GWBS, MHIQ and SELF). However, it was notable that the only scale developed specifically for use with older people seemed to be the most likely to require help to complete (i.e. SELF).

Thus none of the scales, as used here, could be described as ‘easy to administer’ to older people or ‘easy to complete’ by older people; very old people in particular (i.e. aged 85+). If they are to be used with older people, either as measures of ‘quality of life’ (which is not recommended by this thesis) or, more suitably, as measures of the concepts for which they were developed (e.g. health status or psychological well-being), then researchers need to be aware of the considerable amount of time that will be required to administer them and the knock-on effects of this in terms of the validity of responses (e.g. respondents may be more likely to give what they consider to be socially acceptable answers when responding verbally), the impact on respondents (e.g. the potential for emotional upset may be greater where assistance is required or where answers are verbalised), and the economic implications for the wider study (i.e. temporal and financial). In addition, on the basis of these findings this thesis does not recommend the use of these scales in postal surveys of older people.

In terms of content and layout, all of the scales were used as published, with the exception of the SELF scale where a small but important publishing error was detected and corrected early in the fieldwork. No specific adjustments for older people were made to the content or layout of the various scales as it was felt important to test them in the format recommended for use, or previously used, in studies of older people (as described in Chapter 3).

Table 7.9, below, summarises the problems identified with the scales across all three samples, by scale. An ‘X’ in the table represents the presence of a specified problem on a specified scale.

Table 7.9: Summary of problems identified with ‘quality of life’ scales as used in Stage 1a

Scales used in Stage 1a	NHP	ABS	GWBS	MHIQ	SELF	DCCQoL
Print size/font	X					
Line spacing		X		X		
No. items needing clarification	2	3	3	9	8	
Americanisms				X	X	
Irrelevant examples				X		
Loss of temporal context		X			X	
Repetitiveness		X	X			
Length			X	X	X	
Filter questions				X		
Visual Analogue Scales			X	X		
Typographic error					X	
Responses given ‘openly’						X
Visual confusion						X

Based on the data in the table, one could develop a crude indicator of the acceptability and ease of administration/completion for these scales e.g. totalling on the number of crosses (X) on the table for each scale and considering the ‘number of items needing clarification’. Using this ‘indicator’, the table suggests that the most acceptable and easily administered/completed scale, for these respondents, was the single item DCCQoL, followed by the NHP. However, using single item questions such as the DCCQoL may inform us of how respondents rate their quality of life, but tells us nothing about why they rate it in that way, or how it could be improved. The most difficult scales appeared to be the MHIQ and SELF, both of which a considerable percentage of respondents had requested help with.

It is worth recalling here that the table indicates merely the presence or absence of a problem, not the magnitude of that problem, nor the percentage of respondents (or interviewers) who

reported it. In addition, no formal assessment of the acceptability of these scales was conducted e.g. respondents were not systematically asked their views of the scales. The data in Table 7.9 is based on interviewer feedback (including MF) only, and this in itself was not a systematic process e.g. each scale was not considered in relation to each problem listed on the table, interviewers were simply encourage to describe any problems they had encountered when administering the scales, or any difficulties respondents had mentioned when completing them. This data may therefore reflect the acceptability of the scales to the interviewers in terms of administering them to a sample of older people living at home, rather than acceptability to respondents. If it does simply reflect the latter, then this data continues to be important as an interviewer's opinion of a scale is likely to influence how they present it, which in turn may influence the responses given.

Consideration was given to asking respondents themselves to assess the scales but this was felt to be too onerous a task given that respondents were completing the scales following a relatively lengthy interview schedule for the parent study. Had the scales been completed on a separate occasion to the parent study interview then this might have been possible. Similarly the presentation of scale responses might have generated discussion at a later focus group of respondents in relation to the various merits of each scale in relation to measuring quality of life among older people living at home.

However, the table 7.9 does provide a useful summary of the main problems identified with the scales (by whichever agent). For the purposes of discussion, these problems can be grouped as follows: 1) print size/font and line spacing; 2) clarification of item meaning due to

ambiguity of language, Americanisms and the irrelevance of examples to older people; 3) loss of the temporal context of questions; 4) repetitiveness of scales; 5) length of scales; 6) difficulty following filter questions and interpreting visual analogue scales; 7) a typing error transferred from an original publication; 8) responses being given 'openly' rather than selecting from a fixed choice; and 9) visual confusion.

The print size, font and line spacing varied between the scales, but this was usually the responsibility of the researcher, and not the scales' developers, in reproducing the scales. In Chapter 2 the greater potential for visual difficulties among older respondents was noted, and this was reaffirmed by the difficulties experienced by some respondents in this study. Future studies using these scales with older people should consider enlarging the print size, using a consistent (between scales) font, testing the suitability of various fonts for those with visual difficulties and testing the suitability of the line spacing both for reading the questions and selecting and recording answers. The difficulties reported here may, in some cases, have reflected hidden illiteracy (which was not asked about or tested for).

The need for the clarification of item meaning among respondents could only be addressed in this study because of the presence of the interviewers. Interviewers reported ambiguity of language, difficulty in understanding Americanisms, and problems with the irrelevance of examples to older people. Thus, in the absence of adjusting their content, these scales (as used here) can not be recommended for postal use with older people.

The loss of the temporal context of some questions (i.e. where the temporal context was not

repeated at each question but presented as a heading before a series of questions) was only detected where interviewers assisted respondents with the scales and noted that their answers may not be appropriate. In these circumstances, the interviewers could remind respondents of the temporal context (e.g. “And was that ‘in the last week?’”) and respondents could amend their answers accordingly. Thus again, unless the wording and layout of questions is altered to include the temporal context at each question, then such scales can not be recommended for postal use, nor even for unassisted self-completion within an interview setting. Where respondents were not assisted, it is unknown what they considered the temporal context of questions to be.

Where questions did repeat information such as the temporal context of the question, respondents commented that instruments were repetitive which may have lead to boredom. Repetition of information also increases the visual length of questionnaires, some of which were very lengthy already and were a cause for concern in relation to respondent fatigue. In addition, the location of the scales at the end of the interview for the parent study was (although relatively common in such studies) a source of concern: some interviewers (including MF) felt that some respondents found completing the scales at this stage tiring. The effect of boredom or fatigue on responses to such instruments has not been systematically studied, but the potential effect of such feelings on respondents is obvious.

Chapter 2 noted the difficulties older respondents can have in completing instruments that are complex. The finding that some respondents experienced difficulty following the filter questions contained in one of the instruments used at Stage 1a reflects this. Similarly, some

respondents had difficulty interpreting the visual analogue scales contained in some instruments. Once again it was possible to handle both these difficulties because of the presence of trained interviewers, thus (once again) the use of these instruments in a postal setting can not be recommended.

The identification of a typing error transferred from an original publication was a concern, given the impact of that error on the meaning of the question. If the error would have led to all respondents interpreting the question incorrectly, then some adjustment to responses given prior to the detection of the problem might have been justified. However the error was such that respondents could either have interpreted the question correctly or incorrectly. Strict attention to the accuracy of the content of measures is vital when authors check proofs of their manuscripts for publication, on the other hand the researcher (MF) did not detect the error (nor, apparently, did any authors who recommended, used or reviewed the instrument) thus it was initially reproduced; a lay respondent identified it.

The need to remind respondents of the fixed choice response categories to questions they have answered 'openly', has been a relatively common occurrence in the experience of the researcher (MF): some times respondents appear to 'think out loud' before selecting a category, others require prompting to select a category. This was an issue that was noted in Chapter 2 as particularly problematic among older people. Tactfully skilled interviewers are required to manage this.

Finally, the visual confusion reported in relation to the simplest scale (the 'ladder' on the

DCCQoL) was unexpected. It would be interesting to test this scale using the question wording only, and not with the cartoon ladder, or even the figure.

Despite the ability of the trained interviewers to manage many of the problems encountered with the scales used at Stage 1a, questions must remain as to the impact of the interviewers' interventions (as described in Chapter 2). Some of their interventions would have been invited by the respondents (e.g. requests for the interviewer to read out a scale or clarify a meaning), but some may have been interviewer-instigated (e.g. detecting a loss of temporal context or reminding respondents of fixed choice response categories). Both of these types of intervention could impact on the responses given, but the latter type might also have an emotional impact on respondents (e.g. respondents may feel 'upset' at being corrected, however skilfully it was done).

One could also question whether scale response rates and assistance rates were respondent or interviewer driven. Because this was an interview-based study as opposed to a postal one, the way a scale was presented to individual respondents may have had an impact on the way it was subsequently perceived by respondents, both in terms of its credibility and its ease. Some interviewers felt less at ease with some of the scales than others and made this clear to the researcher (MF). Equally some of the scales were more 'popular' with the interviewers than others. Their preferences were usually in relation to the shorter length scales and those with simpler language and less Americanisms (e.g. the short, simple, UK developed DCCQoL was by far the most popular among the interviewers). The demands on them as interviewers were less for these scales. Formal testing for impact of potential preferences

might have been possible with a larger sample size (i.e. comparing scale and item response rates for each interviewer against the researcher's). However the experiences of the interviewers in relation to these scales, as described during debriefing sessions, were similar to those of the researcher (MF) who also conducted interviews and administered the scales.

In addition, there appeared to be a general lack of content (face) validity for the scales used, although this was not formally tested. Only the DCCP and Faces Scales contained the words 'quality of life' within their titles or within the text of the questions. Most of the scales' titles made some reference to 'health'.

None of the problems identified with the scales and reported here could have been predicted based on the information contained in the literature from which they were identified i.e. none authors cited in Chapter 3 noted the difficulties reported here. This may reflect a lack of occurrence of these problems for these authors, a lack of awareness of these problems, or a denial of these problems. However, some of the problems could have been predicted on examination of the scales themselves in relation to the difficulties older people experience with the survey method (as outlined in Chapter 2). Of particular concern is the published recommendation of the use of some of these scales (without the suggestion of amending them) with older respondents, in reviews of measures of quality of life. Such reviews are commonly used among health services researchers in their selection of appropriate instruments and are generally held to be authoritative and well researched. It is unlikely, however, that the authors of such reviews have themselves used all of the scales they recommend; out of necessity they rely on other published studies that have done so. Greater

openness (publication) on the failings of instruments with different sample types and different modes of administration is therefore required, with particular emphasis on the identification of specific problem questions. A good example of this is Mallinson's paper on the use of the SF-36 with older people in a postal setting (Mallinson, 1998).

The overall impression of the exercise reported here (Stage Ia of the quality of life study) is that the scales used, or recommended, for the measurement of quality of life among older people in the literature up to 1990, proved to be problematic among this group in terms of their content (wording) and structure. This is in addition to their conceptual problems in relation to quality of life, as described in Chapter 3. Thus this thesis does not recommend the use of these scales as measures of quality of life among older people living at home. This further enhances the case for the lay definition and measurement of quality of life as presented in Chapter 4 and tested in Stage Ib and Stage II with older people living at home (the results of which are reported in the Chapter 8 and 9 which follow).

Chapter 8: Results III: The Quality of Life Questions

In this chapter I shall report the results of the Quality of Life Questions completed by a sub-sample of respondents at Stage 1b.

Sub samples of one in four respondents from each of the three samples (n=214 in total: 74 respondents from the older Hackney sample (sample 1); and 70 from each of the two younger samples (samples 2 and 3)) were asked a brief set of unprompted open ended questions about the quality of their lives with the intention of eliciting their views about the quality of life as a whole, what gave their lives quality, what took the quality away, what could make the quality of their lives better, and what could make it worse. As described earlier (Chapter 5), responses were categorised as positive or negative or open coded (depending on the question) on the basis of the explicit content of their utterances e.g. very positive (e.g. 'very good'), positive (e.g. 'quite good'), neutral (e.g. 'well, it's OK' or 'I mustn't grumble'), negative (e.g. 'not very good'), or very negative (e.g. 'terrible') response.

Respondents were first asked how they would describe the quality of their lives as a whole. If the responses for the three sub-samples are taken as a whole, 42% (n=88) described the quality of their lives very positively, 21% (n=43) described it positively, 23% (n=47) gave a neutral description, 3% (n=7) described it negatively, and 11% (n=23) described it very negatively. However, treating older people in a homogenous way like this masks differences not only between age groups (as discussed earlier in Chapter 2), but also between area of residence. Table 8.1, below, shows their responses by age and area.

Table 8.1: How would you describe the quality of your life?

Sample	Hackney		Braintree
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)
Very positive	35 (25)	40 (26)	53 (37)
Positive	18 (13)	27 (18)	17 (12)
Neutral	17 (12)	27 (18)	24 (17)
Negative	7 (5)	- (-)	3 (2)
Very negative	23 (17)	6 (4)	3 (2)
No. of respondents	(72)	(66)	(70)

(Kruskal-Wallis Test: $H=7.094$, $df=2$, $p=0.029$)

The table shows that although the majority of respondents across the three samples described the quality of their lives in positive terms, there were significant differences between the samples (Kruskal-Wallis Test: $H=7.094$, $df=2$, $p=0.029$). Comparison of the percentage of respondents who described the quality of their lives very negatively in the very elderly sample (sample 1) to the percentages in the two younger samples (samples 2 and 3), shows differences by age group. For example, 23% ($n=17$) of the very elderly (sample 1), compared with 6% ($n=4$) and 3% ($n=2$) of the two younger samples (samples 2 and 3), described the quality of their lives very negatively (Mann-Whitney U Test of sample 1 against samples 2+3 (combined): $U=3761.500$, $p=0.012$). Similarly, comparison of the percentages of respondents who described the quality of their lives very positively in the two Hackney samples (samples 1 and 2) to the percentage in the Braintree sample (sample 3) shows differences by area. For example, 53% ($n=37$) of the Braintree sample (sample 3) compared with 35% ($n=25$) and 40% ($n=26$) of the two Hackney samples (samples 1 and 2), described the quality of their lives very positively (Mann-Whitney U Test of samples 1+2 (combined) against sample 3: $U=4026.500$, $p=0.040$) (Table 8.1). Analysis by actual age was not possible because of the

small sample size; similarly, analysis by sex was not possible because of the small number of men (as would be expected in a sample of older people).

Six per cent (n=4) of the very elderly sample in Hackney (sample 1) said that the quality of their lives had been good previously, but with increasing age the quality had deteriorated (coded above with the 'negative' group). Three per cent (n=2) of the very elderly sample (sample 1) and 6% (n=4) of the younger elderly sample in Hackney (sample 2) either did not understand the term 'quality of life' or were unable to answer the question (two of the respondents in the latter sample had said it varied too much for them to describe it). No one in the Braintree sample (sample 3) had any difficulty with the question.

Respondents were then asked why they had described the quality of their lives in that way. Tables 8.2 and 8.3, below, summarise their responses. Percentages in these and the following tables do not equal 100% as respondents were free to give as many different answers as they wished to each question. And for ease of presentation respondents were divided into those giving a generally positive description ('very positives' plus 'positives') and those giving a neutral or generally negative description ('very negatives', 'negatives' plus 'neutrals') of the quality of their lives.

Table 8.2: Why do you say that? (positives)

Sample	Hackney		Braintree
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)
Compared to others	46 (17)	25 (11)	29 (14)
Social contacts	53 (20)	41 (18)	51 (25)
Health/mobility/ ability	47 (18)	55 (24)	55 (27)
Positive outlook	32 (12)	20 (9)	16 (8)
Material circumstances	16 (6)	23 (10)	80 (39)
Activities	16 (6)	5 (2)	14 (7)
No. of respondents	(38)	(44)	(49)

The table shows that of those giving a generally positive description, nearly half of the very elderly (sample 1: 46%, n=17) and a quarter or more of the younger elderly (sample 2: 25%, n=11; sample 3: 29%, n=14) compared their lives to the lives of others in some way. For example:

87+ Hackney (sample 1)

0204: *'When you hear of some people what they go through - I've been lucky really.'*

0149: *'I expect some people are worse off than me - and they're younger. The way some of them grumble!'*

67<87 Hackney (sample 2)

4004: *'Well when you look at other people I'm not that bad really. At least I can still use my hands...better than others with arthritis'*

4548: *'When I look around me at so many people - the best way to find out how good your life is is to take a trip to the local hospital!'*

67<87 Braintree (sample 3)

3296: *'I wouldn't say I've always had just what I want - on the other hand I've got a lot to be thankful for. I'd rather be me than a lot of other people.'*

3026: *'Well when I look at others around me - I can at least get out. I've no worries really.'*

About half of each sample referred to their social contacts (usually family, and children in particular) (53% (n=20), 41% (n=18) and 51% (n=25) respectively) and their health (47% (n=18), 55% (n=24) and 55% (n=27) respectively). Others referred to other aspects of their lives. For example, respondents with a positive outlook had spoken of being contented or satisfied, their personality type or mood, and of taking life as it comes:

67<87 Hackney (sample 2)

4461: *'I think, over my lifetime, I've done most of the things that I've wanted to do. I've enjoyed what I've done and I wouldn't want to change anything I've done. I don't want to be a millionaire!'*

4727: *'...we've got a nice little life - we're a happy-go-lucky couple. It's no good moaning!'*

67<87 Braintree (sample 3)

3118: *'Well nothing really exciting - just an ordinary life.'*

3152: *'I've got nothing to make me unhappy.'*

3186: *'There's nothing what you call exciting about it - it's not what I call dull. I can come and go as I wish. I don't always want to be out.'*

Perhaps the most striking difference between these three samples was in their material circumstances. Those living in Braintree (sample 3) appeared far more contented with their material circumstances than those in Hackney (samples 1 and 2) ($\chi^2=45.86$, $df=2$, $p<0.0001$). The 1990/91 follow up data from the parent study had indicated higher percentages of home ownership and higher levels of income in Braintree than in Hackney: 56% of respondents in Braintree (n=111) (sample 3) were owner-occupiers compared with 15% of the younger (n=47) and older (n=37) Hackney samples (samples 1 and 2) respectively ($\chi^2=131.107$, $df=2$, $p<0.001$); and 34% (n=25) of respondents living alone in Braintree (sample 3) had a weekly income of £70 or more compared with 18% (n=30) and 13% (n=17) of the younger and older Hackney samples (samples 1 and 2) respectively ($\chi^2=13.482$, $df=2$, $p=0.001$). When respondents to the quality of life study spoke of their material circumstances, they were usually referring to their financial situation, the fact that they had a good home, or that they had everything they wanted. For example:

67<87 Hackney (sample 2)

4503: *'We're not going to be any more prosperous than we are now. We're better off than some people and we make the best of it that we can...you can't be on top all of the time!'*

4118: *'...things are OK. We've got more money than we've ever had. Financially it's good.'*

67<87 Braintree (sample 3)

3166: *'We've got no real money problems. If we wanted anything we could afford it. We don't want any unnecessary things.'*

3175: *'...and if things remain reasonably as they are we have a reasonable standard*

of living, but the problem is that there are many things that can affect us that are beyond our control. It's a "sod-you-Jack" society.'

Others described the activities they enjoyed such as gardening, caring for their home, trips out, and reading.

Table 8.3, below, shows the responses of those who gave a generally negative or neutral description of the quality of their lives.

Table 8.3: Why do you say that? (neutral/negatives)

Sample	Hackney		Braintree
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)
Helplessness/disability /ill health	41 (14)	32 (7)	24 (5)
Unhappy/miserable	18 (6)	14 (3)	24 (5)
Old age/desire to be young	15 (5)	9 (2)	10 (2)
Reduced social contacts	15 (5)	9 (2)	10 (2)
Material circumstances	- (-)	36 (8)	24 (5)
No. of respondents	(34)	(22)	(21)

The table shows that the very elderly in Hackney (sample 1: 41%, n=14) seemed more concerned with their state of health and reduced functional ability than the younger two samples (sample 2: 32%, n=7 and sample 3: 24%, n=5). This was reflected in the 1990/91 follow up data from the parent study in which 54% (n=135) of the very elderly in Hackney

(sample 1) selected the categories 'severe difficulty/only with someone helping/unable to do at all' when asked about their ability to get around out of doors, compared with 15% (n=50) and 11% (n=21) of the two younger samples (samples 2 and 3) respectively ($\chi^2=186.394$, $df=4$, $p<0.001$). Those in Braintree (sample 3) were more likely than the other two samples (samples 1 and 2) to refer to unhappiness or feeling miserable e.g.

3174: *'What quality have I got? Life to me is living. I'm only existing. I'm only sitting here waiting to die if the truth be told.'*

Perhaps understandably, the very elderly (sample 1) were the most likely to mention their old age and their desire to be young again, as well as to mention reduced social contacts. The latter finding is supported by the 1990/91 follow up data from the parent study: 66% (n=164) of the very elderly lived alone compared with 52% (n=172) and 40% (n=80) of the younger samples (samples 2 and 3) respectively: $\chi^2=29.207$, $df=2$, $p<0.001$. Where respondents spoke of their reduced social contacts, these were usually due to the death of friends or family members. For example:

87+ Hackney (sample 1)

0227: *'Now he's [husband] gone it's not so good. Losing him was the worst thing in my life. I suppose I was lucky to have him so long, but that doesn't make it any better when it comes - my life's gone with him really - the same thing could have happened to him.'*

67<87 Hackney (sample 2)

4488: *'When I'm not well I tend to be withdrawn - when I'm alright I tend to get on*

with things. I get some nights when I think about last year and losing my parents and my little dogs.'

67<87 Braintree (sample 3)

3318: *'I miss the [parental] family.'*

Interestingly, the very elderly sample (sample 1), in contrast to the younger two samples (samples 2 and 3), did not mention inadequate material circumstances here ($\chi^2=13.57$, $df=2$, $p=0.0011$). Two typical quotes from the younger samples (samples 2 and 3) were:

67<87 Hackney (sample 2)

4799: *'I would like a bit more money to be able to get the things I want - or live a bit more better.'*

67<87 Braintree (sample 3)

3095: *'If we had more money we could enjoy ourselves better - shut-up-shop and go. It's just average at the moment.'*

Respondents were then asked what things gave their lives quality (irrespective of how they had described the quality of their lives). Table 8.4, below, summarises their responses.

Table 8.4: What things give your life quality?

Sample	Hackney		Braintree
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)
Nothing	11 (8)	3 (2)	- (-)
Family (children)	32 (23)	23 (15)	49 (34)
Activities	28 (20)	23 (15)	49 (34)
Other social contacts	24 (17)	23 (15)	21 (15)
Health	10 (7)	35 (23)	24 (17)
Material circumstances	10 (7)	23 (15)	21 (15)
No. of respondents	(72)	(66)	(70)

The table shows that eight (11%) of the very elderly (sample 1) and two (3%) of the younger elderly sample living in Hackney (sample 2) said nothing gave their lives quality; no one in the Braintree sample (sample 3) said this. The most frequently mentioned things were family (especially children), activities (both within and outside of the home such as going out to clubs or out to the park, watching television or reading) and other social contacts (i.e. not specifically family, such as friends and neighbours, or simply enjoying other people's company).

The younger Braintree sample (sample 3) were the most likely to mention family ($\chi^2=10.37$, $df=2$, $p=0.0056$) and activities ($\chi^2=11.68$, $df=2$, $p=0.0029$), and both of the younger samples (samples 2 and 3) more frequently mentioned health and material circumstances (their financial situation, their home, or the fact that they had everything they wanted) as things that gave their lives quality than the older sample (sample 1) (health: $\chi^2=12.60$, $df=2$, $p=0.0018$; material circumstances: $\chi^2=4.94$, $df=2$, $p=0.0847$).

67<87 Hackney (sample 2)

4267: *'This is a nice flat. We are quite happy - enough to eat and drink - pleasant company - ...family.'*

4283: *'Seeing my daughter, grandchildren and son-in-law - going to visit them. My brother – what would I do without him? Lots of people envy me.'*

4338: *'The fact that we're happily married and once we close the door we're chez nous. We eat what we want. We go on holiday occasionally.'*

4548: *'I suppose our reasonable income. Were not affluent, but we don't have to say that we can't afford things. We can save up. We can buy our house and still go on holiday, because our son and daughter are helping.'*

67<87 Braintree (sample 3)

3081: *'I'm greatly blessed with my family. I can do what I like – my gardening, my writing, my children's interests.'*

3158: *'When I'm out with other people doing my job. I'm always best when I think I'm helping anyone out - or seeing my grandchildren. [I'm] happily married.'*

3154: *'We've got each other - family near at hand. We've got the dog. That gets me out and he's a lovely welcome when you come in. We get a lot of pleasure from him.'*

3166: *'To get up and go out and spend the day how we like. We don't have to worry. At our age we're lucky.'*

Respondents were then asked what things took the quality away from their lives. Their responses are summarised in Table 8.5, below.

Table 8.5: What things take the quality away from your life?

Sample	Hackney		Braintree
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)
Nothing	13 (9)	6 (4)	21 (15)
Reduced social contacts	31 (22)	30 (20)	31 (22)
Ill health	25 (18)	17 (11)	17 (12)
Helplessness/ immobility	19 (14)	6 (4)	14 (10)
Housebound	15 (11)	6 (4)	- (-)
Material circumstances	10 (7)	39 (26)	14 (10)
Miserable/ unhappy	10 (7)	11 (7)	14 (10)
No. of respondents	(72)	(66)	(70)

The table shows that 13% (n=9) of the very elderly (sample 1) and 6% (n=4) of the younger elderly samples living in Hackney (sample 2), and 21% (n=15) of the Braintree sample (sample 3) said that nothing took the quality away from their lives ($\chi^2=6.97$, $df=2$, $p=0.0306$). Others cited reduced social contacts, ill health, helplessness/immobility, being housebound, material circumstances and feelings of misery or unhappiness.

Reduced social contacts and feelings of loneliness, again often due to the death of friends or family, were mentioned by almost a third of each sample (31%, n=22; 30%, n=20; and 31%, n=22 respectively), for example:

87+ Hackney (sample 1)

0114: *'I miss someone to be able to talk to, to make decisions with. I don't like to be*

so lonely.' (widow)

67<87 Hackney (sample 2)

4461: *'Too much sadness. If you've had friends and relatives die...that probably gives you the bigger things that would upset your life.'*

4070: *'My friends are going one by one...that's hard to bear.'*

67<87 Braintree (sample 3)

3162: *'Losing someone you love.'*

3251: *'I only had my husband for seven and a half years.'*

Ill health, mentioned by a quarter of the very elderly sample (sample 1) (25%, n=18) and 17% of each of the two younger samples (sample 2: n=11 and sample 3: n=12) included pain or loss of sensory ability. Of most note are the higher percentages reporting helplessness/immobility ($\chi^2=5.36$, $df=2$, $p=0.0687$) and being housebound ($\chi^2=12.57$, $df=2$, $p=0.0019$) in the very elderly sample (sample 1) (as reflected in the 1990/91 follow up study data reported earlier), and the higher percentage of the younger elderly in Hackney (sample 2) reporting problems with their material circumstances ($\chi^2=21.11$, $df=2$, $p<0.0001$). For example:

87+ Hackney (sample 1)

0265: *'So many things - the freedom to be able to go out is worth such a lot. You meet people, you converse with them...in this life you are waiting for someone to turn up. I won't be sorry when it's all over.'*

67<87 Hackney (sample 2)

4038: *'The expenses of running the house and the car...the cigarettes...the things that*

give my life quality.'

4727: *'Shortage of money! If you're both healthy when you retire you need money to enjoy your health.'*

4787: *'Trying to make your money go. You keep thinking have you got enough money to get through?'*

Respondents were asked what would make the quality of their lives better. Table 8.6, below, summarises their responses.

Table 8.6: What would make the quality of your life better?

Sample	Hackney		Braintree
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)
Nothing	9 (7)	29 (19)	21 (15)
More mobile/able	38 (27)	11 (7)	16 (11)
Better health	17 (12)	9 (6)	21 (15)
Move house	13 (9)	30 (20)	17 (12)
Company	11 (8)	9 (6)	3 (2)
Material circumstances	10 (7)	33 (22)	34 (24)
No. of respondents	(72)	(66)	(70)

The table shows that 9% (n=7) of the very elderly sample, 29% (n=19) of the younger sample in Hackney (sample 2), and 21% (n=15) of the Braintree sample (sample 3) said that nothing could make the quality of their lives better or that they did not want to change any aspect of their lives.

Given the 1990/91 follow up data from the parent study reported earlier, the very elderly sample in Hackney (sample 1) were the most likely to want to be more mobile or able, usually specifying that they wanted to be able to go out more and not just to be more mobile within their home (38%, n=27, compared with 11%, n=7 and 16%, n=11 respectively). However, this may also have been compounded by structural constraints in Hackney: in the 1990/91 follow up study 48% (n=122) of the very elderly (sample 1) and younger elderly (sample 2) in Hackney (n=160) reported fears about intruders, going out or opening the door at home compared with 23% (n=45) of the Braintree sample (sample 3). Further, in response to an open question in the 1990/91 follow up study regarding things they disliked about their area, 18-21% of Hackney respondents (samples 1 and 2) mentioned 'fears or dangers'; by contrast, no one in Braintree said this (sample 3). Others specified a desire for better health, for example:

67<87 Hackney (sample 2)

4366: *'...being in good health. If you're in good health then you can do anything. If [husband's name] was in good health we could go out some more.'*

4548: *'If my health was a bit better it would make a big difference – I wouldn't miss so much.'*

67<87 Braintree (sample 3)

3162: *'Being blessed with good health for the remainder of my life.'*

3403: *'To have my [eye] operation.'*

The younger elderly in Hackney (sample 2) were the most likely to want to move house, and

this usually related to wanting to be nearer their families. For example: *'to have a flat near my daughter'* (4283) or *'If I was within a short distance of my children...it all comes back to that every time'* (4409). Those wanting more company spoke mainly about a need for 'real' friendships – friendships that were equally balanced and reciprocal. For example one very elderly lady in Hackney (sample 1) said:

'...if only I could be somewhere where there's other people to look at, or to talk to. So many hours of the day I'm on my own. I go and lean on the doorway if it's warm, just to see someone.' (0064)

Given the results so far, neither the higher percentage of very elderly respondents (sample 1) who wanted to be more mobile or able ($\chi^2=16.87$, $df=2$, $p=0.0002$), nor the higher percentage of younger respondents in Hackney (sample 2) who wanted to move or improve their material circumstances was surprising. What was not anticipated, however, was that over a third of respondents in Braintree (sample 3) (34%, $n=24$) also mentioned a desire to improve their material circumstances (samples 2 and 3 compared to sample 1: $\chi^2=14.42$, $df=2$, $p=0.0007$). For example: *'a bit more pension – that would be good'* (3070) or *'financial stability'* (3174). More often though, a reference to material circumstances by respondents from the Braintree sample was in the form of a humorous comment or an 'added bonus' or luxury, rather than a need for an increase in their regular income. For example: *'a windfall of money!'* (3095); *'win the Bingo – a really good win!'* (3154); *'plenty of money!'* (3156); *'money!'* (3199); or *'win the Pools!'* (3028).

Finally, respondents were then asked what would make the quality of their lives worse. Six

percent (n=4) of the very elderly (sample 1) and 3% (n=2) of the younger elderly in Hackney (sample 2) said that to lose anything would make the quality of their lives worse. No one from the Braintree sample (sample 3) said this. Table 8.7, below, shows the responses of these and the other respondents who were able to be more specific than this.

Table 8.7: What would make the quality of your life worse?

Sample	Hackney		Braintree
	Age 87+ (sample 1) % (n)	Age 67<87 (sample 2) % (n)	Age 67<87 (sample 3) % (n)
Losing anything	6 (4)	3 (2)	- (-)
Losing family	40 (27)	52 (34)	56 (39)
Immobility/ housebound	22 (15)	14 (9)	34 (24)
Ill health	21 (14)	23 (15)	21 (15)
Losing home/income	15 (10)	11 (7)	7 (5)
No. of respondents	(68)	(66)	(69)

The two younger samples (samples 2 and 3) were more likely to be concerned about losing their families (52%, n=34 and 56%, n=39 compared with 38%, n=27 of the very elderly) perhaps because this included the loss of spouses. More of the younger samples (samples 2 and 3), probably because of their relatively younger age, remained married (1990/91 follow up data from parent study: 9% (n=22) of the very elderly compared with 37% (n=124) and 52% (n=102) of the two younger samples respectively remained married). Those respondents who mentioned becoming immobile or housebound usually specified the loss of independence associated with this, and those referring to the deterioration in their material circumstances usually spoke of losing their home, their pension, or specific possessions. For

example:

87+ Hackney (sample 1)

0089: *'The loss of the use of my limbs altogether - if I had to sit in the chair and have people wait on me. I'd hate that. That's why I ask my son not to.'*

67<87 Hackney (sample 2)

4267: *'Not to be able to see them [family] any more or to be able to go out at all.'*

4283: *'To be left on my own – I don't think anybody would.'*

4356: *'My life would be finished if anything happened to him [husband] – we've been together so long.'*

67<87 Braintree (sample 3)

3081: *'Losing my children, or one of my grandchildren.'*

3152: *'If I hadn't got my husband - if I was on my own.'*

3175: *'What is going to happen to us when the other one dies?'*

Responses to these latter two questions illustrate that the majority of respondents considered their quality of life to be something that was flexible or open to change: although more could conceive of their quality of life deteriorating than improving. It also gave some insight into the priorities of respondents with regard to such change.

Thus, in summary of Chapter 8, what these analyses reveal is that although the majority of respondents described the quality of their lives in positive terms, there were differences by

age group and area. The very elderly were more likely to describe their quality of life in very negative terms and those living in Hackney were the least likely to describe the quality of their lives in very positive terms.

Social contacts, functioning (health, activities, mobility, ability) and outlook were recurring themes of responses from each of the samples. Age and functioning and social contact all interact and it is the loss of these that these older people indicate would reduce their quality of life. In addition, material circumstances seemed to be important. Those with secure and higher incomes, and better housing conditions described their quality of life in more positive terms, but this appears to interact with age: the very old were not as concerned about their material possessions.

The overwhelming majority of respondents (97-100% by sample) appeared to have an understanding of what the concept of quality of life meant to them, further strengthening the case for the lay definition and measurement of quality of life (as advocated in Chapter 4) among older people living at home.

Chapter 9: Results V: In-depth Interviews

In this chapter the results of the analysis of the 40 in-depth interviews (23 from Braintree and 17 from Hackney) conducted in Stage II will be described. Thus a lay definition of quality of life, at least in terms of the components considered pertinent to these samples of older people, will be outlined. In addition, possible factors influencing these lay definitions of quality of life will be discussed.

Following Charmaz's method (Charmaz, 1995), a series of categories emerged from the initial line-by-line open coding and focused coding (exploration of codes in greater depth) of the 40 in-depth interviews. These included a 'base data' category (containing demographic data such as area of residence and sex), a 'characteristics of interview' category (containing information on the interview process such as interruptions to the interview e.g. a telephone call), a 'quality of life definition' category (for those respondents who offered a concise definition of the concept), a 'set questions' category (indicating questions used in more than one interview e.g. 'can you think of someone who has a worse quality of life than you, and if so what is different about their life?'), and a series of 20 categories suggesting various components of quality of life generated by the responses given.

Within each of these 20 'quality of life' categories were many sub-, and sub-sub-categories. When using NUD*IST software such levels of coding are commonly referred to as 'parents', 'children' and 'grandchildren'; these descriptions will be usefully applied here. Thus the resulting 'quality of life' parent categories that emerged from the thematic analysis of the 40

in-depth interviews were: family, feelings, location, working and retirement, social contacts, the past, material circumstances, personality, activities, tasks, crime, health, independence, control, services, society, old age, and transport. The order in which the parent categories are listed here merely reflects the chronological order in which categories emerged from the data on coding.

Prevalence of emergent 'quality of life' categories

As described earlier, Smith (1995) considers it possible to include some indication of the prevalence of themes identified within a dataset, after the analysis is complete. Using NUD*IST software it was thus possible to identify the prevalence of the emergent 'quality of life' categories across all the interviews. NUD*IST output gives information on the number and percentage of 'retrieved interviews' (i.e. those interviews retrieved from the dataset containing a coded reference to a given category), together with percentage of the talk within these interviews that contained coded references to that category ('% of retrieved interviews'), and the percentage of talk within the entire dataset of interviews containing coded references to that category ('% of all interviews'). Table 9.1, below, presents this output for the dataset, with the most prevalent category first (based on percentages in column 4, '% of all interviews').

Table 9.1: Prevalence of emergent ‘quality of life’ parent categories

Emergent ‘quality of life’ parent categories	‘Retrieved interviews’ n (%)	% of retrieved interviews	% of all interviews
Activities	40 (100)	10.0	10.0
Material circumstances	40 (100)	7.5	7.5
Health	40 (100)	7.4	7.4
Family	39 (98)	6.1	5.9
Location	37 (92)	6.0	5.5
Social contacts	40 (100)	4.1	4.1
Society	32 (80)	4.2	3.4
Services	26 (65)	4.9	3.3
Feelings	39 (98)	2.8	2.8
Past	35 (88)	3.1	2.6
Control	30 (75)	3.1	2.5
Working and retirement	34 (85)	2.7	2.3
Old age	35 (88)	2.4	2.1
Transport	25 (62)	2.2	1.5
Crime	28 (70)	1.8	1.3
Tasks	27 (68)	1.5	1.0
Independence	20 (50)	1.4	0.7
Personality	16 (40)	1.7	0.7
Total	n/a	n/a	64.6

The table shows that ‘activities’ was the most prevalent topic (making up 10% of the content all interviews) followed by ‘material circumstances’ (7.5%) and ‘health’ (7.4%); these three categories, together with ‘social contacts’ (4.1%), were the only categories to be mentioned by every respondent (Table 9.1). ‘Tasks’, ‘independence’ and ‘personality’ were the least prevalent topics, each making up 1% or less of the content of all interviews. In addition, ‘personality’ was mentioned by less than half of the respondents (Table 9.1). Although these figures do not tell us exactly what priority this set of respondents placed on these categories, it may give us some indication of either their relative importance or at least the ease with

which the respondents could talk about them. It should be recalled that topics could have been raised by the interviewer as well as by the respondent.

Table 9.1 also shows that the emergent categories accounted for 64.6% of the content of all interviews. The remaining 35% was made up of introductions to the interview, closure and 'interruptions'. 'Interruptions' referred to anything that changed the flow or pace of the interview, or was extraneous to the most current topic of the interview. Interruptions included, for example, phone calls, knocks at the door, conducting a caring role (e.g. taking husband to the toilet), hearing aids beeping, departures to make cups of tea, people entering or leaving, visitors arriving early, and distractions such as pets entering the room. Some times these interruptions were pertinent reminders of the daily lives of these respondents (e.g. conducting a caring role, hearing aids beeping, and pets) and provided a useful launch into new areas of discussion, others provided breaks for both the interviewer and respondent (e.g. making cups of tea), but others had the potential to either hamper the flow of the interview or bring the interview to premature close (e.g. visitors arriving early).

Each of the emergent parent categories will be examined in some detail below, in order of prevalence. It should be recalled that names of respondents have been changed throughout to assure their anonymity.

Emergent “quality of life” categories (in order of prevalence)

1) Activities:

‘Activities’ referred to those activities respondents enjoyed, or could no longer enjoy, in their leisure time i.e. activities other than their tasks of daily living such as grocery shopping, cleaning and washing. ‘Activities’ was the most prevalent topic discussed and was referred to in every interview. Within this category respondents spoke about attending clubs, church attendance, trips out (e.g. to museums, shows, or visiting friends and family), watching television or listening to the radio, holidays, travelling, special shopping trips (e.g. to towns or shopping centres further away), trips to the library, gardening and other specific activities such as painting or dancing.

Thus, some activities were conducted within the home whereas others involved a trip out; some were regular, scheduled events whereas others were spontaneous or ad hoc events; and some were longer term events, such as holidays, whereas others were briefer events, such as attending a club or church. Whatever the type or form, they were clearly an important part of respondents’ lives which gave their lives quality, and were sorely missed by those who could no longer do them.

Respondents enjoyed going out in order to meet people, either in passing or for a pre-arranged social event, or, where respondents lived alone, even just to be amongst other people and have a change of scene. Many respondents referred to escaping their ‘four walls’. For some it was a huge effort, but one they felt was important for their own physical and mental well-

being. For example:

Hackney 0608 (15-43): Mrs Betty Hepworth

R *[...] I don't like to stay indoors because, after all, if you're getting old well you'll only make yourself a damn sight older won't you if you don't sort of make the effort.*

For others it was harder as their physical abilities had declined. For example:

Hackney 0283 (10-62): Mrs Thelma Jones

R *[...] it's very difficult for me. I'm 82 you know, so it's difficult for me and the steps are high on the buses and I'm afraid that I'll fall [...] I try to go out as much as possible but sometimes I think it's not worth the effort.*

And for a smaller group it was now impossible, and they were housebound. For example:

Braintree 3026 (1171-1220): Mr Hugh Argyle's wife

R2 *[...] I wish sometimes, I wish with all my heart there was a means for getting out and just having a look round the shops. Just going, even if I was pushed round by somebody. See Hugh [husband] couldn't push me now [...] if there was just a minibus who would collect really housebound people and take them to town. If they don't get out even, if they have a look. I mean it's been years since I've saw Christmas decorations [...]*

Clubs appeared to play an important role in many respondents' lives. Some were aimed specifically at older people (e.g. Over 60s' clubs, specialised exercise classes for older

people), whereas others, particularly in Braintree, were simply local community groups such as local horticultural society or local history society.

Clubs provided a place to meet friends and acquaintances, and make new ones; some clubs provided a meal, which some of those respondents who lived alone particularly enjoyed for the break from cooking and the sociability of eating with others; and clubs also provided an regular change of scene and a source of entertainment that respondents could look forward to e.g. games of bingo and raffles, dances, watching demonstrations or listening to speakers, or special events such as Christmas parties or celebrating a birthday. For example:

Hackney 0787 (354-372): Mrs Peggy Woods

R *[...] we have Bingo and there's so many people there and you have a laugh and that, you know, and as I say, you have a little gamble. It's only a few coppers and that, but I mean if you win you only win about 60 pence or something like that, but then when you win it's as if you've won a fortune! (laughter) You know? It's the atmosphere, and not only that, it's a couple of hours in the afternoon and again it gets you out of your flat. So when you come back you appreciate your home more cause you've been away from it.*

Hackney 0712 (209-212, 478-496): Mr Peter Shipley

R *[...] the association I go with are The British Limbless Association, you see? The British Limbless. It's a form of contact but when you're contacting them you're contacting someone in that era.[...] I go to functions now... to mostly military service [...] and I was invited last week to the mess in Windsor. And they're all my, to me that's my big family (laughter). I don't know one of*

them, but their outlooks all the same so it's really nice, it's a little holiday. [...] I've got something in common. Like on Thursday I go to... someone's dedicating a... Field Marshall is dedicating a coach to some disabled people, and I'm going to the dedication ceremony. You know what I mean?

Some respondents, however, were very reluctant to participate in clubs, particularly those aimed specifically at older people. Mr Sid Woolley, a Hackney respondent summed up the views of this group of respondents: when asked if there weren't any clubs for older people locally that he might enjoy he said *'I'll be perfectly frank with you darling, older people of my age are very old. I can't explain that to you'* (0083: 1335-1351).

A few respondents enjoyed active roles within their clubs, such as secretary or treasurer. Mrs Hetherington spoke in some detail of how she had come into the role of treasurer for her Over 60s Club when no-one else was able to fill a breach. I asked her why this role enhanced her quality of life:

Braintree (3145:1423-1447): Mrs Dorothy Hetherington

R Well helping people I think. Doing something that someone appreciates [...] I mean they said 'well we never could have managed if you hadn't have taken it over'. That gives you an awful lot of pleasure, that you've achieved something [...] And I mean everybody that comes to me, they've got to come to me and pay their subs to me, and I always have a word with them and ask them how they are and things like that. And I think they appreciate it, you know, because they're as lonely, probably, as I am.

Six respondents spoke about attending church: five of these were from Braintree and just one from Hackney. Some had started attending regularly on their retirement, whereas others had been life long church-goers. Three respondents spoke of going to the pub regularly to have a drink and socialise (rather than for a meal): two were male and one female, and all were from Hackney.

Some respondents spoke about enjoying particular trips out. Those in Hackney made good use of their free bus pass travelling across London to visit the parks or museums, or going to the West End to visit the department stores. A few residents from both areas enjoyed occasional trips to the seaside or countryside, and special trips to the theatre (Braintree respondents mentioned both local amateur and West End shows). And a few Braintree respondents also spoke of taking trips out for lunch to local country pubs. Some, however, found the rigours of travelling (either by car or public transport) prevented them from making such trips: this will be discussed further under the heading 'transport'.

A number of respondents spoke about holidays in relation to quality of life. Some still managed a holiday, such as Mrs Benson, but for others, such as Mrs Little, problems with their health prevented them from holidaying:

Hackney 0212 (1397-1492): Mrs Patsy Benson

R [...] it was like that this year, whether I went or not. [...] Although we booked our holiday [...] we had to wait for Bartholomew's to give me 'yes' or 'no'. [...] They said 'yes, you can go, but let it be a very quiet holiday', which it

was. I wasn't in the mood for anything else.

Hackney 0267 (1119-1155): Mrs Gertie Little

R [...] We used to have a nice time and different holidays and then I began gradually to lose the use of my legs, you know, like from my hip and that, that was about five years now, that was. That was the last holiday we had.

Some respondents who were either in a similar situation to Mrs Little or for financial reasons no longer holidayed, lamented the loss of their holiday and felt that holidaying had been a component of a good quality of life. For others, holidaying involved too much effort and upheaval, and would be more of a burden to them at this stage in their lives than a relief.

For those that managed a holiday, trips could involve travelling abroad (escaping the British winter was mentioned by a few) or within Britain, and staying with friends and family or in hotels. When asked why holidaying was important, most responded in the same way, referring to a change of scene or a change of routine:

Hackney 0787 (712-739): Mrs Peggy Woods

R [...] it's something to look forward to. Through the winter you think to yourself 'oh hurry up summer and come. Let's get away on a little holiday'. I think it's very important that you have holidays [...] it's getting out of London, going back to the seaside or even the country [...] you come back refreshed and appreciate your home in London [...] if you can escape for a week or two, you know, you don't feel so bad about it.

A couple of respondents in Braintree spoke about Saga holidays (catering specifically for those over 60 years) as being particularly good (e.g. 3403), and a couple of respondents in Hackney spoke of 'borough holidays' (holidays that were supplemented by the council) that they had enjoyed but that had stopped (e.g. 0356).

Respondents also talked about activities that centred on their homes. Ten respondents referred to gardening as an activity they enjoyed: two were from Hackney and eight from Braintree (this distribution reflects differences in their access to private gardens). A wide variety of home-based hobbies were enjoyed by many including sewing, knitting, playing cards or games, painting and drawing, woodwork, puzzle books, astrology, making wirelesses and even decorating.

Ten respondents referred to themselves as 'letter writers' (four from Hackney and six from Braintree). Most of these referred to enjoying writing and receiving letter from friends and family. In the latter case these were usually other older people such as siblings, who often lived some distance away, or grandchildren who were away at university. One respondent from each area described their role within the local older community as a resource with regard to official letter writing i.e. where another older person needed help with a business type letter such as a complaint or enquiry, they would turn to these respondents because of their experience in business during their working lives. This was a role they clearly enjoyed and which gave them a certain status within their communities (i.e. 0712 and 3026).

Most respondents referred to watching television as an activity they enjoyed: 17 of the

Hackney respondents and 15 of the Braintree respondents referred to this. A number of these respondents added that they didn't like to have the television on all the time and that they in fact got fed up with it at times, and were concerned about the violent and explicit nature of some programmes. For most, however, it was a welcome source of entertainment, knowledge and even companionship. Viewing preferences varied widely from news and documentaries, through sport and travel programmes, quizzes, dramas, sitcoms, soap operas and films. A few respondents also reported having, and making use of, a video recorder: particularly for taping films they recalled from their younger days. Typical positive quotes relating to television included:

Hackney 0643 (396-412): Mrs Lily Potts

R [...] I think it's all us old people that sit and look at it. Well it's something for us to do really. Have a bit of entertainment.

Braintree 3081 (672-697): Mrs Eileen Stewart

R Well I enjoy it because I like watching all these marvellous things they do under water and show you all the beautiful fish and the colours and what they do. I think they're terribly clever and show me countries that I'll never go to. But I enjoy watching other people in different countries. It's so interesting. So that is, for me, a marvellous thing.

Fewer respondents made similar comments about the radio, listening to music and story tapes. Respondents again referred to entertainment, education and company: the latter again being more common amongst those living alone. A typical quote came from Miss Young:

Braintree 3118 (1588-1604): Miss Betty Young

R *[...] it's company I think. I come in here when perhaps I've been out shopping. I come in that door and 'oh it's quiet'. It's strange. Whether it's a bit of nerve or what I don't know. I come in here, take me coat off, usually take me shopping through to the kitchen and before I switch the light on, it's the first thing I do is...[put the radio on].*

Nineteen respondents spoke about reading as an activity that gave them pleasure (11 from Hackney and seven from Braintree). Reading matter varied from books, through trade journals and magazines to newspapers. The library had an important role for some (for large print books in particular) and one respondent in Hackney referred to the fact that her local library was under threat and that this would be a great loss to her (0356: 30-37). Respondents in the Braintree villages had use of a mobile library that was welcomed. And for one respondent in Braintree who was housebound, the delivery of her daily paper was a lifeline, her link to the outside world:

Braintree 3026 (2508-2547): Mrs Ruby Argyle (wife of Mr Hugh Argyle)

R2 *[...] It's just the highlight of the day because it lets me know what's happening in the world and in the country and everything and [...] I can't not do the crossword. [...] we take the Daily Mail and I think it's a wonderful paper for people like me, in my position or like my husband, in as much as that they give you separate portions which you can extract [...] it intrigues me and I... I just, don't know, I just love it. It keeps my brain ticking over or starts it ticking over.*

Finally, under the heading of 'Activities', eleven respondents spoke about their roles as carers: five from Hackney and six from Braintree. For four of the Hackney respondents this was a role they had carried out in the past: three of the four had cared for their mothers and one for a sister; for all it had been a time of particular hardship. Only one Hackney respondent spoke about being a carer presently and the limitations and difficulties she faced because of this: Mrs Potts' husband had had a stroke shortly after her retirement (0643). Of the six Braintree respondents, one had been a carer in the past, and the remainder cared for neighbours (shopping, collecting pension, gardening; n=3), helped a handicapped child with exercises and a husband on dialysis. The caring roles of these Braintree respondents were less demanding than those of the carer in Hackney; in addition, with the exception of the respondent whose husband was on dialysis, they had taken on the role voluntarily and so derived some pleasure from helping and could withdraw from the activity if they so wished.

Thus some respondents lives seemed to very busy and they clearly enjoyed this: they liked to be doing 'something'. However, a couple of Braintree respondents described their lives as presently 'too busy' (3162: 656-685, 735-764; 3403: 554-560).

In summary, in relation to 'activities', respondents spoke of things they enjoyed, or could no longer enjoy, in their leisure time such as going to clubs, attending church, trips out (e.g. to museums, shows, or visiting friends and family), watching television or listening to the radio, reading, letter writing, holidays, travelling, special shopping trips (e.g. to towns or centres further away) or trips to the library, gardening and other specific activities such as painting or

dancing. Some activities were regular, scheduled events whereas others were more spontaneous or ad hoc. Some were longer-term activities, such as holidays, whereas others were briefer activities, such as attending a club, or church. They were clearly an important part of respondents lives which gave their lives quality, and were sorely missed by those who could no longer do them due to ill health or financial constraints.

2) Material circumstances:

Some respondents clearly felt that 'money' had a role to play in quality of life. They didn't necessarily want a lot of money, they just wanted sufficient money to make ends meet comfortably, and not have to worry about their ability to pay the bill if they had to turn up their heating. For example:

Braintree 3145 (1588-1604): Mrs Dorothy Hetherington

R Having sufficient helps. You know, so you haven't got to think to yourself 'well I've got me rent to pay this week, I can't do much shopping because I'm not going to have enough'. Um there's the poll tax, electric, um... all these things, when you've got to plan it, if you're not a good housekeeper you've got yourself in a right tizzy.

Hackney 0787 (214-226): Mrs Peggy Woods

R [...] I think money is a problem. Not so much in the summer, but in the winter when you think to yourself 'oh I'd better turn the heating off', you know, 'because I wonder what the bill will be like when it comes in? Will I be able to afford to pay it?' And so you sort of, um, tend to think oh you better not be

too warm, turn it off and have a little rest from, you know, your heating, but when it gets cold again, put it on again. And you're frightened to burn too much in case you haven't got the money to pay for it.

A series of respondents commented on the difficulties of living on a state pension, many described in detail their weekly budgeting. One of the commonly reported frustrations was being given a pension rise on the one hand only to have the majority of it taken away on the other in the form of increases in rent and 'poll tax'. For example:

Hackney 0267 (441-461): Mrs Gertie Little (R1) and Miss Evie Fox (R2)

R1 [...] I got the extra on the, extra money [...] So now I get £64. Well out of that I have to pay now, because the rent went up, so it's... £18.78. That went up from, it was £10. It's gone up £8. That was for £8. And then the poll tax thing that I've got has gone up so the money was gone. Do you know what I mean? The extra money is gone [...]

Living on a pension was reportedly harder for those living alone and indeed, as described earlier, some siblings had decided to live together as a way to combat this (as well as providing companionship). Both Mrs Hepworth in Hackney and Mrs Arnold in Braintree, who lived alone, were among those who described how fuel bills in particular were harder to pay for those living alone:

Hackney 0608 (324-331): Mrs Betty Hepworth

R [...] as the only saying goes 'two can live cheaply as one'. I mean when you're on your own you've still got to do the same amount of cooking. You've

still got to use the same amount of light. You've still got to use the same amount of heating. You've only got your one pension to do it in. Whereas with a partner, you're still using the same amount but you're getting, you've got that extra bit of money, haven't you, from your partner.

Braintree 3183 (121-130): Mrs Enid Arnold

R *[...] I thought when you got to the twilight of your years you should have life a little easier, not harder. But when you lose a partner, I mean when my husband was alive, you got two pensions. Well you had that one fire for two of you, so you got that little bit more money. I've got to have that same fire as I had when there was two pensions coming in, out of one pension. So there is all these things, you know it and you can cook cheaper for two than you can one because you are using the same amount of gas and electricity.*

Others were more accepting of their lot and showed a sense of pride in their ability to manage on a limited amount of money, and reluctance to seek extra help from either their families, or the State. Mr and Mrs White described how they spent every last penny of their savings, in order to pay their bills and help out their family, before turning to the council for a rent rebate and were told that they had been 'stupid' as they would have been eligible for a rebate 'a long, long time ago' (0512: 649-733).

Respondents would sometimes say that part of their desire for more money was in order that they could be in a better position to provide for their families, either in terms of helping them out financially at a time of crisis or in terms of family events, such as Christmas time.

Braintree 3158 (1100-1104): Mr George Baker

R *[...] if the kiddies say 'Dad I want £100' or something, really knowing they need it... you could give it.*

Braintree 3183 (148-152): Mrs Enid Arnold

R *Christmas time, you've got to buy little presents. You just can't do what you want to do. Oh it's hopeless. I enjoy giving as well as receiving and you can't give any more. All these things tend to make life not so good for you.*

Again with the family in mind, a small number of respondents were concerned that they should have enough money put by to pay for their funeral, in order that this expense should not land on their children. For example:

Hackney 0004 (145-147): Mrs Mary Chalker

R *[...] The only thing I've got to save up money and, God forbid if anything happens, so that my daughter and grandchildren, she hasn't got the problem of burying me.*

A large number of respondents wanted to be feel able to buy, or even save more easily for more expensive items, such as a new coat or even a more expensive cut of meat occasionally, without having to watch every penny. A typical quote came from Mrs Potts:

Braintree 3185 (3310-3116): Mrs Hilda Potts

R *[...] to feel you could go out and know you had got, you ain't got to look at every penny. Can I afford this this week? Can I afford that? That's all. I don't ask for much. It would be nice to think well I can save up for a coat or*

anything like that.

But there were a few respondents, those who had had the opportunity to join company pension schemes and who had not had to take early retirement (thus incurring penalties), who were in a stronger financial position and this gave them a feeling of security. For example, Mr Shaw describes the benefits of his company scheme below, whereas Mr and Mrs White lamented the lack of any scheme because of the type of work Mr White had done:

Braintree 3263 (575-585): Mr Terence Shaw

R I'm glad I joined the company pension scheme because, as I say, I don't go out much, I haven't got a car to run. I also don't smoke or drink, so I'm actually able to save on me pension. [...] I still want value for money, what I consider value for money. And if I want it, well I'll have it.

Hackney 0512 (376-379): Mrs Annie White's husband

R2 I wish we would be in a position where it was years ago where we could have had a pension [...] and be independent of any... of asking for help.

I That was not available?

R2 [...] we never had the jobs that did it. Not in our day [...] the majority of them in here now that are retired have all got other pensions.

For some respondents, however, such as Mr and Mrs Tibbs who lived in block of council flats in Hackney, extra money in itself was not sufficient to secure a good quality of life:

Hackney 0338 (303-307): Mr (and Mrs) Derek Tibbs

I Would money improve the quality of your life?

R2 *Not in this building.*

R1 *No, not in this realm, no.*

And others expressed similar sentiments, that sufficient money was a basic necessity of life, and it was good not to have to worry about making ends meet, but a much larger income was not the route to true 'quality'. For example, as Mr Shipley and Mrs Ingles outlined:

Hackney 0712 (128-140): Mr Peter Shipley

R *[...] I think the life is people, not your status, not your financial situation because money can't buy the things really that matter in life: friendship, people.*

Braintree 3296 (837-855): Mrs Amy Ingles

R *Well you've got to distinguish between people who have a lot of money, people who haven't got so much and then people who haven't got enough. I mean they can't have a good life. Because if you're struggling and worried all the time, I mean you can't have a good life. But once you've got enough just to make life go along fairly smoothly... [...] if I could afford to go to Florida for a holiday I'm quite sure it wouldn't alter the quality of my life a bit.*

In the same vein, several respondents commented that money couldn't buy good health (e.g. 0004: 139-139; 0485: 40-41). However, as Mrs Arnold pointed out, in the face of irreversibly bad health, a greater income could enhance the quality of her life:

Braintree 3183 (1686-1707): Mrs Enid Arnold

R *[...] health is the most important thing, good health. But I've got bad health.*

Let's face it I've got bad health, so I'm stuck with it. And the most important thing would be to have some extra money where I could have a few more comforts and not so much worry. That is the most important. Once you've got bad health and it's permanent, they can't cure arthritis and they can't cure my chest... so I'm stuck with that. But if I, you know, was in good health I would say 'well good health is the most important thing you can have', but I haven't got it now, so money to help me live a more comfortable life, that is the most important thing.

Those who were in receipt of financial assistance, such as income support and attendance allowance, found that this made a difference (e.g. 0582: 281-288); those who didn't described being penalised for their savings (e.g. 0338: 172-186). The provision of free bus passes for older people was a welcomed initiative for many.

Besides talking about income, some respondents also talked about possessions in relation to material circumstances and their effect on quality of life, for example, washing machines, telephones and televisions. Things like washing machines were described as making life easier, freeing up time in order that you could spend it on other things. They did not appear to be crucial, however, to these respondents' quality of life, except for a group respondents living alone who referred to their television frequently throughout their interviews as a source of entertainment and companionship (as discussed under 'Activities').

Most of the talk relating to material circumstances, however, was about income, or the lack of

it. Mrs Carter and Mrs Arnold summed up the feelings of most respondents living only on the state pension:

Hackney 0582 (211-224): Mrs Joan Carter

R [...] a little more we would appreciate, because it would just give us a little extra. I mean it shouldn't be that a cup of tea in England is more or less, our little dream. I mean you couldn't go and have a drink or play Bingo or something. All our, our... that we look forward to is a nice cup of tea and that really shouldn't be. Not when you've worked all your life.

Braintree 3183 (186-188): Mrs Enid Arnold

I Financially is it the worst time of your life?

R Yes, definitely yes. The worst time. Completely.

In summary, in relation to material circumstances, respondents spoke about the important role sufficient income had to play. Respondents were not seeking a huge increase in their income, just enough to take them beyond the strict budgets that many found themselves living under in order to meet their basic cost of living. They found it hard to accept that increases in their pensions were taken away in other ways such as rent increases, and those living alone found living on a single pension particularly hard to manage on.

3) Health:

For many respondents, health was one of the most important components of a good quality of

life. Interestingly, when saying this, many contrasted it with money, often referring to their belief that money couldn't buy health. For example:

Hackney 0283 (2189-2215): Mrs Thelma Jones

R *[...] if you've got money it helps a bit, but you can't buy your health. I don't care what anybody says. It does help. It definitely does help. But once you haven't got your health you haven't got anything.*

Braintree 3095 (1652-1711): Mr Harry Able

R *[...] as long as I've got me health, you don't worry about people so much, even if they are better off than me. Sometimes I'm better in my health and I see people who are better off than me but they haven't got their health [...] I'm better, as long as I can get out, than poor people who have got plenty of money what are crippled, you see?*

The main advantages of a reasonable state of health seemed to be that it enabled respondents to carry out activities they enjoyed and it gave them, or would give them, independence. For example:

Hackney 0787 (228-253): Mrs Peggy Woods

R *[...] I mean all I have is a little bit of arthritis in the... in the hands and, but apart from that I can walk, I can do things, do me own housework and, you know, I'm quite lucky like that.*

Braintree 3183 (1686-1707): Mrs Enid Arnold

R *I'm very pleased that I'm able to cope. That's what I like to do, to be able to cope without worrying other people. So if the physiotherapist can get me*

going again, so I can walk a bit further so I can feel a bit more independent, not to have to keep worrying other people, that would make me happy.

As with Mrs Woods above, some other respondents referred to luck in relation to their relatively good health. For example, on describing his and his wife's good health, Mr Stratton said: '*We're still the lucky ones, I say, as far as that's concerned*' (Braintree 3154: 814-848). Many respondents regarded ill health as an inevitable outcome of older age.

Hackney 0267 (277-331): Mrs Gertie Little and Miss Evie Fox

R2 *[...] You have your rough days [...] Some days you're better off.*

R1 *Aching.*

R2 *You're low, you know? Well being our age you expect to be.*

Hackney 0212 (134-217): Mrs Patsy Benson

R *[...] there comes a time when your health, you know, fails you and you thinks 'I'd like to do it but I can't'*

Several respondents, particularly those who were in poor health, commented that those who still had their health probably couldn't appreciate it or took it for granted. Mr Baker and Mrs Ingles' comments were typical of this group of respondents:

Braintree 3158 (1975-1995): Mr George Baker

R *[...] people who are healthy don't know, who've 'never had an illness' as they like to brag, haven't got the Dickens of those who are ill [...] They don't sort of understand what people can feel. I mean you've got to be ill sometimes to appreciate the fact that you're... that other people can.*

Braintree 3296 (964-1062): Mrs Amy Ingles

I So would you say that that operation, then, improved the quality of your life?

R Well yes, because it got rid of the... in so far as I probably haven't been painful, because I haven't thought any more about it because it doesn't hurt anymore [...] because it doesn't hurt I don't sort of think 'oh lovely my toe doesn't hurt me'. You don't do you. I think that's dreadful really, but I don't think many of us stop and really think. Only if you see somebody terribly disabled or something, you spare a moment and think 'oh I ought to be thankful'.

Some respondents, such as Mrs Stewart, appeared to take their poor health in their stride and cope with their difficulties by laughing at the situations they found themselves in (*'They laugh. They say "here she comes". They tease me. They tease me. Sometimes I'm going upstairs I get a push "push me!"'* (3081: 117-122)). Similarly, Mr Able had tried to see the positive side of slowing down: *'I'm getting older, I find that when I do anything that I take my time and I make a better job of it because I take my time'* (3095: 172-194). Poor health did, however, place severe restrictions on other respondents. For example:

Hackney 0488 (349-401): Mrs Elsa Clayden

R I can't have a bath and go out for the rest of the day. You know like how some people like to have a bath in the morning and they are fresh when they go out. I used to but I can't do it now because it takes a lot of strength out of me.

Hackney 0267 (277-331): Mrs Gertie Little and Miss Evie Fox

R1 [...] the thing is your life is restricted with it, see?

R2 *Constricted. We feel frustrated sometimes.*

R1 *You take so much for granted really don't you?*

There was a feeling among a few respondents that some of their peers gave up too easily when it came to problems with their health and that it was up to the individual how they wanted to respond to ill health. For example:

Braintree 3154 (2399-2508): Mr Frank Stratton (and wife)

R1 *[...] I think that depends a lot on the individual too a lot Morag, with these things. Some people give over too easily to anything. You know? But I don't. I don't. If I want to do anything then I'll do it.*

R2 *He'll do it. It'll hurt him, but he'll do it.*

Arthritis and rheumatism, stiffness of muscles and joints, were common complaints amongst respondents. One of the key problems with these diseases was their unpredictable nature: respondents reported experiencing varying levels of pain and stiffness over a course of a few days, making planning ahead difficult (e.g. 0212: 134-217). Mrs Parker opted to take her analgesia in advance of events in order not to miss out on them:

Braintree 3037 (769-777): Mrs Betsy Parker

R *[...] I couldn't stick in the house all the time, although I enjoy my home, I do enjoy going out and meeting people [...] when I go to a meeting I make a point of taking a tablet because I don't want to be in pain and have people sort of say 'oh, don't you feel very well?' I don't want sympathy. But of course a lot of people enjoy ill health!*

Respondents spoke most often about episodes of acute illness, restricted mobility, suffering chronic pain and experiencing falls, in relation to health. With regard to the latter three problems, sometimes these were the same group of respondents who were suffering from a chronic condition that reduced their mobility and caused them pain, thus increasing their risk of falling; and sometimes they were respondents who experienced considerable co-morbidity.

Episodes of acute illness that had led to periods of hospitalisation, were a source of worry and were a particular concern to those living alone: several respondents related stories of acute episodes at various times in their lives when they thought the end of their lives was imminent. Those with restricted mobility, as touched on already, spoke of reluctant reliance on others either to get out and about where this was still possible, or to help them with activities of daily living such as shopping and cleaning (this will be described in more detail under the heading 'Tasks'). Aches and pains were a drain on respondents, and again prevented them or restricted them in doing the activities they wanted to, as well as causing problems with sleep disturbance. And falls were experienced by a few making them feel vulnerable to further falls both within the home and outside, thus again restricting their activities. Other physical problems spoken about by a smaller group of respondents included problems with their vision, lack of energy, and coping with the loss of a limb.

Only one respondent spoke about problems with their mental health and the effect this had had on the quality of their life (i.e. 3158) and one further respondent spoke about the problems of forgetfulness (i.e. 3026).

In summary, in relation to health and quality of life, respondents spoke about how good health enabled them to carry out the activities they enjoyed and needed to conduct on a daily basis, together with leading an independent lifestyle. Those with good health considered themselves 'lucky' as most regarded poor health, or at least problems with health, as an inevitable outcome of old age.

Several respondents suggested that one had to experience poor health in order to truly appreciate good health. Respondents also suggested that once poor health was incurable, the goal posts changed in terms of what became important, with a financially 'comfortable life' becoming more of a priority. Those in poor health described the limitations this placed on them, but some considered it was up to the individual how much they would let this restrict their lives. The effects of acute episodes of illness, problems with mobility, pain and falls were described in some detail by a number of respondents.

4) Family:

Families were frequently cited, in general terms, as the most important things in respondents' lives, as the following examples illustrate:

Hackney 0608 (1307-1319): Mrs Betty Hepworth

R Well most again, as I say, my family is the most important thing to me...

Hackney 0787 (1261-1271): Mrs Peggy Woods

R Most important thing is to see that my family are all well and happy [...] my

family would really come first.

Braintree 3081 (1728-1734): Mrs Eileen Stewart

R *[...] being happy I should think, happy and contented and being with your children and your family, you know, it's everything really.*

Braintree 3145 (1786-1792): Mrs Dorothy Hetherington

R *Your family dear.*

Respondents' talk about families frequently centred on family social events. Family events seemed to be particularly enjoyed as they came as a 'package': they provided a chance to be with people respondents felt comfortable and at ease with, they provided entertainment, the 'resource' of the family often also provided the transport to and from events as well as a 'taken-for-granted' attitude or an 'insistence' by their relatives that the older person remain involved in such family gatherings. These gatherings made the respondents feel they belonged. They felt wanted and a part of something. They made a break from the usual routine of daily life. For example:

Hackney 0083 (1306-1326): Mr Sid Woolley

R *...it's wonderful of them, you know...and...what was it, a couple of weeks ago on a Saturday, West Ham is his team. They were playing Arsenal and he went to Arsenal to see them. And it was the eldest boy [Paul], they've got his birthday on the Saturday. So he said 'I'll pick you up when Paul's finished Grandad' he said 'and I'll take you home'. He said 'we've laid out the table for the boy's birthday' he said 'and I'll run you back at night'. Well it made an evening... so I came back here about ten o'clock.*

Braintree 3152 (378-382): Mrs Ivy Watson

R *My daughter's in Norfolk so we don't see her very often but they're coming on Sunday, her and the family, for the day. Oh that does help brighten your life. It gives you more to think about later on and I think it makes them seem more caring too.*

Braintree 3185 (60-62): Mrs Hilda Potts

R *Well whenever they go out they, they'll always take me, and they grumble if I don't go and they're always here and they're never any agro whatsoever.*

Families also played a more routine role in terms of maintaining regular contact, either in person or by telephone:

Hackney 0512 (2362): Mr Arthur White

R *I mean my daughter, they visit and they call and they come about once a week.*

Hackney 0608 (519-521): Mrs Betty Hepworth

I *How often do you see them?*

R *Oh every week and me son he phones me every day to see that I'm alright, you know? Oh yeah, he phones every day.*

Braintree 3263 (346-353): Mr Terence Shaw

R *Well he's [brother] generally here most Saturday afternoons as long as he's free. He's generally here half two to three Saturday afternoons, stay to tea and generally leaves 'round about half past eight at night.*

Families were also regular sources of help with tasks of daily living. For example:

Hackney 0485 (727-730): Mrs May Trentwell

R My sister-in-law came round, she said to me 'where you going?' I said 'I'm going to take me washing'. She said 'you're not'. She done it for me, she done it here for six weeks.

Braintree 3145 (1557-1561): Mrs Dorothy Hetherington

R Yeah, they change me curtains because I can't climb, you know, sort of thing. And the electric light bulbs and things like that. Those jobs that you can't... you can't do yourself.

In addition, families (including those who were not necessarily able to help on a regular basis) were also important sources of help in emergencies. Families could be relied upon.

Hackney 0787 (349-351): Mrs Peggy Woods

R Well I think if you was in any great trouble a family would rally round. They wouldn't let you, how can I say, a family, my family anyway, are very close.

Braintree 3152 (372-374): Mrs Ivy Watson

R I don't know what we'd do without them really. Well we've got a son. He's only 10 minutes away from here... and we call on him if we're in any sort of difficulty.

Mrs Thorpe, a Braintree respondent, described in some detail how her husband had fallen. He was a tall man and she, being very slight and suffering with arthritis, needed help to get him up again:-

Braintree 3279 (529-554): Mrs Isobel Thorpe (with Mr Thorpe)

R *...because Dad fell over some, a few weeks ago in the front room there [...]
And I couldn't pick him up of course. We tried everything. So he said 'right
I'll crawl through to the kitchen on my behind. I can get up on those steps'*

R2 *I couldn't.*

R *So he came through and sat on those steps. Sat there, said 'oh I wish I was
dead'. So I said 'so do I!'. But I didn't wish he was dead (laughter). I thought
'what can I do? If I can get to the gate, somebody would come up the road
who would give me a hand', you see? But I couldn't get past him and I
suddenly thought 'James is home this morning'. He's one of my grandsons,
James... so I rang James. I said 'James can you come over? Grandad's fallen
over and I can't pick him up'. He said 'yeah, I'll be there in five minutes'. So
he was here too pretty quick (laughter) and he came in the back door and he
said 'what the hell are you doing Grandad?' (laughter)*

Instead of being the recipients of help, some respondents were the sources of help for their families, and clearly enjoyed this role:

Hackney 0727 (650-660): Mr Jack Whitelaw

R *Well, our sister-in-law [...] we used to visit her every Monday. And when she
had her sort of sudden bouts of being quite OK, she'd come round in the car
and visit us. But mostly we used to go and visit her. That was Mondays for
three years. That's stopped now. But before she became... what she is, like*

bad legs. We still used to go and visit your brother, didn't we, you know because he was a bit down and a bit sort of lonely

Braintree 3251 (2101-2123): Mrs Maud Turner

R But like last Christmas I went with John because it's the first year he's on his own with the children.

I This is your nephew?

R [nods] I could have gone to my daughter's for Christmas. I said 'well I can't leave John alone with those two dear little children... like that'. So of course I went there. So I did say to him 'if I'm asked to go to Brenda's I shall have to go this year'. But I have to wait till I'm asked... so I shall have to wait and see. I may not get asked.

Perhaps the greatest amount of talk in the interviews relating to families, was in relation to respondents' now adult children. On the whole their children were sources of great pride both in terms of what they had achieved in building families of their own, building careers and lives, and yet still finding time for and caring for the respondents.

Braintree 3323 (2241-2247): Mrs Dot Wickford

R We've never had any trouble with them right from the start. And I think that's a good thing because you hear from people with children. They have trouble with them don't they? So we sailed through that quite peacefully. And, you know, they both married and... quite happy... their children. So really I don't think we've got anything to complain about at all.

Hackney 0787 (836-844): Mrs Peggy Woods

R *I've been quite contented with my life but as I say it's because of my family... I've had no trouble with them, daughters and grandchildren, they're all, what can I say? Got their feet firmly on the ground and that. They've been no trouble. They've not got into any trouble or... or anything like that. They all work and that. Like my daughters have brought their children up the same way I suppose as what I've brought them up, you know, not to get into any trouble or anything like that, to work.*

Similarly, respondents spoke of their grandchildren very much in terms of their achievements; perhaps because of the grandchildren's age group these were academic achievements in particular. For example:

Hackney 0004 (491-505): Mrs Mary Chalker

R *She's not married [granddaughter]. She won't get married because she's too interested in her career... studying now. She went for, she got an interview with, there was 12,000 people advertised for that interview what she's studying; a psychoanalyst. And they only took 12. And she was picked one of the 12 [...] she was thrilled to bits [...] brilliant she is.*

Braintree 3081 (167-169): Mrs Eileen Stewart

R *And he's [grandson] trying to, what is it, a BA, Bachelor of Arts and he's got on well and he hasn't been... only last year he started. He's already had something published.*

What is notable in all of these quotes so far is the absence of any negative comments about families. Some older people reportedly find families oppressive and controlling, have problems with regard to inheritance and, in extreme cases, experience physical and mental abuse by their families. This was not found in this present study. Respondents may in fact have experienced such problems but chose not to reveal them to a young (mid twenties at the time of the interviews), middle class researcher (MF). This may have been due to feelings of shame or embarrassment on their part, or a feeling of not wanting to embarrass the researcher (MF). For most of those respondents who were married, interviews were conducted with their spouses being present thus intra-marital problems were perhaps less likely to be revealed. In addition, such problems were not specifically asked about or probed for.

Interestingly, however, for a few respondents the point when their children left home was considered the best time of their lives. Given the very positive findings so far this may appear to be a contradiction, however, the fact that their children were ready to move on, be independent and start their own lives was perhaps one of the respondents' own achievements. In addition it provided greater freedom in terms of lifestyle, material circumstances and a liberalising release from responsibility.

Hackney 0727 (296-302): Mr Jack Whitelaw

R *[...] I feel the best time was when the children... after the children had left. Let's put it that way [...]...one of them got married and the other one went to Spain and we was alone and we had a house on our own, you know, a six-roomed house.*

Braintree 3183 (828-833): Mrs Enid Arnold

R *[...] then, he [husband] got a good job and that was the best time of our lives because the children were off our hands and by that time, you know, we come closer together because there was just the two of us and we could go and have holidays and this sort of thing, do things that we hadn't been able to do because we gave them both a good education.*

These preceding quotes also suggest that married life itself has a role to play in quality of life. There was a lot of talk in the interviews about the benefits of a good marriage and some on the problems of difficult marriages. It wasn't marriage per se that gave life quality, it was the type of marriage; one based on trust, respect and sharing the good and the bad things life threw at you as a couple and as a family.

Similarly, there was a lot of talk amongst those who were widowed about the impact of losing their spouse both at the time that it happened and how they felt today. A few respondents lost their spouses early on in their married lives and subsequently brought up their families single-handed, which had a huge impact on their quality of life. The following quote from Mrs Turner was typical, although she ends it on a more philosophical note than others, wondering what life would really have been like if her husband was still alive:

Braintree 3251 (1335-1353): Mrs Maud Turner

R *[...] I missed my husband and if anything went wrong, you hadn't got him to turn to [...] It would be nice to be, you may not understand this, but it would*

be nice to be what I call really loved. Your children do but it's a different sort. It's altogether different. I can't explain it. You've got to have it to understand it, you know? I mean it's the same with death, you cannot explain death to anybody. You've got to experience it to know it. And there are times, well not so much now, but there used to be when you used to, 'oh if only I'd got him to ask or talk to'. And of course as time goes on, there's times even now when you feel that would be nice and then sometimes you hear these two queer old people and they get on each other's nerves. And you think 'would it have been like that?'

Thus, families were almost always spoken of, in these interviews, in positive terms. The only occasion when families were spoken of in negative terms was in reference to worries about the family or specific family members. These worries could be for a variety of reasons such as ill health, loss of work, or problems within marriages. Whatever the circumstances, the resulting worries reportedly had a negative effect on quality of life, particularly where respondents felt powerless to help. For example:

Hackney 0485 (197-205): Mrs May Trentwell

R ...when he [divorced son] brings the children here. But I don't want to know too much about that side of... because what you don't know you can't worry about. I am inclined to be a worrier as regards my son's feelings towards his children and I mean I can't do it now. I just... as I said to him 'Terry, what you don't know, boy, you can't worry about'. So he don't say a lot but he dotes on his children and I feel, please God, I might not be able to see it but I

hope they appreciate what my son is doing. I mean because he dotes on them.

Braintree 3296 (39-52): Mrs Amy Ingles

R As long as things go right... I can cope with my troubles but I can't cope with their's [the children's].

I Right, so seeing them with problems or trouble, that's...

R Yes, that worries me. I don't panic when I have to deal with things but I am a dreadful worrier. I imagine all sorts of things are happening and if they say 'oh I shan't be able to do this or that, something's come up'. You have no idea what I can imagine has come up. Anything from bankruptcy to marriage! It's ridiculous (laughter) and they arrive in and 'oh no it was just that somebody was calling... and I couldn't leave'. You know (laughter).

A number of respondents, however, wanted to see more of their families than they did. Visits were limited either due to the busy nature of their families' lives (e.g. caring for young families, working, caring for other relatives), the ill health of the respondents or other family members, family feuds, or simply the geographical distance between them. For example:

Hackney 0512 (1120-1123): Mrs White (Mr Arthur White's wife)

R2 We used to see more of our relations... but they're all getting old. They can't travel. Like us, if we've got to go anywhere 'cause Mr White [husband] won't go anywhere, not unless someone takes him in a car.

Braintree 3152 (1009-1016): Mrs Ivy Watson

R ...I would like to see more of my daughter really but she is far away and of course she works part time in the week. And with teenage sons and a husband

they haven't got a lot of spare time.

In terms of what it consisted of, 'having a family' meant different things to different respondents. For example some spoke in terms of their own siblings (sisters, in particular, probably due to gender differences in survival) and siblings-in-law, some spoke in terms of their own offspring (and grandchildren), others referred to a wider pool of relations such as nephews and nieces (usually depending on their geographical location and the presence or absence of respondents' own children).

Several respondents described social events with their siblings where they lived locally, either meeting up at one another's houses or, in the case of Braintree respondents, meeting in town for a meal or at a café during a shopping trip (this was not reported in Hackney). One respondent in Hackney and one in Braintree described the advantages of sharing their home with their sibling. These were both female respondents living with their younger sisters:

Hackney 0283 (1346-1353): Mrs Thelma Jones

R I'm quite happy here. If I never had my sister I don't know what would happen. [...] See... she does everything for me.

Braintree 3183 (2318-2413): Mrs Enid Arnold

R [...] we have breakfast together [...] we'll sit down and have a chat and we do our chores and then by this time we're ready for our midmorning cup of drink and our biscuit, then I usually read the paper to her, anything interesting because her eyesight isn't too good [...] So I read titbits out of the paper. We read our fortune every day and get a laugh out of that, you know?

I've got romances in the air for me today! (laughter) [...] And then she'll take herself upstairs and does her morning bits and pieces she does up there. And I cook a midday meal and we have that together. But she does have her tea upstairs because she likes to watch different programmes to me [...] She comes down for the toilet and that sort of thing and she'll pop in and in the afternoons sometimes she'll sit in here with me and if we both want to watch the same thing we'll watch a film together. But we're not in each other's pockets 24 hours a day because it wouldn't work.[...] I let her have the two rooms upstairs. She's got a small bedroom and a little sitting room [...] so she can be independent if she wants. But she's never liked cooking you see. She's never got on with cooking, so I do the cooking and she cleans my brass for me cause I don't like cleaning that (laughs).

Others did speak of the negative impact of sharing their home with a sibling. Mr and Mrs White, from Hackney, spoke of the constraints of sharing their marital home with Mrs White's brother, after her mother died:

Hackney 0512 (2693-2701): Mrs White (Mr Arthur Whites' wife)

R2 *He was a good brother what I had... but it got that if I went anywhere and I was a bit late he would say to me... 'where have you been?' And it wasn't good, you know? [...] we would never row. We never had a bad word but there were times when I used to get right charged up.*

The difference between this case and those above is that Mr and Mr White were a married

couple trying to share their home with a third person, albeit a family member. For the two pairs of sisters described above, the sharing provided a degree of support and companionship for one another where the respondents and their siblings would otherwise have been living completely alone.

In summary, in relation to family, respondents spoke positively of family social events, the maintenance of regular contact, sources of help (regular or emergency), recipients of help from respondents, sources of pride (in relation to adult children and grandchildren) and marriage. In negative terms a few respondents described family worries, and the limited opportunities they had to see their families (due to distance or the busy nature of family members' lives), but no respondents mentioned oppression or abuse by family members. Families were frequently cited as the most important things in respondents' lives.

5) Location:

There were a large number of comments about the location the respondents lived in and these were equally divided between Hackney residents and the Braintree area residents. Interestingly, all of the comments from Hackney residents were negative about their area (except for two who were reportedly indifferent to it) and all of the comments from Braintree area residents were positive about their area.

Where respondents were life-long residents, some from each area mentioned that their respective areas had changed during their life times: in Hackney this was described in

negative terms as deterioration, in Braintree this was described in more positive terms as modernisation and an increase in facilities.

Typical quotes from Hackney residents included:

Hackney 0582 (915-923): Mrs Joan Carter

R I don't think there's anyone likes Hackney [...] No one. I've never heard anyone say that they like living in Hackney, no.

Hackney 0608 (833-867): Mrs Betty Hepworth

R [...] I don't let people know I live in Hackney. I always class myself as Shoreditch. I don't like Hackney [...] I think Hackney's horrible.

Hackney 0712 (1349-1414): Mr Peter Shipley

R [...] it [quality of life] can be eroded by the activities around you. In other words you can get up in the morning, feel buoyant and everything... and go down there [communal stairwell] and someone's done this and someone's done that and those windows in the stairs, you know what I mean? [...] We're not talking about isolated incidences; we're talking of the environment throughout the year. And throughout the years.

Deterioration of the area and the housing stock was a frequent theme of comments made about living in Hackney and the effects this had on quality of life. Respondents spoke, in some detail, of how when most of their current blocks of flats were built to replace the old terraces with outside toilets, a move to the new flats was initially seen as a positive move. However graffiti, vandalism of communal gardens and areas (i.e. stairwells, lifts etc), noise at

night time (both within the buildings and from outside), increased density of people, pavements damaged by cars parking on them, lack of council property maintenance, lack of/reduced hours of caretakers, squatters, an increase in traffic, the knock-on effects of 24 hour food bars, and a perceived increase in crime (mugging was particularly feared by some e.g. Mrs Trentwell 0485: 1048-1061) were described in some detail by Hackney residents.

Two Hackney respondents spoke very positively about the views they had from their flats (one thought she could see almost to Southend on a clear day) (0283: 1673-1691; 0338: 669-675) and two others spoke of the benefits of having a balcony (0356: 1691-1694; 0512: 1332-1344, 2946-2960). However, some particularly missed not having a private garden. For example:

Hackney 0212 (522-526): Mrs Patsy Benson

R [...] Just a little bit of ground, not a big garden. Just a little bit to do a bit of gardening, you know? Be out of the house. Be able to hang the washing out.

Hackney 0267 (612-614): Mrs Gertie Little

R That's when we lost our original place. We were very happy there. We had a lovely garden.

By contrast, typical quotes from Braintree area residents regarding their area included:

Braintree 3081 (1411-1419): Mrs Eileen Stewart

I Does the area you live in affect the quality of your life?

R I shouldn't like to live in a big town. I don't think so. I love the country. Yes, I love the country.

Braintree 3037 (17-24): Mrs Betsy Parker

R *[...] I find Braintree a pleasant little town, though over the last 30 years they have modernised it too much. It used to be a small market town and we used to have a little market. Well there's still a market, but they've got these supermarkets and all that, and all the little individual shops, a lot of them, have gone. But I find here I have a good bus service. If there's a problem with the buses sometimes, I can walk in.*

Respondents made a number of comments about areas other than those they lived in. Almost without exception, respondents from Hackney spoke favourably about locations other than their own (ranging from Woodford to Cornwall). However, respondents from Braintree, again almost without exception, spoke unfavourably about other locations (ranging from London to Lancashire). The exception in Hackney were Mr Whitelaw and his wife who graphically described their time living on a troubled council estate in Mile End (0727: 46-82); they regarded their move to Hackney into a housing association flat with a garden as a good move for them, although they would have preferred to have gone to Tower Hamlets where they already had friends.

There were three exceptions in Braintree: Mrs Prior, who lived in a small village outside Braintree and would have preferred the convenience of living in the town itself (3167: 1435-1453); Mrs Williamson, who now lived in the town of Braintree, missed the countryside where she had previously enjoyed walking in the hills (3162: 229-237); and Mrs Whitwell, who was fairly disabled and lived in one of a short run of farm-workers cottages up a country

lane, who found her isolation difficult having previously lived in London (3403: 1125-1136).

Several Braintree area residents spoke favourably about the pleasures of having a garden, which was much more common in Braintree than in Hackney e.g. Mrs Parker (3037: 15-15), Mrs Thorpe (3279: 855-913), and Mrs Wickford (3323: 648-682). However, although they liked having a garden, three other Braintree respondents found their gardens too big for them to manage as their functional ability declined, and they had become a source of worry i.e. Mrs Hetherington (3145: 633-661), Mrs Watson (3152: 939-967) and Mrs Prior (3167: 362-363; 822-850). Mrs Hetherington's quote was typical of these three:

Braintree 3145 (633-661): Mrs Dorothy Hetherington

R I can't do my garden. I've got a big garden out there and I just can't do that. I'm the same with the front. I just can't do it. I keep it tidy, reasonably tidy and that's it, you know? You don't want these things. I can't understand, I mean they're building bungalows and things with huge gardens. It doesn't make sense to me. Old people can't do it, you know? You just don't want a big garden. I mean I can't understand whoever does all this planning, to sit in an office and for an old age pensioner... to sit in an office and plan a bungalow with a huge garden.

Grouped in with comments on their environment and location were comments about their homes. Eight Braintree area respondents (3026: 1082-1104, 3037: 13-15, 3152: 1489-1513, 3162: 383-387, 3175: 146-162; 592-611, 3185: 870-931, 3323: 825-844; 928-993, 3403: 394-427) and two Hackney respondents (0512: 1198-1252; 2205-2216, 0787: 695-703) spoke

positively about the pleasure their homes gave them either as places to relax, to have privacy, or to entertain. What came across most of all though, was that the home was a place of comfort and respondents had a sense of pride in their surroundings.

Four respondents spoke about practical problems of the layout of their homes and the homes of others, and how these impinged on the quality of their lives. For example, Mrs Hetherington (Braintree) lived on an upper floor and had to carry coal up for the fire (3145: 672-702), Mr Dunlin didn't have a downstairs toilet (3175: 1226-1265) and neither did Mrs Watson (both Braintree) (3152: 939-967), and Mrs Little (Hackney) described the worry of visiting others (usually younger family members) who lived in modern houses that tended not to have a downstairs toilets (0267: 260-275).

There was quite a lot of discussion within the interviews about the idea of moving house and how that would impact on the quality of respondents' lives. Eight of the nine Hackney respondents who spoke about this in any detail, indicated that they would have liked to have moved out of the area completely, usually to be nearer family who had themselves moved out of Hackney. They wanted to move to places such as Hertfordshire (e.g. Enfield, Hoddesdon, Broxbourne, Bishop's Stortford), Essex (e.g. Rayleigh, Harlow), the outskirts of London (e.g. Cheshunt, Chadwell Heath), or to the coast (e.g. Worthing, Clacton). All eight were currently in council properties and had been on the council exchange, charity (e.g. the British Legion) or housing association lists for between three and more than 20 years; so for some this had been a very long-term plan. For example:

Hackney 0338 (1909-1913): Mr Derek Tibbs

R *We don't really want anything except that we want to be moved from here so that we can have the rest of our lives, as long as they might be, in somewhere with a different environment to this pit at the moment.*

Hackney 0787 (1116-1124): Mrs Peggy Woods

R *[...] I would like to be living out of London in a nice little flat. Walk down country lanes and that sort of thing. Sit out in, perhaps, a little garden... in the summer of course, you know? And I would really love to get out of London.*

Most, however, were resigned to the fact that a move was extremely unlikely. Some blamed their own local council, but others understood the fact that the host councils couldn't accommodate every request. For example:

Hackney 0338 (1676-1696): Mr (and Mrs) Derek Tibbs

R2 *We've been on council lists for over 20 years. They're not interested in anything now except housing the homeless. Which is a good thing...*

Hackney 0503 (1359-1370): Mr (and Mrs) Bill Parkes

R2 *He's got a cousin lives there [Clacton] and lots of friends live there. But we did know the housing manager and he said 'I only allow one family a year to come from London'.*

R *That's all he can do. You see cause everything else, as I say, the people in Clacton grow up and they have families and so on.*

However some had been made offers by other councils but had not taken them up because they found the properties were much smaller than those they were currently living in and this, interestingly, was not something these respondents were prepared to trade. Others questioned whether they really wanted the upheaval of moving at this stage in life:

Hackney 0608 (959-984): Mrs Betty Hepworth

R [...] *And then I sit and think about it at times and I think 'would I be doing myself a favour?', cause at least I know everybody here. You know?[...] So I probably won't give up my flat. Because I tell you for why, if I wanted to go desperately I would worry them and I would keep going up there. But I've never ever been up there. So it makes you think. Probably, at the back of my mind, it's just that I don't want to go.*

Four Braintree respondents spoke of a desire to move, but only one of these wanted to leave the area: two wanted local bungalows (3263: 361-400; 3279: 39-99, 164-217, 406-470, 1719-1740) and one wanted a detached property locally (3158: 1319-1346). The respondent who wanted to leave the area wanted to be nearer family who were based in Lincolnshire and Suffolk, however they described this as '*only a dream*' and said they wouldn't actually want the '*upheaval of moving and changing*' (3174: 185-242).

Three other Braintree respondents had moved in the past few years and were all pleased with their moves. Mr Stratton and his wife had moved into a local bungalow because of their arthritis; it was a council transfer and they were fortunate enough to have only had to wait two months and were given the choice of three bungalows (3154: 1607-1647). Mrs Wickford and

her husband were owner-occupiers who had moved to the area from Potters Bar to be nearer their daughter (3323: 213-226). And Mrs Whitwell sold her bungalow following the death of her second husband and bought a larger property with her daughter and son-in-law, which they converted into two linked properties (3403: 394-427).

In summary, in relation to location, respondents spoke in positive terms about the friendliness of the area they lived in, the countryside, having gardens of a manageable size, good local facilities, having a comfortable home and closeness to family. Respondents spoke in negative terms about the deterioration of the area they lived in (vandalism, graffiti, damaged pavements etc.), lack of gardens or even balconies, lack of local facilities, lack of pride in their surroundings, impractical housing, and the distance from their families. Hackney respondents had generally negative views of the area they lived in, whereas Braintree respondents expressed generally positive views.

6) Social contacts:

The respondents spoke a great deal about social contacts that were not family. These were broadly classed as 'friends' although several acknowledged that there was a distinction between true friends (usually old friends), neighbours and acquaintances (usually newer friends). New friends were never quite the same as old friends.

Hackney 0712 (580-592): Mr Peter Shipley

R [...] ...old friends have got a greater depth. A lot of their friendship is... is sort of a family friendship, if you know what I mean, because they just don't

know me but they would have known me brother, they would know your son when he was born, they would know my wife... so those sort of friends are your foundation. They are, you know, if you have anything to confide then that's the area where you would go.

Braintree 3118 (66-103): Miss Betty Young

R [...] The new friends, yes, they're nice, they're all right but they're not like the same as my... I lost one friend and we were friends... she was two years older than me and she took me to school! [...] Now her son took over where she left off, and he's wonderful. He was here a week ago.

Whatever the length or strength of the friendship, friends were regarded as very important to the quality of life. The most frequently cited reason for this was that they were someone to talk to, laugh with and chat with, which was particularly important to those who were now living alone.

Hackney 0512 (1099-1104): Mr Arthur White

R Well it's nice if you've got friends and that you can call on them any time. I just think it's nice that you have got some people that you can be friends with and talk and that. Yeah I think it's very important. I think it helps in a lot of ways really. And we have got good friend and neighbours and that.

Braintree 3263 (325-331): Mr Terence Shaw

I How important do you think friends are to the quality of your life?

R Well I think they're very important because I'm here on me own... and I've got no one to talk to and it's nice to go and see a friend and have a talk with them,

you know, put the world to rights sort of thing (laughter)!

Friends could be related to in a different way to family. Sometimes this was because they were of the same age group as the respondents and sometimes simply because the nature of the relationship was different. Mrs Watson described this in terms of being on the same wavelength:

Braintree 3152 (616-629): Mrs Ivy Watson

I Do you find that you perhaps rely on your friends for different things than you rely on your family for?

R Yes, yes, because they are of an age group. You see they understand and you sort of, different books you read you recommend to your friends where probably your children wouldn't want to read them. They're not your generation are they?

One of the difficulties associated with friendships at this stage of life was that as friends were usually peers, they too were reaching an age when their own ability to get out and about and meet up was becoming more limited. Some moved away to be nearer their families, who had themselves moved out of the area, and of course there was the inevitability of friends dying.

Hackney 0267 (1269-1282): Mrs Gertie Little (R1) and Miss Evie Fox (R2)

R2 But there's been a lot of people we've lost in the block. We've been here 30 odd years you know. So there's been a lot of people passed away.

R1 All the friends like.

Braintree 3026 (682-687): Mrs Ruby Argyle

R *[...] when you get to my age or any around my age group I should say, you see your friends dying one by one. And whilst I am one of these people, I'm not afraid of death whatsoever, it doesn't... upset me in that respect, but it upsets... upsets me the fact that I've lost yet another dear friend.*

Some respondents found it easier than others to make new friends, although this depended to a certain extent on their own physical ability to get out and about. In addition, changes in their lifestyle as they got older made it more difficult for some respondents to make new friends. For example, Mrs Watson described how, for women in particular, it had been easier to make friends as a young parent through one's children:

Braintree 3152 (586-609): Mrs Ivy Watson

R *[...] A lot of it is with your children, you make friends. When you've got little children, you go out for walks and you go to the clinic and that sort of thing and you get friendly with people [...] you've got a lot in common. But when you're older you don't mix up the same. And I'm not keen... I have a Friendship [Club] here but I'm not keen on that kind of thing.*

Some respondents valued the longstanding friendship of just one or two very good friends, whereas others seemed to prefer knowing a larger group of people.

Hackney 0503 (762-767): Mr Bill Parkes

R *I mean we've plenty of friends around which we've collected over the years. And that helps.*

Braintree 3158 (955-959): Mr George Baker

R *[...] people say they are friends but when it comes to a crisis they're not. And that's what I find a lot of people. They say 'oh' they've got 'lots of friends' but when they want help there's nobody there. But if you've got two it's better than a lot isn't it?*

Social contacts could take the form of bumping into friends in the street, attending a regular club (as discussed under 'Activities'), visiting others and receiving regular visitors. For example:

Braintree 3154 (1327-1356): Mr Frank Stratton

R *[...] me sister comes round maybe once, twice a week. Twice a week in the evenings till about nine, quarter past nine. [...] Quite often comes up on Sundays too.*

Braintree 3316 (1525-1543): Mrs Elsie Pritchard

R *[...] it makes a lot of difference if you've got someone coming in. Now I've got someone coming this evening [...] she mostly comes around Friday night, [...] we just have a coffee and a sandwich and some little things like that, you know? We just sit here talking [...]*

Mrs Turner described a surprise visit that had clearly delighted her for its spontaneity and break with routine:

Braintree 3251 (351-366): Mrs Maud Turner

R *Sunday, my friend comes here one Sunday and I go to her one Sunday. And it*

happened to be her Sunday here and her niece came from Saffron Walden, turned up with her husband. They knew where she'd be when she wasn't home. Well that was lovely. I enjoyed getting a little bit for them to eat. You know, a sandwich and a cup of tea, and having them here, and enjoyed it. It was nice. It livens up your home. You know, you feel it's a home more, you know? It's not just you sitting in four walls and that.

When talking about social contacts, a small group of Braintree respondents talked about the various benefits and restrictions of having a pet, a dog in particular, and the effect this might have on their quality of life. Only one couple, Mr and Mrs Stratton who were relatively agile, reported having a dog and thoroughly enjoying it. They had made a conscious decision to get a dog on retirement to keep active (3154: 2192-2251). Others, particularly those who had had a dog previously, would have liked one now but were concerned about their ability to care for them properly, or what would happen to the dog if they became ill or died (e.g. 3183: 1945-2016; 2079-2121, 3263: 1046-1085).

In summary, in relation to social contacts, respondents spoke of various types of friendships ranging from 'true' (usually old) friendships to acquaintances, and the different roles they had. Friends were regarded as very important to the quality of life. Loss of friends due to house moves, ill health or death, was an inevitable problem, and respondents reported varying abilities and opportunities to make new friends. A few respondents spoke about the advantages and disadvantages of owning a pet.

7) Society:

A number of respondents made comments referring to their local community that did not fit under the heading of 'location'. They referred more to the people of the community and its services (i.e. the council) than the physical environment. Respondents also made comments relating to the wider world such as world events and the state of the world, and also more specific topics such as education, race and parenting. This fairly disparate set of comments seemed all to be referring to societal issues, rather than issues relating to individuals, and thus these comments were subsumed under the heading of 'society'. As Mr Peter Shipley described it *'It's quality of people, not the actual individual. It's the actual quality of... society'* (0712: 1533-1534).

The subject of 'community' was discussed by some respondents in both a positive and a negative way. One respondent related a story of others being neighbourly to her (3118: 692-714) and others related stories of themselves being neighbourly to others (0503: 1191-1248; 3145: 1412-1447; 3162: 1173-1220): both had a positive impact on the quality of life, the former by making the respondent feel cared for and part of a wider community and the latter by making the carers feel good about helping others.

Eight respondents (seven from Hackney, one from Braintree) spoke about a lack of help from their local council in relation to their housing needs e.g. repairs and relocating (0267, 0283, 0338, 0356, 0582, 0608, 0712, 3081). Several others lamented the loss of a 'sense of community' that they had enjoyed during the war years, and how this detracted from their

quality of life: this was particularly mentioned in Hackney (e.g. 0503, 0608). Braintree respondents seemed to speak more often, and positively, of local community events, usually linked to the church or a community club, such as Christmas bazaars and fetes. Mr Parkes, a Hackney resident, missed such events:

Hackney 0503 (1830-1836): Mr Bill Parkes

R [...] but people today have done away with lots of little things such as lighting of candles. They don't go in for Christmas bazaars or anything like that. Now we used to always run that regular, three things during the year. But they don't do it here. People don't seem to get involved enough, you know?

On a wider scale, a minority of respondents spoke of feeling that society as a whole had given up on older people, and didn't care; these comments sometimes related to pension levels, but were levelled at society as a whole. Mr Woolley and Mrs Jones summed up the views of this group of respondents:

Hackney 0083 (1471-1479): Mr Sid Woolley

R [...] I think it's the general view of people that are over pensionable age, I think they are all of the same mind: 'you've done your work, you can't pay no more taxes, sod you'. That's what I think, the way we're treated now, because I hear on here [points to TV] and I read in the papers that in other countries a pensioner gets a reasonable decent pension. All right, they can't be a playboy but he can live comfortably.

Hackney 0283 (106-148): Mrs Thelma Jones

R *[...] I fell off the bus; nobody helped me. [...] it's terrible. If I see an elderly person, you know that's on the bus with me, I help them off the bus. But these people, they don't seem to bother. Sometimes, I don't say they're all the same, sometimes they do, but other times they just ignore you, you know?*

One of the difficulties older people appeared to face was coping with what they frequently described as a 'different world' or a world that was 'changing'. Respondents described the world in the 1990s as more affluent than the world they grew up in, with a greater reliance on the state for support and a greater tendency to blame the state or the police force in times of crisis. Children were seen as more streetwise in the 1990s, and better educated (although some reflected that they perhaps knew too much too young), and thus more adventurous than respondents had been in their youth, more risk taking, only looking at today and not planning for tomorrow (particularly with regard to finances). At the same time children were seen as more cosseted in the 1990s in that they didn't have to walk three miles to get to school and then three miles home again.

The world of credit was quite alien to some of the respondents, and they were very concerned for the levels of debt they saw around them; respondents commented on the higher levels of home ownership in the 1990s, yet also on the higher levels of homelessness (particularly in London). Cohabitation and unmarried mothers were reportedly scarce in their youth, and many felt crime levels used to be lower and there was less reliance on 'fast food'. Families were more geographically spread out and family unity was felt to be weaker. Hackney, in

particular, was a much more multi-cultural area than it had been in respondents' youth (all eight of the comments relating to race came from Hackney).

Respondents had also witnessed many technological advances (e.g. Mrs Ingles described seeing farm workers using hand tools as a child in rural Essex, yet watching someone walk on the moon as an adult (3296: 713-758)). As a result of such advances, respondents had seen a huge change in home life from the introduction of washing machines and televisions, to computers. The knock on effect of this, for them, was that more people spent time in their own homes and less being entertained as a community, and they saw this as a disadvantage today. For example:

Braintree 3233 (1297-1343): Mrs Dot Wickford

R [...] we had so many things to do [...] we had gymnastics. We had on the nights we didn't go to night school we went to church affairs [...] there were sales of work. There was parties. There was slides on African journeys [...], Christmas fetes and Harvest fetes. You were always out [...] we so much enjoyed it. But I think to myself 'what are the children doing today? What do they do? Where do they go?'

Thus some of these changes were seen as positive changes, but others were regarded as negative. More than anything, it was the faster pace of life today that older people felt out of step with. For example:

Hackney 0485 (1454-1469): Mrs May Trentwell

R [...] it's like I say Morag, our life is finished now. My life is finished now.

I'm living, OK, and I'm glad to be alive. Don't get me wrong. I'm glad to say 'thank God for another day'. But we've got no say in the matter now. None at all. None at all. It's their... it's their world and that's how it seems.

Braintree 3118 (239-256): Miss Betty Young

R *[...] I mean in the world today everything's happening. All this rushing and tearing about. But as you get older you say to yourself 'no', you know, you can't keep up with it. You just can't do it.*

Other societal factors that had a negative impact on quality of life included upsetting events in the immediate local community (e.g. flooding within a block of flats (0283: 773-786) or incidents of joyriding (3185: 1258-1295)) and events on the world stage (e.g. the Gulf War or the break up of the Soviet Union (0338: 1235-1293)). With regard to such events, respondents were concerned for those immediately involved in them, but were also concerned about the knock on effects for themselves (e.g. in terms of rising crime levels) and their families (e.g. in terms of economic recession):

Braintree 3185 (1258-1295): Mrs Hilda Potts

R *[...] I think it's dreadful. You don't know what's going to happen next do you? And we never used to lock the doors. Never.*

Hackney 0787 (1062-1074): Mrs Peggy Woods

R *[...] I don't worry for meself but I worry for me children. As long as they don't get put off work or anything like that. Of course, my youngest daughter, she's got a business and so has her husband. And I think 'oh I hope this doesn't affect them'.*

Finally, a number of respondents spoke about the differences in parenting styles today and the knock on effects this had on society: these comments were mixed, some being positive and some being negative i.e. some felt children were encouraged more today (e.g. 0004, 0028, 0485), whereas others felt children were more neglected today or left to fend for themselves more (e.g. 0503, 0512, 3158), were spoilt (e.g. 0485, 0787, 3026, 3158) and they lamented the lack of discipline and respect (of older people and authority), as they saw it (e.g. 0338, 0485, 3158).

In summary, in relation to society, respondents referred to members of the local community and its services (i.e. the council), and made comments relating to the wider world such as world events, and also more specific topics such as education, race and parenting. They described the mainly negative knock on effects these aspects of society had on the quality of their lives in terms of crime levels (which will be considered in more detail under the heading of 'Crime'), societal attitudes to older people, the loss of 'community', feeling 'out of step' with the pace of life and concerns for their families' lives in the future.

8) Services:

Respondents spoke about both positive and negative aspects of health and social services, and how these affected the quality of their lives. With regard to health care, negative comments included being on mixed sex wards (3026, 3174), long waiting lists for outpatient appointments (3183), waiting in accident and emergency departments (0028), hospital

transport (0028, 3152, 3174), hospital nurses being overworked or poor quality hospital nursing care (0028, 3026), and general practice (0283, 3174, 3251). Positive comments referred to general practice (0356, 0512, 3026, 3145, 3183), the quality of hospital nursing care (0608), and the quality of medical care in hospital (3174).

Of the nine respondents who commented on how living in institutional care might affect the quality of their lives, eight made negative comments (usually referring to loss of independence) and just one, Mrs Hetherington, spoke quite positively about it. Mrs Hetherington had applied to move into the old people's home in her village which was across the road from her house; she had recently been diagnosed with Parkinson's disease and lived alone, and knew a number of ladies who were living their already through her club. She returned to the subject of her move several times throughout her interview (3145: 98-105, 239-289, 579-605, 1689-1710).

Similarly, positive and negative comments were made about social services. Negative comments included reference to a neighbour and the lack of support they received (3145), lack of financial help for a caring role (0028), and difficulty accessing services (0083, 3175). Positive comments included prompt receipt of Giro (0488), the provision of Lifeline Alarms (0267, 3316), the provision of home adaptations and gadgets (0267, 0283, 3316), and the fact that the services were available if you needed them (3026, 3316). Two respondents spoke extremely positively about the contribution that the Crossroads care scheme made in their lives (0643: 515-561, 607-614; 3026: 304-308, 345-423).

Several respondents made comments about the home help service. Some spoke positively about the service (0083, 0267, 0338, 0643, 3316), others negatively (0488, 0512, 3026) and some were reluctant to take it up (0283). Mrs Pritchard spoke in some detail about the home help service and returned to the subject several times throughout her interview (3316: 123-181; 200-270; 970-975; 1543-1614): she acknowledged the limitations of the service but was grateful for the support it gave her.

Braintree 3316 (123-181): Mrs Elsie Pritchard

R *[...] Twice a week she comes in and just gets my pension and she'll do the things I can't do. I mean I can't climb up and I can't kneel down [...] But she is quite good, you know? Quite a little understanding between us, you know? [...] you do have to close your eyes at times [...] sometimes things aren't done the way you do them, but you've got to realise that you are not the one doing it now, you see?*

A few respondents mentioned that they found dealing with agencies difficult. Mrs Jones described having to 'be in the right mood' to deal with social services (0283: 480-499), Mrs Clayden spoke of agencies not giving her enough time to get to the front door when they knocked (0488: 303-322), Mrs Hetherington had found that contacting social services on behalf of her mother took up a lot of time (3145: 378-411), and similarly, Miss Skipton found it took a lot of effort (0028: 142-198). At the time of her interview Miss Skipton was having to deal with number of agencies as her sister, who was currently in hospital, was about to move from her flat on the floor above Miss Skipton, to an old peoples' home:

Hackney 0028 (142-198): Miss Beryl Skipton

R [...] *I've got phone calls. It's all phone calls, phone calls, and phone calls are not cheap now. Phone calls and phone calls [...]*

In summary, in relation to services, respondents made a mixture of positive and negative comments, usually referring to specific incidences, regarding health and social care. Comments relating to institutional care were generally negative and those relating to the home help service were generally positive. On the whole, comments made about accessing services or dealing with agencies were negative.

9) Feelings:

Respondents referred to many different aspects of their feelings in relation to their assessment of the quality of their lives. Feelings can be considered in three different ways in relation to the quality of respondents' lives: they could simply provide a good or bad quality of life, they could enhance or detract from the quality of life, or they could be a reflection of a good or a bad quality of life.

The most commonly recurring themes talked about in relation to feelings were negative ones such as boredom, loneliness, and feelings of regret, although some respondents spoke of experiencing the opposite, positive aspects of these feelings i.e. 'never bored', 'never lonely', and 'no regrets'. The most common positive feelings described in relation to quality of life, however, were happiness and contentment. Each of these will be examined in turn.

Boredom was a factor to be contended with by many respondents, reportedly something that had not featured so much in their younger, busier lives. Some related this to retirement and stopping work, rather than old age per se.

Hackney 0083 (591-599): Mr Sid Woolley

R Oh blimey, I've never been so bored in all my, cause all right although I used to, you know I was going out, I mean you come to think you work in a trade all your life and it's something that you enjoyed doing and I did, I liked my work and then you find out that you've got to stop. It's a bit of a wrench.

Others referred to their living environment and the restrictions this imposed on them, resulting in boredom. This was particularly true of those living in high-rise blocks of flats in Hackney, where easy access to outside, and a change of scene, was limited.

Hackney 0212 (390-408): Mrs Patsy Benson

R I mean it's not like you've got a house. You've got a garden or if you've got a balcony, you can sit out and read. There's nothing else in the flat to do. I'm not a television fan [...] I mean I get bored. I mean, they say that's the trouble with flats [...] In houses you can get out in the garden and tinker about. But in a flat, no.

For others boredom was considered to be the result of the restrictions imposed on them by their health or functional ability. A decline in their health or functional ability meant that activities they had previously enjoyed were now more difficult, or even impossible.

Hackney 0356 (2877-2881): Mrs Doris Trundle

R I do get bored at times, yeah. Because, as I say, we used to go out and go to shows. We always looked forward to a holiday but when I had the angina... I couldn't go away that year and then we managed to get the... the last holiday we had was at Bognor and that was over two years ago now.

A few respondents described the lack of local amenities, and had been sorry to see the closure of older people's clubs and activities.

Braintree 3095 (28-53): Mr Harry Able (and wife)

R When you think of Braintree actually, well there's not a lot to do in Braintree really [...] There used to be a club down there what was for the over 60s but we don't keep going up there. That's shut down now [...]

R2 We used to have a whist drive and that's closed down [...]

R There weren't enough interest [...]

R2 I used to go. I used to love it. He didn't go.

R There's not a lot of social things around here.

Sunday was considered to be a particularly difficult day for some respondents, resulting in feelings of boredom.

Hackney 0608 (746-770): Mrs Betty Hepworth

R Sunday, I think, is a boring day for me [...] you get up, you have your breakfast, you do a bit of work and then you start getting the dinner. You know, you do your dinner, you have your dinner, you wash up, you clear up.

So what else is there to do than sit and watch television?

Braintree 3037 (233-235): Mrs Betsy Parker

R But I always feel that Sunday is a nothing day. Do you know that? I'm not lonely but it's... very peaceful. If only I had a car...

As well as Sundays, there were a considerable number of respondents who also referred to winter as being a difficult time in relation to feelings of boredom. They described the darkness of the evenings and a feeling of needing to be indoors, and the restrictions this imposed on them.

Braintree 3095 (392-411): Mr Harry Able

R This time of year there's nowhere to go. There's nothing in the dark is there [...] *This time of year I'm indoors most of the time, you know?*

Braintree 3145 (86-88): Mrs Dorothy Hetherington

R ...in the winter I think I find it worse, you know, because you're shut in from about four o'clock. You're shut in all the time.

Similar comments were made about evenings in general.

Braintree 3279 (1215-1220): Mrs Isobel Thorpe

R In the evenings it seems the worst. I get tired of sitting. Tired of reading and I'm... I'm not keen on television. If there's somebody come over and we have a chat that's nice.

This last quote indicates an element of loneliness as well as boredom. A number of

respondents referred to loneliness as problem that affected the quality of their lives. As with boredom, many respondents identified the evenings, winter-time and Sundays as being particularly difficult, and some also referred to effects of being widowed.

Hackney 0787 (798-810): Mrs Peggy Woods

R *[...] sometimes I do feel lonely, yes. And I envy couples who've grown old together, you know, still got one another.*

Braintree 3118 (446-449): Miss Betty Young

R *[...] I do like company. I like somebody to talk to. It's the evenings, worse than anything. I enjoy the television but after about half past eight there's nothing to look at, that I want to look at.*

Mr Philipson, a resident of one of the villages surrounding Braintree, noted that it wasn't just his own reduced ability to get out that led to his loneliness, but the reduced ability of his peers to come and see him. He also, later in his interview, commented on the demographic changes he had observed in the village and the effect this had had upon him.

Braintree 3174 (83-90): Mr Bill Philipson

R *You know you also reach a stage, you see, where you are isolated to a certain extent [...] because you can't get out and about and mix with people. Even your own friends eventually come less and less to see you [...]*

Braintree 3174 (251-269): Mr Bill Philipson

R *[...] It's very quiet. And you see it's developed into a strange sort of village now [...] because you know we have lived here 50 years now [...] and of course everybody I knew has grown up with me because the youngsters, the*

young generation of them, you know the daughters and sons of the people you know, have all moved out [...] and we have, you know, houses built all around us but they are all strangers. They're all youngsters, I mean, you know?

In terms of combating loneliness, respondents used a variety of means. Although respondents had expressed mixed views on the usefulness of television as a source of entertainment, most comments were, on balance, positive and a few respondents described their television or radio as a source of companionship, reducing their feelings of being alone in their home. For example:

Hackney 0608 (806-831): Mrs Betty Hepworth

*R [...] as soon as I get up I go to the radio, must have a bit of noise around me
[...] it makes you feel as though you're not entirely on your own.*

Mrs Woods had a different scheme to combat loneliness. She held spare keys to her daughter's, granddaughter's and nephew's homes, all of whom lived locally in Hackney. She had taken on the role of caretaker and pet sitter whilst they were at work or on holiday. They had gardens and had offered her the use of their gardens (she lived in a council flat) whilst they were not there:

Hackney 0787 (634-676): Mrs Peggy Woods

R [...] if I do feel a little bit lonely or anything, feel as if I want to get out, I can always go along there [...] She'll phone me up and say 'oh I see you've been in Mum. Thanks for washing up or thanks for doing this.' [...] So I've always really got something to do and it's nice to know you're missed, you know?

Like when I go on my holidays, when I go on my holiday they say 'we did miss you Mum', you know 'missed you doing that little bit of washing up'. And that's nice to know you're not a burden to them.

There were a group of respondents, in both areas, who insisted that they were never lonely.

These respondents often commented on how lucky they were to be this way. For example:

Braintree 3037 (474-478): Mrs Betsy Parker

I Do you ever find you get lonely?

R No! Never! And it's wonderful I know! No I don't get lonely.

Some regarded their lack of loneliness as being a result of their personality. They believed that some people were just better at being on their own than others. They were comfortable in their own company and even relished it, but at the same time were happy to socialise with others.

Hackney 0028 (522-541): Miss Beryl Skipton

*R [...] I'm not what you call a lonely person. I like, sometimes, to be on my own
[...] I like to be on my own. I've not married [...] so all my life I've been on
my own. I'm used to it. I don't take no notice. When I go out shopping you
meet a lot of people and they speak to you. They're very nice.*

Braintree 3296 (1322-1345): Mrs Amy Ingles

*R [...] I like my own company [...] I have been known to go up in the loft and
rake through the boxes up there and just sort of be on my own.*

Others explained their lack of loneliness by referring to visiting, or receiving visits from, their friends and family, or the fact that they were still married. For example:

Braintree 3152 (1127-1142): Mrs Ivy Watson

R *[...] I don't get lonely. I've always got things to do [...] and as I say, I've got friends. I've got two good friends in the village [...] and of course my husband is always in you see, he can't get out so...*

Mr Shipley, a Hackney respondent, described avoiding loneliness by going out and running some errands; actively seeking something to do.

Hackney 0712 (772-786): Mr Peter Shipley

R *[...]if it's in the day I get a little bit, you know, fed up with meself I say 'well you know this is not helping me', so I would go and visit, you know... or... visit or, what can I say, go down town, have a look around and see if there's anything I want... and then I'll go and have a look at it, you know? Birthday cards, or anything (laughter)!*

Similar to those who were reportedly 'never lonely', was a small group of respondents who vehemently described themselves as 'never bored'. For example, Mr Stratton and his wife proudly referred to themselves as 'too busy' to be bored.

Braintree 3154 (438-448): Mr (and Mrs) Frank Stratton

R *[...] actually Morag, we've been too busy since we've retired (laughter) to be bored [...] I've worked a lot harder since I've retired than I did when I was working and that is the truth (laughter).*

Others enjoyed the quieter lifestyle their retirement had brought them, and accepted their changed circumstances, acknowledging the new opportunities this opened for them to pursue hobbies.

Braintree 3081 (203-219): Mrs Eileen Stewart

R Sometimes I like it a bit quiet, you know. Oh no, as you know if I felt at a loose end I would do some drawing, or painting or crayoning. I mean I've got all the utensils for it and which is very nice, what they've all bought me [...] so I don't have time to get bored.

Braintree 3152 (1143-1154): Mrs Ivy Watson

R No, no I'm never bored. I always see things what wants doing and I can do them. I can't understand people that get bored [...]. There's so many things. You can sit and relax. You can do a crossword can't you? Or you can do a jigsaw puzzle. I like to sit and do anything like that... and I like my own home too. I don't always want to be out.

A further, usually negative, feeling referred to was that of regret. Three respondents referred to children in their responses: Mrs Little (Hackney 0267: 1363-1371) wished she had had children, Mrs Trentwell (Hackney 0485: 1613-1664) wished she had had more than one child, and Miss Young (Braintree 3118: 1476-1485), who was childless herself, wished she had trained as a children's nanny and worked with children.

Decisions made earlier in life were also a feature of other respondents' regrets. For example,

Mr and Mrs White spoke at some length about the decision Mrs White had made early in her married life to remain under the wing of her mother and later, to offer a room to her bachelor brother within her marital home after her mother had died (this was also referred to under the section on 'family'). The knock on effect of these decisions had clearly troubled her over the years:

Hackney 0512 (2640-2724): Mr (and Mrs) Arthur White

R2 *[...] we [...] lived with my Mum in the house. Well maybe I was wrong but it don't matter where we went, if we went on a holiday or anything, we took my mother [...] and my brother never ever married [...] Well now, when my mother died she did say to me 'you will look after Jack', my brother. So of course we did. So I said 'well you don't need to keep your room, you can come and live in with us. Saves expenses and that'. Well I had him for 20 years [...]. Now that I think was wrong [...]*

R *[...] there was always times when you want to be on your own... because you weren't leading a normal life really. If you wanted to say something to one another you couldn't. You'd have to go out of the room [...]*

R2 *And then what did I say when we was out of the room, when you...*

R *'Don't stay out too long he'll wonder what's up' [...] what a life (laughter)!*

Others' regrets were more practical, such as Mr Able's regret that he had never completed the process of learning to drive (Braintree 3095: 577-597), and similarly Mr Shaw's regret that he did not have a car instead of his moped (Braintree 3263: 1111-1142). For both of these men, a car would have been convenient, and both describe the pleasure of just taking a run out in

the local countryside; in the case of Mr Shaw he also commented that it would be a lot more comfortable in adverse weather, than his moped.

Mrs Prior (Braintree 3167: 1675-1687) spoke of her regret that, due to her husband's habit of gambling, they had been unable to buy their own home. She considered that this would have provided an investment that she could have passed onto her son or her grandchildren.

There were a small group of respondents who had regrets relating to factors beyond their control e.g. the death of a spouse (Mrs Chalker (Hackney 0004: 783-791); Mrs Turner (Braintree 3251: 3008-3029)), death of a sister (Mrs Prior (Braintree 3167: 1647-1687)), a difficult marriage (Mrs Chalker (Hackney 0004:1202-1203)), or the decline in health or functional ability (Mr Woolley (Hackney 0083: 1674-1680); Mr White (Hackney 0512: 2031-2076); Mrs Thorpe (Braintree 3279: 1744-1763)).

Just as there were with the negative feelings of boredom and loneliness, there were a small group of respondents who denied having any regrets at all. There were certainly things they wished they had done, but had not had the resources to achieve, but they accepted this as a matter of course. This kind of response may be a reflection of personality type. For example, when asked if she had any regrets, Miss Skipton could think of nothing that '*stuck out*':-

Hackney 0028 (974-982): Miss Beryl Skipton

R [...] I mean, for instance, I like travelling but you've got to have a load of money to travel [...] so what's the good of worrying about it? If you haven't got the money to travel you can't do it, you forget it. You see?

A smaller number of respondents referred to other negative feelings. Several respondents, most of whom were male, spoke about their concern at the lack of respect afforded to older people, or to authority, by younger people, and some related this to an increasingly materialistic world. For example:

Hackney 0712 (1116-1121): Mr Peter Shipley

R There's no respect for authority. No respect at all [...]...it's a sad thing really.

Braintree 3158 (1543-1546): Mr George Baker

R You sort of respected a policeman. You respected him because he was a policeman. But now they don't. They don't care. If a policeman said anything to them they think 'oh I'm too young'. Little devils.

Braintree 3174 (790-822): Mr Bill Philipson

R I think that the situation will arise, it's gradually creeping that way isn't it, where values are depreciating [...] we have a fast approaching situation where only the individual counts. There is no room for a world where living in harmony or [...] I dread to think what my grandchildren will face.

I Why do you think it's changed so much?

R Well I think it's all material isn't it? I think we are no longer prepared to accept that there should be a bottom of the ladder [...]

Two female respondents from Hackney referred to envy or jealousy, and how that affected the quality of their lives. Both of these quotes related to the women's marriages, but for opposite

reasons: one questioned why her marriage had been so difficult (0004: 1519-1526) and the other lamented the loss of her husband (0787: 808-809). Other negative feelings referred to by individual respondents in relation to the quality of their lives included grief (0267: 177-178) (although this was alluded to by others under 'regrets'), depression (0488: 852-868), frustration (0267: 501-508), moodiness (0283: 503-514), being a worrier (3174: 2015-2048), and sadness (0004: 216-220).

The most common positive feelings referred to in terms of giving a good quality of life, enhancing quality of life, or reflecting a good quality of life, were happiness and contentment. For some respondents happiness and contentment appeared to be the corner stone of quality of life, but they acknowledged that other factors (such as health, for example) might influence whether or not one was actually happy or content. Thus happiness and contentment were not regarded as states that occurred independently of other factors. For example:

Hackney 0004 (732-751): Mrs Mary Chalker

R I'm quite contented, but I am not happy when I'm not well and I don't feel well. I'm anything but happy.

And the following quotes are typical of several who referred to quality of life and happiness as inextricably linked.

Hackney 0512 (2164-2179): Mr (and Mrs) Arthur White

I Right, let's think about... if you were in my position and you had to ask people about the quality of their lives, what their lives were like, what sort of things would you ask about? What questions would you ask them?

R2 *Well always one thing I say, right away 'are you happy?'*

Hackney 0643 (1068-1070): Mrs Lily Potts

R *Well I'd ask if your quality of life... if you was happy? You had peace of mind and if you could do the things that you would like to do?*

Some respondents noted, however, that states of happiness or contentment could occur in seemingly adverse conditions. For example, Mrs Trundle described her granddaughter's reaction to her description of her own childhood:

Hackney 0356 (211-214): Mrs Doris Trundle

R *And she said to me 'oh Nanny, wasn't you poor!' I said 'well we haven't been totally rich now but we're happy!' (laughter) That's the main thing.*

Some quotes alluded to the idea that the factors that influence happiness vary throughout one's life. For example Mr Philipson, a respondent from Braintree, had clearly given the matter a lot of thought:

Braintree 3174 (2069-2132): Mr (and Mrs) Bill Philipson

R *One of the things I was thinking about, I think you mentioned something about happiness the last time you were here. And I've thought about it once or twice. I suppose happiness is a relative thing isn't it, really? There must be, you know, degrees of happiness I think.*

I *Certainly, yes.*

R *I think as you get older you lose, perhaps the opportunities aren't there, but you don't get these big kicks that you do [when you're younger] [...] I*

suppose the opportunities aren't there for the things that made you happy when you were younger, you know? I mean your happiness might be things that you don't... [...] For example, your team's won the cup. Was that happiness or was... it's, you know, what we believe to be happiness. But happiness is much deeper, I think, really.

A lot of respondents talked about contentment in relation to quality of life, and often at the same time as talking about happiness or in a similar way to the way they talked about happiness. As with Mr Philipson's comments about happiness, a number of these respondents commented that what made one person content might be inadequate for another, and that as one got older one was more easily content with one's lot. For example:

Braintree 3154 (225-236): Mr Frank Stratton

R [...] See when you're older you're content with what you've got [...] you have to adapt to a different lifestyle.

Braintree 3323 (2925-2953): (Mr and) Mrs Dot Wickford

R2 But other than that, Morag, I don't think as far as I'm concerned, and my wife will agree, we're very happy. Very happy. We are happy and contented. I say we've got a simple life. It is simple.

R Oh it is simple. I mean it might have drove some people crazy the way we live (laughter) [...] Simple but happy. [...] I mean, as I say, other people might think 'oh my goodness I couldn't live the life you live'. But it suits us.

Related concepts referred to were fulfilment and life satisfaction, although these were terms

used by a smaller number of respondents, and optimism. With regard to the latter, as with some of the comments made by respondents about negative feelings, there was a sense that a positive view of life was perhaps related to personality. For example:

Braintree 3316 (1794-1808): Mrs Elsie Pritchard

R *[...] I mean a lot of it is your outlook on life. I think I've always been a little bit optimistic, sort of thing. I mean I've never, touch wood, I don't think I've ever been a moaner or anything, you know? And we've had our bad times. I'm not a moaner but some people can't help it can they? I don't think they all exactly mean it... but the way I mean, some people are really moaners, you know? And that, you go to the next one, she's just ready for a laugh. I like a laugh myself, you see?*

Other individual respondents talked about other positive feelings in relation to quality of life, such as dignity (0712: 143-166), pride (3251: 3008-3029), enjoyment (3154: 13-13), and honesty (3251: 541-566).

In summary, in relation to feelings, respondents spoke negatively about boredom, loneliness, and feelings of regret, envy, jealousy, lack of respect. Some respondents spoke positively about being 'never bored', 'never lonely' and having 'no regrets', and many described feelings of happiness and contentment. Others referred to fulfilment, satisfaction and optimism.

External factors appeared to be key to these emotions with respondents referring to their

environment, retirement, role changes, ageing, local amenities, companions, hobbies, level of activity, functional ability and health when describing their feelings. It is noteworthy that many of these external factors could be equated with the other emergent quality of life categories from the respondents' interviews (e.g. 'activities', 'health', 'social contacts', 'location' etc). In addition, some respondents referred to certain days of the week, seasons, and times of the day as having an effect on their feelings. Others, however, referred to their generally positive outlook on life. Thus, feelings could provide a good or bad quality of life, they could enhance or detract from the quality of life or they could be a reflection of a good or a bad quality of life.

10) The Past:

When discussing the concept of 'quality of life', 'the past' was referred to by a number of respondents. The most talked about subject (as opposed to the subject covered by the most people) relating to 'the past' was, perhaps inevitably, the Second World War. Fifteen respondents referred to the war during their interviews: eight from Hackney and seven from Braintree. The majority of the comments were negative, with some respondents even describing it as the worst time of their life (this will be discussed separately below under 'Set Questions Category: The Worst Quality').

The difficulties described ranged from air raids, rationing, fears for loved ones, coping with young children alone, living through the blackout, deaths of family members and evacuation to the post war struggle. Two Braintree respondents also described their experiences as

Prisoners of War. In addition to these negative comments some respondents described positive aspects of the war such as the neighbourliness, yet only one respondent spoke about the war in entirely positive terms. For Mr Baker, the war had occurred at a time in his life when he was young, single and without responsibilities:

Braintree 3158 (645-663): Mr George Baker

R *[...] best years of my life [...] The war made us fit. I didn't care enough to know nobody; nobody cared for me like. I had some good friends in the Forces and we were fit, you know. I mean we had good training. I was overseas before I was 19: Prisoner of War at 19; wounded twice at 19. But that didn't worry me.*

The topic relating to 'the past' that was talked about by the most respondents was the description of 'the past' as being a 'hard life'. Nineteen respondents spoke in this way: nine from Hackney and ten from Braintree. They described in some detail the lack of modern appliances and facilities (e.g. washing machines, mains water and inside toilets), the lack of space (e.g. a family living in one room, or four families to one house), larger family sizes (e.g. 10 children), lack of state support (in terms of pensions and benefits), poverty, unemployment, long hours of work for those in work, and working from an early age (e.g. 14 years). Typical quotes came from Mrs Jones' brother in Hackney and from Mr Dunlin in Braintree:

Hackney 0283 (2016-2025): Mrs Thelma Jones' brother

R2 *I remember when kiddies ran about with no shoes on. Another house I knew where they had no furniture, they had an orange box as a table. They used to*

sleep on the floor.

Braintree 3175 (1558-1574): Mr Henry Dunlin

R Well of course we're happier than my parents were because money was a continual problem. We also used... it's a bit true, you know, is that when poverty comes in the door then love goes out the window. And it is true that if you're scraping away all the time you have very little quality of life. I mean people used to say 'ah but of course it used to be wonderful in the East End and you know everybody was friendly, the doors were open...' Of course they were, they had nothing to lose (laughter)!

Like Mr Dunlin, three Hackney respondents spoke about the past as being 'safer' (0028, 0212, 0267). A typical memory came from Mrs Benson, who shared Mr Dunlin's view that the safety was more a result of lack of possessions:

Hackney 0212 (1568-1581): Mrs Patsy Benson

R [...] You never had a bolt on your door, never had it. Nobody had keys. [...] The thing was, they hadn't, we had nothing for them to burgle!

In a similar vein, there were several quotes from respondents relating to 'the good old days'; the majority of these quotes came from Hackney respondents (0083, 0212, 0485, 0488, 0512, 0787, 3081, 3167). Respondents would describe quite difficult times from their younger days, but refer to them as happy times with fond memories. Whether this is a 'rose coloured spectacles' effect is unclear, but respondents clearly enjoyed reminiscing about life standards and how they had changed.

There was a similar set of quotes relating to memories specific to childhood. Most described simple lives which respondents considered a better grounding in terms of outlook on life and future self-sufficiency than children have today. For example, Mrs Hepworth described how, in the absence of television, videos and computers, they would entertain themselves as children:

Hackney 0608 (1124-1129): Mrs Betty Hepworth

R [...] we used to go out playing, it used to be all kids playing together with a big skipping rope and dads would come down and turn the rope while all the kids skipped and everything. Jesus, we don't see nothing like that today!

In summary, in relation to 'the past', respondents spoke passionately, and in some detail, about the Second World War and the negative aspects of this. Many described the 'hard life' they had endured as children in terms of facilities, income, the working conditions of their parents, and housing conditions. There was a sense that 'the past' was a safer time, partly because of a lack of material possessions, and for the same reason it was regarded as a simpler time.

11) Control:

Respondents from both areas made a series of comments that were grouped under the broad heading of 'Control'. These comments all related to the idea that respondents either had, or did not have, an element of control over their quality of life. This category perhaps sits in

opposition to the category headed 'Society' where some respondents laid the blame (or an element of it) for their poorer quality of life on society rather than relating to their own judgements, decisions and outlook on life.

For example, those comments suggesting there was an element of control over one's life spoke about life being 'what you make it' (0212, 0338, 0503, 0582, 0643, 0712, 3095, 3145, 3158, 3316). Several times throughout his interview Mr Tibbs returned to the idea that the quality of life he and his wife enjoyed in Hackney was of their own making: they had saved throughout their lives, had not been reliant on the state, and were now in a position to enjoy a relatively comfortable life style with occasional holidays (0338: 61-72; 88-101; 187-189; 1805-1806; 2185-2191). Several respondents made similar comments. Mrs Benson and Mr Parkes' comments were typical:

Hackney 0212 (14-23;485-486): Mrs Patsy Benson

R [...] you can live a morbid life. You can live a hectic life. You can, you know, waken up to live an active life. But there's no need to just sit in four walls and mope, is there? [...] I don't sulk. You've got to make your own life.

Hackney 0503 (1906-1912): Mr Bill Parkes

R Now these people they're walking around with bags every day of the week. They're eating out. They've got a house but they can not stand stopping in. We've got two or three women that do that. They come along to any dos and all that but they make something, they try and make something of their life. It's up to the individual all the time.

Some respondents referred to actively trying to ‘keep their brain going’ either by keeping active and going out, being ‘where they action is’, keeping their ‘finger in the pie’, having interests, being involved in a good cause, maintaining an interest in local affairs, and pushing themselves that little bit further (0503, 3026, 3175, 3296, 3316, 3323). The majority of these comments came from Braintree respondents. For example:

Braintree 3296 (191-204): Mrs Amy Ingles

R *[...] it's a combination of all things. One is the determination not to let go of life, sort of thing [...] I've seen people who gradually sort of said 'no, I don't feel like going out' and it gets a habit.*

This was a topic that Mrs Ingles felt very strongly about. She returned to it later in the interview, describing her philosophy on life:

Braintree 3296 (372-437): Mrs Amy Ingles

R *[...] I do do some things deliberately rather than let myself get just into an old woman [...] I suppose if have any illness I mean that's something you can't help... but I've got a bit of sort of allowing age [not] to govern what I do, because I don't think it should. I think a person is a person whatever date there is on their birth certificate. [...] There's nothing annoys me more than people saying 'oh well you can't expect me to do that at my age' because you can. I mean I don't think you should ever say you can't do anything unless you've tried it and found you can't do it. And I think that... is an attitude that perhaps helps... helps you to keep the most dreadful aspects of old age at bay. Perhaps if you just don't allow it to play a great part in your life... the fact*

that you're old.

As with the category on 'feelings', it is difficult to untangle here whether the degree of control respondents felt they had over their lives was a reflection of its quality, or whether this degree of control was a factor influencing the quality. For example, having a degree of control over one's life could be as a result of good health, financial security, education and opportunity (0004, 0212, 0267, 0512, 0643, 0712, 3162, 3174, 3323).

Hackney 0004 (349-351): Mrs Mary Chalker

R I never had the chance and that. None of us had the chance.

Hackney 0712 (77-99): Mr Peter Shipley

R [...] we all retire at different levels [...] for instance a labourer [...], he's done a life long work. But when it comes to his retirement he's got a very narrow path [...] by the nature of his background. There's other people that are more fortunate. People that go into professions, whose range is wider. They can draw on more people to converse with, you know?

Having control could also impact on quality of life allowing for greater freedom in life, a 'good life', a peaceful life and an appropriate level of privacy in life (0004, 0028, 0356, 0485, 0512, 0727, 3026, 3162, 3185, 3323). For example:

Braintree 3323 (56-125): Mr Wickford (Mrs Dot Wickford's husband)

R2 [...] when you get older you feel that you want to live peaceful and quietly. You don't want any upsets or disturbances [...]. If you can keep on that keel then you're on a good wicket.

Braintree 3162 (852-867): Mrs Marion Williamson

R *[...] I can say 'no, don't come tomorrow' or 'I can't come'. [...] I get the privacy I want.*

Even though some respondents may feel they had a good degree of control over the lives, and that this was important to them, others acknowledged that control could not be exerted over all aspects of life and that external factors had a role to play. For example:

Hackney 0712 (1416-1461): Mr Peter Shipley

R *[...] we have got, you know, our own contribution to it. And as good as we make our own contribution... we can't guarantee at all we'll enjoy that contribution we've made, because that contribution can be lost by walking out your door.*

External factors included the wider society (as discussed earlier) and societal attitudes, the immediate neighbourhood or neighbours, and even the weather (0028, 0267, 0283, 0338, 0356, 0488, 0787, 3026, 3095, 3145, 3183, 3263).

Those who felt they had little control over their lives often described themselves as having had good or bad fortune, being lucky or unlucky, and believing in fate (0004, 0028, 3145, 3162, 3316, 3323). For example:

Hackney 0004 (1186-1215): Mrs Mary Chalker

R *You can't pick your life. It's fate. I say this much, if you're cut out to have trouble, you'll get it wherever... no matter where you hide.*

Braintree 3323 (2211-2317): Mr Wickford (husband of Mrs Dot Wickford)

R2 *[...] Whether you call it luck, I don't know whether you call it luck or good fortune [...] even if you've got the force of religious tendencies and you think somebody's guarding and looked after you [...] yet in the same breath you see other people who do their best and they don't achieve anything.*

In summary, in relation to control, a group of respondents described the fact they felt they had, or did not have, an element of control over the quality of their lives. Those with a sense of control spoke of life as being 'what you make it': they actively sought activities that would 'keep their brain going' and maintain their involvement in society. Those without a sense of control spoke about fate, misfortune and being unlucky. It was unclear whether respondents consistently regarded control as a result of a good quality of life, or the cause of a good quality of life.

12) Working and retirement:

A number of respondents from both Hackney and Braintree spoke very positively about their working lives and the affect this had had on their quality of life. They reported that they had liked working: they had enjoyed the work itself and enjoyed the money and the independence that gave them, but most of all they liked the contact with other people, the company of workmates or dealing with members of the public. A few described it as the best time of their lives, the time that had had the best quality. For example:

Hackney 0787 (445-469): Mrs Peggy Woods

R *[...] I worked in a factory, a handbag factory. And it was a wonderful experience because we were then, we was all friends in the factory. We used to go on outings, you know. We was always celebrating something and it was a marvellous atmosphere. And I worked in that factory for about 16 years... and I really enjoyed myself! [...] I think it was the company and we was... we was all started there round about the same time, you know? We used... if like we had families and he was a very good Governor and he used to, if you was expecting a baby, you had your baby and you went back again and yeah, I think I went back to that factory about three times!*

Although the very positive quote, above, was typical of the quotes about work, there were a small group of respondents who described the negative aspects of work. For example, Mrs Potts recalled that there were good days and bad days at work, but she still missed it and again it was because of the company:

Hackney 0643 (919-955): Mrs Lily Potts

R *[...] some days are rough, you know, and you've got this and that to do and all that. You think 'why are you doing all this?' But you miss it [...] company and people. You like... company and you switch off from here [...] and some days you think 'cor, I don't know what I'm here for', you know... it's a rough day and all that, but you do miss it. And you miss the money.*

A few respondents spoke about the working conditions and regimes at work, and how these

had made their working lives difficult (0028: 771-802; 3158: 550-591), and several referred to the fact that they had started work at 14 years of age, getting up early in the morning for a low wage (0004: 330-332, 352-354; 0028: 769-782, 792-815; 0083: 217-224; 0787: 888-894).

For some, however, the process of retiring had been a difficult time. It meant adjustment to a whole new way of life and a change in their level of income. For example Mrs Hepworth, who had been a widow for a number of years before her retirement and had worked in a local school, found the adjustment to retirement had been difficult and even now would happily return:

Hackney 0608 (785-800): Mrs Betty Hepworth

R [...] I worked with children over the school, you know, and I really miss them children, you know, and I did miss the company to be honest. And it was quite a time afterwards, you know, that I thought, you know, but... of course now I'm used to being home because it was 1986 I retired. So I'm used to being at home now, but believe me I'd sooner be at work.

Mr Woolley, who had only retired a few months previously and only then because of problems with his health, was already noticing the reduction in his income:

Hackney 0083 (71-89): Mr Frank Woolley

R But I've had to take off work.

I When did you stop that?

R August. Middle of August [...] It's a pity because, I'm being perfectly frank

with you, I'm finding it hard to manage.

And Mr Parkes seemed to find life less satisfying since retirement:

Hackney 0503 (36-44): Mr Bill Parkes

R *[...] when you're at work you can do this, that and the other. But when you're retired, to me, you've got to make a... try and make a new sort of life. Some people can and some people can't. I mean I have one or two hobbies. I go out [...] here and there, wherever I can and that... well that satisfies me to a certain extent.*

For Mr Phillipson, however, it was not the loss of income, the loss of contact with others, or reduced satisfaction with life, but a loss of independence and change of status:

Braintree 3174 (2270-2295): Mr Bill Philipson

R *[...] It was the acceptance that you were not the man you thought you were. To reconcile to the fact that not only had you lost independence in other respects, but you had lost what you felt had been your own independence, you know? You could spit in anybody's eye and you certainly discovered that you had to look to other people to... to, to not help you but to allow you to... in many respects. I think that was the worst bit. Took me quite a while... to reconcile myself.*

However, others commented on the positive side of retiring and how this improved the quality of their lives. In particular they liked the flexibility and freedom it gave them in their

daily lives. For example:

Hackney 0338 (942-949): Mr (and Mrs) Derek Tibbs

R [...] I'm enjoying my retirement. It's nice to say today 'right we'll go to so and so tomorrow' and then be able to change your mind in the morning, saying 'we won't go'! That sort of thing is nice about retiring.

One of the new opportunities that retirement had afforded was the chance to take on some voluntary work. It could be argued that voluntary work was simply a substitute for paid work in the lives of these respondents, but whatever the reason for doing it, it was clearly an activity a few enjoyed. Five respondents spoke in some detail about the voluntary work they did: one was from Hackney and the other four from Braintree. Work varied from being a church warden or deacon to working with mentally handicapped children to being voluntary drivers for social services. The scale of the work varied widely from twice yearly activities (mentally handicapped worked) to activities up to three times a day (voluntary drivers). What was interesting, in terms of the effects on their quality of life, was the reason why these respondents did this work. Some did it to occupy or satisfy themselves, to broaden their outlook on life, stop themselves 'vegetating' and not feel wasted, and others said they just loved helping and that it was a pleasure. For example:

Braintree 3158 (350-361): Mr George Baker

[voluntary driver; up to three times/day]

R [...] I don't like to think I'm wasted. You know? I don't want to do it for the... so people know that I do it. I just like to do it, if you follow what I mean?

Braintree 3296 (1481-1543): Mrs Amy Ingles

[helps local mother with handicapped daughter's exercise regime, following an appeal in local press; once a week for last seven years]

R *[...] Once you get... take something on, you're committed really. Well I hope to carry on. [...] People, you know what they are like 'oh I do think you're so good to go over there' but it isn't because it's not a hardship [...], it's no great deal doing things for her [...], you're not really proving yourself because Becky's a joy [...]*

A couple of respondents spoke about 'jobs' they did to help out their families or neighbours, and how they enjoyed having this role. For example, in Hackney the role of family caretaker and pet sitter taken on by Mrs Woods (0787) was described earlier (under 'Feelings') and, in Braintree, Mrs Whitwell described helping out her neighbours:

Braintree 3403 (1755-1758): Mrs Mabel Whitwell

R *[...] like my next door neighbour, Paula, will come and knock on the door and say 'Mabel would you mind having the key, the gas man's coming, or somebody's coming. Will you let them in?'*

There was one small group of respondents for whom retirement plans went awry when their retirement coincided with, or was closely followed by, a death or severe illness of a loved one. For example, three months after Mrs Potts retired her husband suffered a severe stroke, which left him with a dense hemiplegia, and she became his full time carer (0643: 957-991). And Mr Shaw (3263: 511-519) described retiring early because he knew his wife was not

well, but she died just three months later.

In summary, in relation to work and retirement, respondents described the positive and negative aspects of work and the subsequent positive and negative aspects of retirement. Retirement allowed for greater temporal freedom, but also meant financial hardship for some together with a loss of status, role and company. A few respondents enjoyed taking part in voluntary work.

13) Old age:

Respondents spoke about specific aspects of being an older person in relation to quality of life. Some described how their expectations of old age had not been met (e.g. 0083, 3183, 3263, 3316), others said they had had no expectations and had never thought about what their old age would be like. Those who found old age to be worse than they expected usually referred to their financial situation, the area they were living in, or their health. For example:

Hackney 0083 (1558-1573): Mr Sid Woolley

R Well I thought over the years I paid in, I thought that I'd have a reasonable existence. I didn't particularly expect to be treated like a Lord or to be able to go here or there. All I expected was that I would be able to pay my way [...] I just expected to go along and live as an ordinary person, as I'd lived when I was working.

Braintree 3183 (3168-3182): Mrs Enid Arnold

R [...] I thought it would be better as regards health [...] I thought it would be

better as far as money, because I thought 'the world's getting better now. Things are going to improve'. But I didn't realise that things in the world were going to get worse instead of better. I thought 'well things will be better as you get old because everything's improving and that people will be looked after better' and this sort of thing.

Being older changed the outlook some respondents had on life. For example Mrs Trentwell, a Hackney respondent, described how her surroundings no longer mattered to her: '*not at my age*'. She felt that older people had '*got no say*', and suggested that she had few expectations of the future: '*what do I want in my life now?*' (0485: 1063-1081, 1255-1264).

A few respondents commented that they either didn't feel old or that old age in the 1990s began much later than in their parents' generation: respondents in their 70s said they felt younger than they believed their parents had at 60 (e.g. 3158, 3251). However young they felt, being aged over 65 still meant the respondents were potentially labelled as 'old', and this frustrated some. For example:

Hackney 0712 (114-120): Mr Peter Shipley

R *[...] Another sad thing is that there is a terrific lot of knowledge and craft amongst people who have retired, but age takes over their capabilities. 'Ah, he's 65 getting on for 70'. I mean I'm 70 but I feel like 65!*

A number of respondents did refer to slowing down as they had got older (0727, 0787, 3026, 3118, 3152, 3263) and this frustrated some. For example:

Hackney 0787 (926-936): Mrs Peggy Woods

R *[...] You can't rush about so much as you used to. You do tend to slow down and so sometimes you get a little bit frustrated if you can't go about things as quick as you used to, like a few years ago.*

Braintree 3118 (293-302): Miss Betty Young

R *I don't recommend it [...] old age. Well you want to do things and start them and find that you can't... you just get tired so quickly.*

But for others old age had its benefits. Mr Baker (3158: 7-50; 64-80) described how the experience of life had taught him that problems were not insurmountable; he felt less inclined to dwell on any difficulties, could put things in perspective and was more accepting of life's ups and downs. In addition, the problems that did face him now were usually of a more immediate nature and of a smaller scale, and this gave him a sense of security.

Braintree 3158 (7-50): Mr George Baker

R *[...] I don't think you have quite the worries and uncertainties, you know?
[...] You don't sort of worry about what the future's going to be, or wonder 'what am I going to be?' or 'what should I do?' so much [...] You are inclined to overlook it.*

A small group of respondents described planning for their old age, particularly in terms of their finances. For some this had worked well and they enjoyed a comfortable retirement continuing to holiday abroad, but for others a lifetime of saving had simply meant that they were less entitled to help in their later years and this led to hardship in some instances, and

ill-feeling. Planning for old age also went awry when respondents had lost a spouse much sooner than they had anticipated, or they or their spouse have suffered ill health. Mr Dunlin summed up the views of these respondents:

Braintree 3175 (433-446): Mr Henry Dunlin

R *I think old age has got to have the worst quality because you're coming towards the end of an era in that sense because we know there's no continuity and it's all very well for people to say 'now you've got your old age and relax' and what have you, but in fact you find that there are many things that arise that make it difficult to relax. If you had all the money in the world and all the facilities in the world which maybe would enable you to offset some of your physical disadvantages, it might be a good life. But for most people it is... it's a reasonable quality; it could be a lot better.*

Those that didn't plan, either in terms of finances or appropriate housing, had taken a more fatalistic view (0582, 0643, 0712, 0727, 3279, 3323), but some regretted this. For example:

Hackney 0727 (217-237): Mr Jack Whitelaw

R *[...] this was where we did go wrong [...] there was a general consensus of opinion: don't buy, why put away for your old age pension and insurance. I mean if you do that you get nothing off the state. And you pay in all your life so you're entitled to take it out again, you know? [...] I realise now it's completely wrong, but there you are. That's what it was then. We didn't prepare a thing.*

Braintree 3279 (1689-1723): Mrs Isobel Thorpe

R [...] you don't realise there's coming a time when you can't even manage the stairs properly and things like that [...] I think we should have been prepared but you don't realise that you are going to get old until it comes.

In summary, in relation to old age, some respondents indicated that their expectations of old age had not been met: they had unexpected problems with health, finances or housing. Others stated that they had never thought about what their old age would be like. In a similar vein there were some who had clearly planned for their old age and some who had not. Amongst those that had planned some were pleased with the way things had worked out, but there were some whose lives had taken an unexpected turn (e.g. sudden loss of a spouse) and felt the forethought had been a waste of time, effort and resources. Amongst those that had not planned there were a group who now wished they had given their old age more thought, either in terms of their financial security or their longer terms housing needs.

A few commented that old age had changed their outlook on life, altering their priorities: this had both a positive and negative effect on outlook in that with old age came the wisdom of years of experience of life, but also a fatalistic view that life was coming to an end and things like their surroundings no longer mattered to them. Old age was frustrating for some in relation to reduced physical ability. For others who had fewer physical problems, 'old age' was equally frustrating because of the labelling of those over the age of 65 years as 'old': they lamented the resulting waste, as they saw it, of skills and knowledge.

14) Transport:

Problems with transport were issues that reportedly affected several respondents' quality of life, particularly those living in the villages around Braintree. Very few respondents were now able, either physically or financially, to run a car; those that had had to part with their cars had found life without one more difficult, (3037, 3152, 3154, 3162, 3251, 3279, 3316: these were all Braintree respondents). They missed the convenience for shopping trips, as well as the pleasure of taking trips out to see friends and family or visiting various places:

Braintree 3162 (907-937): Mrs Marion Williamson

R [...] we used to go out quite a lot on a Sunday evening, not far, but just round the countryside and we miss that. And I also missed it more than anything for shopping, because now I depend on one of the family taking me to do a big shop.

Others regretted never having got a car or learning to drive, particularly when it came to going out in the winter months (3263, 3403). Those that had cars commented on the expense of running them in terms of petrol, insurance and maintenance costs (0338, 3183). A few commented that they would be lost without their cars (0338, 3316, 3323) or moped (3263).

A large group of respondents were therefore reliant on others to provide them with transport (friends or family), or used taxis, public transport or voluntary transport services (such as hospital transport). Mrs Parker, a Braintree respondent, was grateful for the lift a friend gave her to a community group once a week, but now found the process of getting in and out of the

car very difficult (3037: 31-47). Getting on and off buses was a problem for others, particularly since the introduction of driver-only buses and the resulting loss of conductors to assist them (0267, 0283, 3026, 3081). Travelling by bus could sometimes mean travelling some of the way by bus and some on foot (3145), or getting on and off several different buses to reach a destination (0727, 3081). For example:

Braintree 3081 (796-823): Mrs Eileen Stewart

R [...] when I go and see my sister I get a bus from here to the bus park, from the bus park I get another bus to Colchester, from Colchester we catch another one to the other side of Colchester [...] sometimes it's only been for an hour and a half in the winter because I like to get back before it's too dark.

The fact that some bus services stopped too early was a limiting factor for Mr and Mrs Dunlin (3175: 1088-1169) and Mr Able (3095: 603-662). Lack of frequency of buses was a problem for Mrs Jones (0283: 45-52) and Mrs Prior (3167: 681-702), and the increasing cost of bus fares were mentioned by Mr Stratton (3154: 1146-1178) and Mr Philipson (3174: 993-1012) (both Braintree respondents). Changes to the pick up point for coach services meant that Mrs Little and her sister (Miss Fox) could no longer make the trip to see friends in Cambridge (0267: 59-76) and Mrs Jones (0283: 150-171) and Mrs Trundle (0356: 1362-1387) found the crowds on public transport overwhelming.

However several respondents made positive comments about bus services and the freedom it gave them (0356, 0488, 3037, 3095, 3118): some Braintree respondents described improvements in the frequency of bus services (3145, 3152, 3162, 3175) and those in

Hackney spoke about the benefits of a bus pass (which was under threat at the time the interviews were conducted) (0356, 0512).

Other modes of transport mentioned were Dial-a-Ride (0283) and a village minibus service (3167). Dial-a-Ride was available to some respondents in Hackney, but only mentioned by Mrs Jones who was frustrated by the inability to be spontaneous when using the service:

Hackney 0283 (150-171): Mrs Thelma Jones

R *[...] I had got one of those Dial-a-Ride things, but I've never bothered with them because I make up my mind suddenly to go somewhere. You've got to give them a day's notice, so what's the good of it really? I mean, see, I don't know how I'm going to feel tomorrow, whether I'll, where I'm going, or what I'm going to do...*

By contrast, Mrs Prior enthused about a minibus service based in her village outside Braintree, which was run by her older people's club. It ran a regular service into Braintree and back for £1, and because it was a service dedicated to older people part of the driver's role was to help people on and off the bus (3167: 559-583).

In summary, in relation to transport, car ownership was a luxury that few respondents could afford in their later years, thus the majority of respondents were reliant on public transport. Although some commented on the positive aspects of transport services (such as increased frequency of a service in Braintree and the provision of bus passes for pensioners in Hackney), limiting factors included the cost (Braintree), the infrequency of services, difficulty

getting on and off buses, the early ceasing of services in the day, and problems with routes.

15) Crime:

Fourteen Hackney respondents (0004, 0028, 0212, 0267, 0283, 0338, 0485, 0488, 0503, 0512, 0582, 0643, 0712, 0787) and six Braintree respondents (3037, 3154, 3183, 3185, 3263, 3323) spoke about crime and feeling unsafe, and the detrimental effect this had on their quality of life. Miss Skipton's comments were typical of Hackney respondents:

Hackney 0028 (1310-1363): Miss Beryl Skipton

R Do you know there isn't one night... I'm not a good sleeper now [...] and sometimes I'm up at 2 o'clock in the morning. I'm walking round the flat and one night you don't get police along here [...] you can get it every time here, every time.

Comments from Braintree respondents usually referred to their fears for the safety of their grandchildren. For example:

Braintree 3185 (1258-1295): Mrs Enid Arnold

R [...] me granddaughter [...] she's out a lot. [...] So when she goes I say 'be careful Julie where you park' and what have you. 'Yes Nan'. So I said 'no talking to strangers'. They've heard it so much from me (laughter).

The effect that these fears had on respondents' quality of life was a reluctance to go out alone, and a reluctance to go out at all after dark which could be relatively early in the day in winter

months. This had the knock-on effect of increasing loneliness and boredom as described earlier under 'Feelings'. When they did go out some experienced anxiety (e.g. 0712: 1501-1594) and felt they had to be 'on their guard' (e.g. 0787: 86-110). For example:

Hackney 0512 (186-204): Mr White

R [...] You're frightened in case you're going to get mugged. Because like [...] the wife bought me a nice watch when we was younger. Well I treasure it really. I say to meself 'well it's something lovely'. But I'm frightened to wear it to go out. So I'm leaving it put away somewhere, so I'm not getting the beauty of it.

It wasn't just street crime that was a concern, some feared crime in the home, especially those living alone. Mrs Arnold, a Braintree respondent, had always had a dog but was no longer able to have one as she couldn't manage to take it for walks: not having a dog any more made her feel more vulnerable to burglary (3183: 2000-2077). Respondents in both areas mentioned the visible lack of policing (0267: 551-566; 3167: 1604-1640).

Some respondents reported that they simply didn't open the door after dark (e.g. 3152: 1453-1486). And several respondents described steps they, the council, or housing associations had taken to increase their home security (such as door chains, security locks, bolts, entry-phones/intercoms, and door grilles/security gates, steel doors, and alarm systems) but how saddened they felt at having to do so (0356, 0503, 0608, 0643, 3026, 3037, 3185, 3279, 3316). For example:

Braintree 3279 (1442-1498): Mrs Isobel Thorpe

R [...] *I don't see why you should have to lock yourself in. It's all wrong isn't it.*

In summary, in relation to crime, respondents described a fear of both street crime and crime in the home and the effects this had on the quality of their lives. There was a reluctance to go out alone, particularly in Hackney, and a reluctance to go out after dark. When they did go out some reported feelings of anxiety and an awareness of the potential for street crime. In addition, respondents described a variety of steps that had had to be taken to protect their homes against crime, either by themselves or by outside agencies.

16) Tasks:

The relationship between quality of life and the process of carrying out tasks of daily living was spoken about by some of the respondents. This has links with the earlier category headed 'Health' because health affected respondents' ability to carry out tasks, the category headed 'Control' and the category to follow, headed 'Independence'. Most of the tasks related to activities within the home, with the exception of shopping.

The ability to do their own shopping appeared to be one of the respondents' strongest yardsticks, or indicators, of a sense of independence and a source of pride (*'I do my shopping and I'm quite happy – providing I feel well'*: Hackney 0004: 160-162 Mrs Mary Chalker; *'I do my own shopping'* Braintree 3081: 62-64 Mrs Eileen Stewart). Some were unable to do any of their shopping, others could do the light shopping, and a further group remained totally

independent.

The difficulty of relying on others to do some or all of the shopping, be they family or friends or service providers, was that respondents did not have the opportunity to select their own produce and those who were totally reliant on others didn't get the opportunity to browse the shops, compare prices and see new products. In addition they could not impulse buy and if they forgot to put anything on their list they had to wait for the next shopping trip to request it. For example:

Hackney 0267 (177-180): Mrs Gertie Little and Miss Evie Fox

R1 [...] The only thing is we grieve that you just can't, you know, you might forget something to put on your shopping list. And things like that. You can't get out.

Braintree 3316 (885-919): Mrs Elsie Pritchard

R [...] it would be nice to be near shops or somewhere where I could go and do my own little bit of shopping. You see I write my shopping list and I get all I want brought in, but you tend to live at basic. I mean if you go round [...] the street and the market and say 'we haven't had that for a long while'. You get it, you see? [...] But when I write a list out it's more 'bread, butter, tea' [...] but there's lots of little things that you miss that you don't see and you don't think of.

But the process of shopping had changed over the years for this cohort of older people. There was less emphasis on markets and small specialist shops such as butchers and greengrocers,

and a greater proliferation of supermarkets and shopping centres. Although supermarkets had advantages in terms of streamlining the process of shopping, some of the social elements of shopping had been removed and some respondents found supermarkets overwhelming and confusing (e.g. 0512: 1392-1415). In addition the introduction of supermarkets to the Braintree area had led to the closure of some local shops in the outskirts of Braintree, as well as in some of surrounding villages. Where some respondents had formerly been able to walk to a local shop they now had to travel further to a supermarket, and at greater cost:

Braintree 3118 (804-826): Miss Betty Young

R We haven't got the shops have we now [...] we all have to shop at the Co-op. It's the only shop there is [...] if you go to Braintree you've got to get the shopping home. And you've got to pay your bus fare. So you don't really gain anything.

Whereas in the mid 1930s the larger villages surrounding Braintree had had clothes shops, shopping for items such as clothing in the 1990s always meant a trip into town for those living in the villages. Again the cost of travel on public transport was a concern for those that had to do so (e.g. 3152: 32-41; 3167: 751-789). Some had tried mail order shopping, but were still reliant on others if they had to return items via a post office (e.g. 3316: 952-959).

Tasks that respondents referred to within the home included housework, laundry, cooking and personal care. For those who could no longer do their own housework or do it as thoroughly as before, coming to terms with this fact and accepting different standards, was difficult. Mrs Argyle's and Mrs Whitelaw's comments were typical of others in the same predicament:

Braintree 3026 (58-60): Mrs Ruby Argyle (wife of Mr Hugh Argyle)

R2 [...] *having been a workaholic all my life, I am not now able to keep my home clean... in the way it should be kept and in the way I've always lived.*

Hackney 0727 (757-794): Mrs Whitelaw (wife of Mr Jack Whitelaw)

R2 *I used to strip my place every week but I don't now [...] I used to do it every week at one time. All me ornaments used to be washed every week.*

Waiting for others to help with incidental tasks was also a source of frustration. For example, Mrs Prior, a Braintree respondent, described waiting several days for someone to ask to change a light bulb for her. She finally asked someone who had come to do her garden to help, but had clearly found this frustrating: '*you sit here and watch*' (3167: 1404-1426).

A few respondents mentioned the help they got, usually from family, with their laundry; dealing with bigger things in particular, such as sheets (e.g. 0083, 0485, 3081). A few had help from family with cooking, particularly if they were living with family or if they were single men living alone (e.g. 0083: 1174-1198). But for most respondents, cooking the main meal was an important part of the day, which most prepared for lunchtime (e.g. 0267: 214-216; 0608: 703-707; 3263: 175-185; 3279: 0085-1203), and most took pride in. For example:

Braintree 3081 (107-107): Mrs Eileen Stewart

R *And I do me own cooking. And everything's lovely.*

Respondents took a similar level of pride in their ability to look after their own personal hygiene. Even if they had difficulty with shopping, cleaning and cooking, their personal care

tasks were perhaps the last vestige of independence:

Hackney 0083 (1681-1683): Mr Sid Woolley

R [...] I've always been fairly clean with myself, and I couldn't imagine if I was incapable of doing it.

The process of getting in and out of the bath was difficult for some but there was a reluctance amongst some respondents to accept help with this (e.g. 0283: 401-451). Those that did accept help were extremely grateful for the help they got:

Braintree 3026 (348-380): Mrs Ruby Argyle (wife of Mr Hugh Argyle)

R2 [...] she's a lovely girl, she just looks after me wonderful. In fact I can't wait for her to arrive...

In summary, in relation to tasks, respondents spoke with a certain pride about those activities they were able to carry out for themselves, and about the frustration of having others to do tasks for them, shopping in particular. Changes in shopping styles, as well as their own abilities, had had an impact on the quality of their lives. Respondents also spoke about tasks within the home such as cooking, housework, laundry and personal care tasks.

17) Independence:

Respondents spent some time talking about independence in relation to quality of life: those that felt they still had it relished their independence and were determined to hold onto it for as long as they could despite offers of help from family, friends or services. Mrs Trundle's and

Mrs Arnold's comments were typical:

Hackney 0356 (1048-1051): Mrs Doris Trundle

R [...] and me husband still cleans the windows and my grandson said 'I don't know why you do', he said 'just tell me and I'll come and do them'. He said 'when I need help, I'll ask for it'.

Braintree 3183 (290-306): Mrs Enid Arnold

R [...] I feel that if I give up now, that would be the beginning of the end of me. I feel I've got to, I was saying to my sister only the other day, I said 'I don't want people treating me as an invalid, because once they start [...] I shall develop into an invalid'. I feel that while I can struggle round and make myself do things it's better for me, cause I've seen it happen. They've just given up.

Respondents also referred to independence when they spoke about living on their own, or rather apart from their families and other dependents. Two slightly different examples of this came from Mrs Woods and Miss Skipton:

Hackney 0787 (767-791): Mrs Peggy Woods

R I think it's very important to be independent, you haven't got to call... I mean your family's good to you, it don't matter how good they are, I would never want to live with them. I would always want to have, even if it was one room, I would never want to live with them [...] it's nice to know you can get up in the morning at whatever time you want to, you can use your own bathroom, whereas if you lived with relatives you've got to share a bathroom. And you

can do your own bit of cooking, your own kitchenette. And I think it's very important.

Hackney 0028 (466-481): Miss Beryl Skipton

R See that quality is nice... I can go out and meet people [...] But if my sister hadn't gone into a home I wouldn't be able to do that because I couldn't leave her. [...] You see that would be hard.

Respondents sometimes spoke about other people that they knew or were acquainted with, who were more dependent on others than themselves, and they sometimes referred to these people as having 'no life' (e.g. 3118: 313-333; 3145: 1503.1534). Respondents who were dependent on others for help didn't rate their quality of lives as very good. For example:

Braintree 3183 (60-78): Mrs Enid Arnold

R [...] when you have to get to the stage where you've got to rely on other people, you know, to run you around, get this for you, get that for you, it's not so good. [...] compared to some people I'm lucky there's people on hand that will help. And some people haven't got that even, you see, so compared to some I'm lucky, but I don't enjoy my life very much.

Where respondents did have to accept help from friends or family, there was a frequently repeated fear of being a burden (e.g. 'I've got to bother her again', Braintree 3183: 1461-1489, Mrs Enid Arnold). This was not mentioned in relation to help from services. Respondents wanted to be able to reciprocate in their relationships, to maintain a balance. For example:

Hackney 0004 (449-451): Mrs Mary Chalker

R [...] Whenever she comes here she brings... say I want shopping, she won't take a penny and I get so annoyed. I can't bear it.

Hackney 0083 (1322-1322): Mr Sid Woolley

R But there's nothing I can do in return.

Some respondents did manage, in a small way, to achieve reciprocity and it clearly pleased them:

Hackney 0356 (1833-1836): Mrs Doris Trundle

R [laughing] Well we help one another. Now he washes my back, I wash his.

Braintree 3251 (596-609): Mrs Maud Turner

R Sometimes I take him a cake or two to eat but not a lot, you know, just to help cheer him up a little bit and he has... he's had, sometimes, a beetroot given to him and he'll cook it and bring me one round. [...] You see, you help each other you see.

In summary, in relation to independence, those respondents who felt they still had their independence clearly valued it and were determined to hold on to it despite offers of help. Independence could refer to being able to carry out tasks on their own, particularly those outside of the home such as shopping, but it also referred to living a life independently of others i.e. away from family and dependents.

Those that were more dependent clearly indicated that this impacted negatively on their

quality of life and that they were fearful of becoming a burden to family or friends; this was not mentioned in relation to services. Respondents who were able to reciprocate help appeared to be the most accepting of help.

18) Personality:

A small group of respondents (less than half) spoke about the effects of individuals' personalities or natures on their quality of life. Although this was alluded to when respondents spoke about happiness, contentment and even loneliness (as described earlier), some respondents spoke specifically about the effects of personality or outlook on life in relation to quality of life. They broadly suggested that 'happy-go-lucky' types were more inclined to take life in their stride, have an easier time and thus better quality of life as compared with 'moaners' or those who were 'down-in-the-dumps' all the time. For example:

Braintree 3174 (2015-2053): Mr Bill Philipson

R [...] I think the individual's personality would be a big factor in that. I think it's essential to have a sense of humour, for example, and no matter how you might moan about being deprived of various things, if you can within yourself to a certain extent say 'well it's all a bloody joke anyway' (laughter)

The importance of 'having a sense of humour' featured in a several interviews in relation to having a good quality of life, as was politeness and having an 'even temperament'. Thus respondents spoke about those who were 'worriers', 'loners' and 'complainers' as having a poor quality of life. Some respondents referred to themselves as 'worriers' or 'loners', but

none admitted to being a 'complainer' or a 'moaner'. Mrs Jones's quote in relation to 'moaners' or 'complainers' was typical of others:

Hackney 0283 (516-533): Mrs Thelma Jones

R *[...] they moan a lot about different things whereas me, I just say 'well if I can't help myself just pass it by'. That's all. 'It will come out alright in the end'. But these people when they go to a friend they keep telling me what's wrong with them, 'what's wrong with me, I've got this hospital appointment, I've got that hospital appointment'. And I think to myself, 'what am I doing here? Why do I want to hear all their troubles for?' [...] I wouldn't talk like that. I mean to say, you know, everybody's in pain. We know as you get older you can't, you can't be perfect, can you? [...] It's a different outlook on life.*

Those who described themselves as loners saw this as a positive trait in that they didn't get lonely and were happy in their own company; whereas those who described others as loners saw this as a negative trait in that they 'kept themselves to themselves', or were 'unsociable'.

In summary, in relation to personality, respondents felt those with a positive outlook on life generally fared better with regard to their quality of life than those with a negative outlook.

Quality of life definition category

Although respondents were not systematically asked to provide a definition of 'quality of life', some respondents did spontaneously provide what could be termed definitions,

commenting on the concept as a whole as opposed to its various components. Others provided summary statements listing potential components. These two types of concept 'definition' could be used to organise lay definitions in the taxonomy of quality of life definitions presented in Chapter 1. Just as it proved possible to classify 'expert' or professional definitions into three subtypes depending on their structure and content, so it could be possible to organise lay definitions in a similar way. Thus, within the broader category of 'lay definitions', there could potential be two sub types e.g. type I, global definitions, and type II, component definitions. If such a classification remained limited to these two types (type I and type II) and the focused definition type (type III, in which definitions were focused on just a few of the potential components of quality of life) did not emerge, then we could perhaps consider the lay definitions to have greater validity. The development of such a classification would require further systematic questioning of laymen regarding their definitions of quality of life, and the questioning of respondents from different age groups of the population e.g. younger adults.

There was a general suggestion that quality of life meant different things to different people, that it varied between individuals or depended on the person. For example:

Hackney 0004 (14-15, 879-882): Mrs Mary Chalker

R Well each one has got their own different opinion haven't they? [...] It depends on the person. Some people are so, they're just simple, let's look at it that way... they're not, they just don't think, you know, but it depends on how they want to live... what they call a good life.

Hackney 0338 (1805-1813): Mr Derek Tibbs

R *It's rather difficult to define. As I say, quality of life is what you make it. You could have a couple, like us, that have no money but they could be quite happy with their lot. They just have enough to live on and they're not bothered by anything else. That is their quality of life. I think it depends on the individual, personally.*

Braintree 3323 (400-413): Mrs Dot Wickford

R *It depends on the individual. I mean we're quite happy leading a simple life. But other people may think it's dreadful. It's the individual.*

Others referred to the nebulous nature of the concept:

Braintree 3296 (2075-2101): Mrs Amy Ingles

R *I don't know. It seems such a nebulous thing, quality of life. I don't really know what it means. I mean to me you get up in the morning and you go through the day and if you haven't tipped a kettle of boiling water over yourself it's probably been a good day. I mean, how do you... I don't know how you define quality of life.*

Hackney 0712 (1557-1592): Mr Peter Shipley

R *[...] I don't know how you... how you assess it or how you restore it or how you, how it's analysed, what is... how I think quality of life is anything what takes the problems away from you. More so mentally. I mean nothing to do with physical or anything like that. It's just... psychological and mental. What people go through now. You know? If you've a window broke... 'it's*

going to be my one next'. That's the sort of thing and that's just an isolated incidence. If you hear a row... 'that sound's getting nearer to me'... 'coming on this floor and I hear it getting nearer'. Now all those are the sort of thing that I say is... you know, is the quality of life. And it's disturbing. Very disturbing. More disturbing for elderly people who are on their own where there is no hand to reach out, even to say 'did you hear this, did you see that?' Nothing.

Most frequent, however, was the suggestion that it was a multifaceted concept. When respondents started to summarise the various components of quality of life, the lists seemed to grow and grow. A typical quote came from Mrs Clayden:

Hackney 0488 (1819-1855): Mrs Elsa Clayden

R I'd ask them whether they was satisfied with what they, with what they was... what amount of money they had and could they cope with it? I would ask them what kind of life they lead if they was married, between husband and wife? I would ask them what their little comforts they liked? Maybe it could be chocolates, sweets, ice cream - it's little things like that that mean a lot to old... not to me... I'm not talking about me, I'm talking about old people generally. A man, he might like to go and put a bet on. He might like to go and have a pint and his wife might not like it. So that's a comfort that he can't have. I'd ask them if they felt confident with their doctor. If they felt their doctor was prescribing the right thing or doing their best to his knowledge to what they were telling him [...] And also what... are they happy with their

parents or grandchildren visiting them? [pause] And when they are alone, completely alone, did they get distressed, anxious or whether they was happy to be left sometimes without anybody [...] What else? Are they warm enough? Have they got enough bedclothes? [...]

In summary, some respondents spontaneously provided a definition of quality of life, or listed potential components, and acknowledged that quality of life meant different things to different people. Some described it as nebulous concept and others as a multifaceted concept. Given this, there may be potential, through further studies, for elaboration of the lay definitions category of the taxonomy presented in Chapter 1.

Set questions category

‘Set questions’ refers to questions that, although not prescribed, tended to appear in several interviews, particularly the later interviews, and so are useful sources for comparisons. These questions were more prevalent in the later interviews because of the nature of the interviewing process and the attempt to attain saturation of themes. The questions were very simple in format but had the potential to generate quite complex answers. The aim of each was essentially to encourage respondents to talk about the concept of quality of life. Their precise answers were perhaps not as important as they way they spoke and the themes underlying their answers.

The 'best quality':

The question asked most frequently was a variation on '*When you look back on your life, which time so far do you think has had the best quality?*' (0083: 731-732). Variations on this question were asked in 16 of the 17 Hackney interviews and 22 of the 23 Braintree interviews. There were a considerable variety of answers, but some patterns of responses came through.

Interestingly, four Hackney and three Braintree respondents said that their old age was the best time of their life: these respondents reported having no responsibilities, a steady income, a comfortable home, not having to go to work, and an easier pace of life. For example:

Hackney 0283 (607-617): Mrs Thelma Jones

R Oh definitely this is the best time. Oh yes. I mean to say you're... money wise I am quite contented. I've got everything I want, so I think this is the easiest time really.

Braintree 3185 (744-750): Mrs Hilda Potts

R Well I think now. Well how shall I put it? Well I had to work hard for a little. I didn't have much but, you know, it was all go and I had different ones staying here in the war.

Four Hackney respondents and seven Braintree respondents chose their married life when they were together as a family. They enjoyed the companionship of marriage and the pace of family life. All of these respondents were now widowed. Four of the Braintree respondents

particularly singled out the period when they were first married, their children were young and they were embarking on a new life. Mrs Watson's quote was typical:

Braintree 3152 (448-458): Mrs Ivy Watson

R Well I think the nicest time really is when your children are young. I think so because you always keep together. Once they get grown up and sort of out on their own, they're more worry. And em, you've got to let them go.

By contrast, three Hackney respondents and five Braintree respondents opted for a later period, usually from their mid 40s, when their children were either old enough to leave home, or old enough to be relatively independent. This increased respondents' freedom at a time when they perhaps had more disposable income and fewer responsibilities at home.

Three Hackney and three Braintree respondents chose their youth (18-25 years) as their best time in terms of quality. They had started earning money, enjoyed their work and lived for Saturday night. They looked back on it as a time of limited responsibility and a lot of fun.

For example:

Hackney 0512 (2442-2471): Mr Arthur White

R [...] you went to work, you went to work for only one night only and that was Saturday. And then you used to put your new clothes on. You only had one suit. And nice shoes [...] and though you didn't have a lot of money, but you went and you could enjoy yourself.

Two Hackney respondents selected the period when their grandchildren were born and they

participated in their care. One respondent from each area chose their childhood as the best time.

Finally, three respondents from Braintree found it difficult to answer the question as each period of their lives had had good and bad times, and no one point stood out as particularly better than the others. For example:

Braintree 3175 (421-431): Mr Henry Dunlin

R *Um... it's very difficult to say because when you're young and you have your health and vigour and a lack of worry about the future, which means that you enjoy the things that are there. In the middle vantage in life you've got a wife and your children and you're settled in business or in a job and your life is taken up with a sort of consolidation and that is also a good but worrying period. When you get, when you get elderly that is not a good period because you've lost all those things really... you've lost your youth and your vigour, you've lost that feeling that you're still building something inside because you've built and you're passed that.*

Braintree 3296 (1946-1964): Mrs Amy Ingles

R *[...] I think it's been a sort of mixture all along. There's some good bits and bad bits all along the road, just the same as there is now. There's still jolly good bits and I hope there are more to come (laughter). I couldn't, I mean I've had some bad bits. The War years were... I lost a brother in the War. On the other hand they were... you know we had some jolly good times in those years. I think that's the same all through really [...] But I couldn't honestly*

say, I think the worst time I had recently was when my daughter's marriage failed. That was a very unhappy time. But in the main there's more good bits now than bad bits. Not madly exciting although I do have one or two moments, I mean I spent my weekend in Paris and things like that. And, you know, they're the high spots.

Together, all of the responses to this question and its variants indicate is that this cohort of respondents appears to have valued periods of financial security, together with the companionship of marriage and friends, relief from responsibility, and the acquisition of independence, flexibility and freedom in their daily lives.

The 'worst quality':

The opposing question to the question of which period of their lives had had the best quality so far, was of course which period had the worst quality. For example '*Looking back again then, which period do you think had the worst quality of life so far?*' (0503: 1628-1629). Variations on this question were asked in 10 of the 17 interviews with Hackney respondents and 15 of the 23 interviews with Braintree respondents. Thus it was less frequently asked than the positive question.

As alluded to earlier, by far the most common response to this question was a reference to the War. This was true both for those living in London and in the Essex countryside: four respondents from Hackney and six from Braintree spoke about the War. Some spoke about

the difficulties of bringing up children alone whilst their husbands were away fighting, others spoke about the blackouts and air raids, and some about rationing. Most commented that there were positive aspects to the War: the friendships that developed and good experiences of some of the Londoners during their period of evacuation.

Hackney 0582 (728-730): Mrs Joan Carter

R Well I think in the War. I was on my own, dreadful that, with two children under my arms running to the shelters. And then we was evacuated when the shells come.

Hackney 0608 (1220-1230): Mrs Betty Hepworth

R For me? Well my hardest time was when war broke out. I was 19 when the war broke out and I think that took five years, six years of everybody's life at my... that was the worst time. Being in the shelters all night and just coming out and the sirens goes on and you had to go again. And then you've got to go to work. That was the worst period really in my life. It was terrible. I would never like to see it again.

Braintree 3162 (121-148): Mrs Marion Williamson

R Well I suppose the '40s, the war years really. A lot of people may say we had rationing and things like that, but I don't think... we had ample to eat and that you know. But perhaps we always had the worries of wondering if your loved ones would come home... family and friends.... And yet having said that, everybody was very friendly to one another during the war years. Although it was a bad, a war... it was still, an awful lot of good things came out of it.... You now, you didn't lock your doors and neighbours popped in and they had

had letters from their husbands, and likewise [...] there were really good relationships with everyone I think.

Just three respondents chose their old age as their worst time, three selected a time when they had to care for a close relative who was ill (e.g. their husband or mother), and a further three a time when they themselves were ill. In each of these cases one respondent came from Hackney and two from Braintree. Two respondents (one from each area) spoke about aspects of their working lives and a further two (again, one from each area) spoke of the year following the death of a daughter-in-law or son-in-law, and the role they had had to play in helping in the care of young children. One respondent, who was widowed at an early age, spoke about bringing up her family alone. One further respondent was unable to identify a period with the 'worst quality' in their life.

'Better than you':

Twelve respondents in Hackney and eleven in Braintree were asked variants of the question '*Can you think of someone who you think has got a better quality of life than you?*' (0503: 442-443). Nine of the twelve Hackney respondents referred to people who had more money than them, often referring to the fact that others were homeowners; by contrast just two Braintree respondents said this. Two further Braintree respondents described other older people who still ran cars and the freedom this gave them, they usually also referred to the fact that they themselves could not afford the running costs of a vehicle; no one in Hackney mentioned this. A further two Braintree respondents who were widowed spoke of others who

were still married.

Individual respondents spoke of others who were still in their youth (Hackney), who were stronger (Hackney), who did not have to care for a sick husband (Hackney), who were still mobile (Braintree), and those who truly believed in God (Braintree).

Three of the eleven respondents in Braintree who were asked the question were unable to identify someone whom they felt had a better quality of life than them. In addition, one of the Hackney respondents, Miss Skipton, who had referred to people who had more money, also added that if she compared herself to her neighbours, rather than to those who were financially better off than her then she was in fact satisfied with life:

Hackney 0028 (746-752): Miss Beryl Skipton

R I can't think of anybody. I suppose the, the... rich people have got a better life. A different life but... then I won't compare myself with these people, you see? But if I'm going to compare my life with say the neighbours next door, I'm satisfied with my life here.

‘Worse than you’:

The opposing question to identifying someone with a better quality of life was of course trying to identify someone with a worse quality of life. For example, ‘*can you think of somebody who you think has a worse quality of life than you?*’ (3154: 2401-2402). Variants on this question were asked in 20 interviews: six in Hackney and 15 in Braintree.

Three of the six Hackney respondents and six of the Braintree respondents spoke of others they knew or imagined were disabled in some way, usually in terms of their mobility and usually rendering them housebound. One of the Hackney respondents added that to be housebound and alone would be particularly difficult. Four other Braintree respondents also spoke about others who were, or might be, alone or widowed.

Three respondents (one from Hackney and two from Braintree) referred to individuals' personalities: that is people who had a negative outlook on life, or whom they regarded as 'bitter' or 'moaners'. For example:

Braintree 3162 (422-429): Mrs Marion Williamson

R Well they seem so bitter of what life's dealt them like, you know? [...] One friend in particular who's financially very comfortable, but who lost their daughter through not accepting her son-in-law. So she's turned out to be a very bitter lady. [...] you know she had so much and yet she had nothing did she really?

Two respondents (one from each area) referred to younger people who had difficult lives: either children of families who had broken up and lived in difficult circumstances, and women whose marriages had failed leaving them with young children to bring up alone. One other respondent from Braintree spoke of the potential difficulty of caring for a husband who was immobile.

‘What would make the quality of your life better?’:

At Stage 1b of the study, respondents were asked ‘what would make the quality of your life better?’. At this later stage of the study, variants on that same question were asked in 28 of the interviews: 14 in Hackney and 14 in Braintree.

Nine respondents (five from Hackney and four from Braintree) wanted more money, either in the form of a windfall or an increase in their regular pension. Mrs Arnold, who was effectively housebound by severe arthritis and shared her home with her sister, spoke in some detail of what life was like living within her income, and how she had learnt to be economic.

Below is just an excerpt from her detailed description:

Braintree 3183 (3398-3421): Mrs Enid Arnold

R [...] well I have to be economical. That's the thing and I would really like to have some more heat, to be able to have more heating. Well if I've got money I could have more heating. I mean at the moment I can manage with that one bar but if the weather turns really cold, even two bars is not enough for me. If it's really cold and I have to walk about with my anorak on during the day. Oh yes, if you sit down for half an hour or so even that's not warm enough during the day. But I mean I manage. I'm not going to say that I go hungry or anything like that. I always get enough food. I'm not going to say it's always the food I'd like to have, but I don't go hungry. We don't go hungry. I've found out ways and means of stretching things, you know. You can have one egg for two of you instead of two. If you boil them you use two, but if you

scramble it and put milk in you can make it go on toast and one egg will do for two. All things like that you learn to do. But at the same time it would be nice to have one to yourself sometimes (laughter). You do learn. You have to. I mean I've never had to watch the pennies like I have now. Never. It is really hard, really hard.

Three respondents mentioned gardens: one Hackney respondent wanted a garden or a balcony and two Braintree respondents wanted either a smaller garden or a gardener. Two Hackney respondents wanted to move out of Hackney (one of these wanted to move to the seaside), and a further Hackney respondent wanted to see an improvement in their living conditions. Just one Braintree respondent talked about moving in response to this question, and that was in relation to a move to a bungalow, but within the Braintree area. Another Braintree respondent wanted a car.

Two Braintree respondents referred to a need for greater companionship: one in terms of an awaited move to an old people's home and the other in terms of his desire for his wife to be alive again. One respondent in Hackney spoke of a desire for her family to be nearer.

Two respondents in Hackney spoke of their desire for better health, usually in relation to a desire to go out more. Mrs Clayden, a Hackney respondent, listed this as one of several factors that could improve her life, but most of these were related, in some way, to her failing health and increasing frailty:

Hackney 0488 (1501-1523): Mrs Elsa Clayden

R *[...] To be able to walk properly would make my life much better. Or to be able to get out [...] If I have to go to the hospital they send me transport. [...] I think a doctor should visit their patients say once in three months if they don't see their patients.*

And finally, six respondents (two from Hackney and four from Braintree) could not identify anything that would make the quality of their lives better, although several of these added that they would not like to make any changes at this stage in their lives.

‘What would make the quality of your life worse?’:

Variants on the above question, again also used in Stage Ib of the study, were asked in just five interviews, and all of these were in Hackney. Three of the respondents spoke about losing their independence (for example, having to move into an old people’s home, not being able to get out, or having to get someone else to do the shopping), and two spoke of losing friends or family.

It would be interesting to compare the responses given to these latter two questions (what would make the quality of your life better/worse?) at this stage of the study (Stage II) to those given at the earlier Stage Ib, by respondent. If differences in responses were found these might reflect the timing of the two stages (there was a time lag between the two data collection points) or the different interview styles (e.g. Stage Ib followed a the structured

interview for the parent study and was a brief, structured (although open questioned) format whereas Stage II was an in-depth interview). The number of respondents who were asked these questions at Stage II were, however, rather small and the question wording varied slightly by respondent.

‘Compare back’:

In 20 interviews (seven in Hackney and 13 in Braintree) the respondents were asked to think back and compare their quality of lives to their parents’ lives. For example *‘when you think about your life when you were younger, when you were a child maybe, can you think about what the quality of life was like for your parents?’* (0787: 396-398). All but two of the respondents who were asked this (or a similar) question, described their parents’ lives as much harder. They described differences in the way homes were run in terms of the lack of modern appliances, lack of space, poor living conditions and poverty, despite being ‘hard workers’. Yet at the same time many described happy homes where family life and values were considered paramount, and a greater feeling of safety. Respondents contrasted this sharply with life today. For example:

Hackney 0028 (600-631): Miss Beryl Skipton

R Well don't forget my mother had 12 children. See? And it was only my father working. He was a hard working man, but they never had wages like they do today. Although the cost of living was different. It's a different life. It was a different life in those days. There wasn't all these killings. There was killings, but not like today. And muggings. I mean you could go out at night. Now you

think to yourself 'should I go out?' Literally you can't go on your own. You see? But in those days it was a different thing. You... in those days you could leave your door open. A neighbour could walk in and out. But you can't do that today. You've got to lock yourself up.

The two respondents, both from Braintree, who did not respond in this manner, both felt their parents' lives had had a good quality. Mrs Williamson described her parents' lives as 'very comfortable' due to her father's job as a sea captain which provided a good income (3162: 549-565), and Mr Shaw considered that, for the time, his parents' quality of life had been 'good' although compared with life today it would have been very poor (3263: 711-734).

'Future':

Fourteen respondents were asked variations on the question '*what do you think the quality of life will be like for say my generation when I'm your age?*' (0338: 1419-1420): five were from Hackney and nine from Braintree. Nearly all the responses were negative, with three of the respondents from Braintree using the expression '*I dread to think*', before going onto elaborate.

The most common response was from Braintree respondents, five of whom described a world where there were greater material goods, more automation and more money, but with lower values and less family unity than in their youth, or even than 'today' (the 1990s). There was a general feeling among these respondents that younger people had an easier life than they

themselves had had, and they wondered how they would cope in the event of a downturn in circumstances. A typical quote came from Mrs Watson:

Braintree 3152 (917-931: Mrs Ivy Watson)

R [...] I mean I've got three teenage grandsons and they always say 'thank you' for what we give them and that kind of thing, but I don't think they appreciate the effort that goes behind. Everything comes so easy.

I Yeah. They've got a different set of values really, haven't they?

R Oh yes. Different altogether. I don't think that's a good thing really because if things do get harder for them they're going to be pretty miserable.

Only one respondent, Mr Dunlin, from Braintree (3175: 1309-1326), considered that life would be better. He described how better education would increase standards and create a population who would be less tolerant of poor standards. He illustrated this by comparing the differences between servicemen returning from the First World War to those who returned from the Second:

Braintree 3175 (1309-1326): Mr Henry Dunlin

R I think they are going to be much better because they, they'll be that much more educated and therefore be much more understanding and less accepting of the situation. As the generations go on, you see, there's a difference between the servicemen who were in the First World War who came back and were disgracefully treated and the servicemen in the Second World War who came back and insisted that they were going to have a share and that in fact forced the National Health Service.

‘Most important’:

Fifteen respondents from Hackney and 18 from Braintree were asked variants on the question ‘*what do you think is the most important thing to the quality of your life?*’ (3158: 1975-1976). Usually this question was asked towards the end of the interview and was frequently prefixed by a reminder to respondents of the various factors they had mentioned throughout their interview. For example: ‘*We’ve talked about health, we’ve talked about money, things like holidays and family, which thing do you think is the most important to the quality of your life, particularly in your old age?*’ (3403: 1715-1718).

Health alone was considered the most important thing to their quality of life by five of the Hackney respondents and six of the Braintree respondents. A further three Braintree respondents mentioned health in combination with other factors i.e. with happiness (two respondents), with family or with sufficient money.

Family alone was chosen by three Hackney and three Braintree respondents, but a further two Braintree respondents chose family alongside happiness, or health and sufficient money. Happiness, contentment or personality factors alone were considered the most important by two Braintree respondents and a further three Braintree respondents opted for these factors combined with health (two respondents) or family. No one in Hackney suggested happiness, contentment or personality as the most important thing.

Two Hackney respondents and one Braintree respondent chose their immediate environment, social world or locality (including their home) as the sole most important factor and one further Hackney respondent chose their home combined with sufficient money and companionship (or marriage). Three Hackney respondents chose companionship or marriage as the most important factor, but two of these combined this with sufficient money (two respondents) and a good home.

Three respondents said that sufficient money alone was the most important factor: two were from Hackney and one from Braintree. One of these Hackney respondents, Mrs Chalker, described the usefulness of money in terms of the independence it provided:

Hackney 0004 (995-997): Mr Mary Chalker

R The most important thing is not to go hungry and to be able to, not to depend on other people to give you things. To be a little bit independent.

Two further Hackney respondents had mentioned money in combination with marriage or companionship (two respondents) and a good home. And finally, one respondent from Braintree described music as the most important thing in their life.

As can be seen above, some respondents were unable to identify one single factor as the most important to the quality of their life, thus demonstrating the multifaceted nature of the concept. For example, Mr Baker described the interconnectedness of the various components of quality of life as he struggled to identify the most important one:

Braintree 3158 (1985-1995): Mr George Baker

R *The most important... certainly not money. It's nice to have money when you're not well so you ain't got to worry about paying the bills. And it's nice to have a job. I don't really know. I suppose they're all sort of combined aren't they? You've got to have good health to get to work and you've got to work and be happy at work to survive, but I think family really. I mean you can be ill and if your family will care enough and keep you cheerful then you can cheer up in yourself. The family is nice. But if you're ill... I don't know really. I don't know how to put it shall we say. I think it all depends upon the family really.*

Similarly Mrs Wickford and her husband identified a link between health and independence:

Braintree 3323 (1309-1326): Mrs Dot Wickford (and husband)

R *[...] I mean the point is if there is something wrong with you and you can't get out and about, life becomes a little bit, well, monotonous, doesn't it? So I think that is top of the list. That's my opinion.*

R2 *[...] being able to do for yourself... that you are independent [...] but your health leads to independence because if your health is poor you would be very dependent on other people, wouldn't you?*

R *So the two go together, practically, don't they.*

In summary, there was a set of questions that, although not prescribed, did tend to appear in several interviews, particularly the later ones: questions identifying the time in their lives

which had had the best and the worst quality; questions asking respondents to think of some one with a better and a worse quality of life than themselves; questions asking what would make the quality of their lives better and what would make it worse; questions asking respondents to compare back and to consider the future in relation to quality of life; and questions asking respondents to identify the most important factors to them. The questions generated a variety of answers but some underlying themes came through.

Themes referred to in relation to a good quality of life (i.e. in response to questions relating to the best time of their lives, people with a better quality of life than them, and factors that would make their quality of life better) repeatedly included their families, being still married, the companionship of friends, being financially secure with a comfortable home and pleasant and safe surroundings, having few responsibilities and maintaining independence, with an adequate level of freedom and flexibility in their daily lives.

Themes referred to in relation to a poor quality of life (i.e. in response to questions relating to the worst time of their lives, people with a worse quality of life than them, and factors that would make their quality of life worse) repeatedly included reference to the War years (specifying the difficulties of bringing up children alone whilst husbands were away fighting, and coping with blackouts, air raids and rationing) and also included reference to ill health, reduced functional ability, loss of independence, being alone (including loss of friends and family), taking on a caring role and personality traits.

Based on these responses and the response to questions seeking specifically to identify the

most important factors, the most important factors appeared to be health, family (including marriage), social contact (including companionship), financial security, environment (home and surrounding area) and happiness.

It is useful here to utilise these findings when considering the methodology of one of the early stages of the study, the Quality of Life Questions (Stage Ib). It should be recalled that the questions followed on from a structured interview for the parent study about respondents' health and social care needs. The influence of the content of this structured interview on subsequent responses to the Quality of Life Questions is unknown, however the responses to these (Chapter 8) and the in-depth interviews which were conducted on a separate occasion (Stage II), were remarkably similar, as reported here. It is always possible that the structured interviews for the parent study had an influence beyond their immediate temporal location, but then any number of factors could also have influenced responses to both the Quality of Life Questions (Stage Ib) and in-depth interviews (Stage II), such as whatever respondents watched on television the preceding evening. Indeed, such factors might be legitimate in that they also affected their quality of life.

With regard to the methodology of the in-depth interviews (Stage II) it may be considered that it was inappropriate to ask respondents to identify others with a higher or lower quality of life than them as they may not be best placed to judge others lives. However this is justified as the practice of asking respondents to describe and consider another who specifically comes to mind and then questioning about the characteristics of that person and why he/she stands out, can be used to investigate the respondents' concept of quality of life. The aim of these

questions was therefore to further investigate the concept of quality of life rather than to pass judgement on the lives of others.

Factors influencing lay definitions

Factors influencing the definition of quality of life by *'experts'* or *professionals* within the literature of the various disciplines using the concept of quality of life were described earlier in Chapter 1. As well as identifying some of the components of an (older) lay definition of quality of life, the analysis of the in-depth interviews also identified some of the factors that may influence the ideas and valuations of older laymen, or at least these respondents in particular, regarding the quality of their lives.

When respondents spoke about various aspects of their quality of life, either positive or negative, they tended to describe them in terms of their expectations. They spoke of whether their expectations had been realised or not, both of themselves and of the world around them. In turn, their expectations appear to have been based on their life experiences or social histories. When describing their lives, respondents frequently compared their lives not only with their peers, but also with their parents' lives either as young adults or when they were older, and with how their children's and grandchildren's lives were now and how they would be in the future. In addition to this, respondents were able to think back over their lives and identify times which 'had the best quality' and times which 'had the worst quality'. They were also able to say why these were the best and worst of times.

Thus respondents set their lives, and their descriptions of the quality of their lives, in a context: the context of time. Wadsworth (1991) describes three aspects of time and change: the development of the individual, historical or social time passing, and attachment to a particular period of time. The respondents' in-depth interviews contained references to each of these aspects of time and change.

In terms of the development of the individual, respondents spoke of their own physical development and then decline as old age brought changes in their health and functional ability. In terms of historical or social time (i.e. chronological events that shape our lives and social roles e.g. births, deaths and marriages or work histories), respondents spoke of their changing societal roles throughout their lifetimes: changes from becoming and being spouses to being parents, and then to being grandparents, as well as changes in their economic activity from work to retirement and what that meant to them. And, in terms of their attachment to a particular time period, these respondents invariably located themselves firmly as being the survivors of World War II. It is this latter aspect of time that probably had the most profound impact on their valuations of the quality of their lives. It coloured their future life course, their opportunities, their achievements, their disappointments, and their resulting expectations of life and the world around them.

One can only speculate as to whether such a huge event as a world war had a unique cohort effect for this generation or whether, when asked, we would all look back and place ourselves in our 20s, early in our adulthood, beginning a life of independence in our assessments of where we have reached, and what we have achieved by the time of our 'old age'.

Chapter 10: Discussion

In this penultimate chapter I shall first summarise the findings of this thesis in relation to each of its aims, explaining them within the context of the thesis and the literature (under the heading ‘Conclusions about the aims of the thesis’), then examine the implications of these findings for furthering understanding of the research problem through insights discovered using the qualitative methods, but rarely considered by the literature reviewed (‘Conclusions about the research problem’). And finally, I shall set out the implications of the thesis for the wider body of knowledge through related disciplines (‘Implications for theory’).

Conclusions about the aims of the thesis

This thesis had two overall aims. The first was a context setting exercise and literature review on quality of life, and the second an empirical study of quality of life in older age. The specific aims of the context setting exercise and literature review were: (i) the identification of previous work in the field of quality of life definition and measurement, focusing on literature up to the year 2000, with particular reference to older people; and, (ii) the development of a classification or taxonomy of quality of life definitions to demonstrate consensus, or its lack, in the field. The aims of the empirical study were: (iii) the identification of lay definitions of quality of life among people aged 65 and older living at home; and, (iv) the examination of the relevance to older people of scales commonly used to measure quality of life.

Aim (i): Identification of previous work in the field:

Thus the first aim of the thesis was the identification of previous work in the field of quality of life definition and measurement, focusing on literature up to the year 2000, and with particular reference to older people. This was addressed in chapters 1 through 4.

Chapter 1 set the context of the research problem by demonstrating the unprecedented popularity of the term 'quality of life' in both lay and academic usage, charting its principal rise from the end of World War II up to the year 2000, focusing on its use within health-based disciplines. The chapter revealed that the principal problem associated with the continued use of the term 'quality of life' within the context of health and social research and policy, concerns the very fundamental issue of its definition and measurement. With regard to definition, the wide variation in the style and content of definitions of the concept was highlighted in Chapter 1, and it was demonstrated that some definitions misleadingly refer only to a few selected dimensions of the whole concept. Similarly, with regard to measurement, the tendency to operationalise 'quality of life' using scales designed to measure health and functional ability was critiqued.

Chapter 2 reviewed the literature relating specifically to quality of life in older people. Existing studies, which tend to rely heavily on the survey method, were presented according to their setting i.e. institutional or community, followed by literature relating to the established process of measuring quality of life among older people at the time of the

empirical study (circa 1990). The foundations of these literatures were then critiqued by outlining the issues of quality of life measurement in older people and issues relating to the uncensored use of the survey method with older people.

Chapter 3 described the ‘quality of life’ scales identified for use in the empirical study. It demonstrated that, regardless of the purpose for which they had been developed (e.g. usually as measures of health/functioning or psychological well-being), each of these scales had been previously used, or recommended, for the measurement of ‘quality of life’ among older people. Chapter 4 set out the case for the lay definition and measurement of quality of life by describing the growing body of literature reporting an absence of significant correlations between subjective and objective indicators of quality of life, and refuting the criticisms levelled at lay assessments of the concept.

Rarely have these issues been addressed in the published literature prior to any attempts at measuring quality of life in older age. Thus, in achieving its first aim, this thesis has made a unique contribution to the knowledge base of the definition and measurement of quality of life in older age.

Aim (ii): The development of a taxonomy:

The second aim of the thesis was the development of a classification or taxonomy of quality of life definitions to demonstrate consensus, or its lack, in the field. It was proposed that the organisation of the existing definitions into a framework would identify common elements

and underpin the discussion of factors influencing definitions.

Contrary to the view of some authors that a consensus definition exists (see, for example, Sullivan, 1992), the process of reviewing of the literature on 'quality of life' for this thesis identified a plethora of 'expert' or 'professional' definitions which varied widely in form and content. It proved possible, using a qualitative method (as described and demonstrated in Chapter 1), to organise these existing definitions into a taxonomy which highlighted both consistencies and inconsistencies in definitions. Most importantly, the taxonomy identified the explicit and, more worryingly, implicit use of selected dimensions of quality of life to represent the whole concept e.g. health and functional ability. In no other area of health and social research has a concept been defined in such a selective or inconsistent way, and such manipulation of definitions been so unquestioningly accepted. If the definition of a concept cannot be established, or is so flawed, then any operationalisation of that concept into measurement will also remain flawed.

The diversity of published definitions identified by the taxonomy was shown to be influenced by a number of external factors such as the multidisciplinary use of the term, the focus and scale of the research employing it, the cultural setting of the research, the inappropriate use of operational definitions, the interchangeable use of the term with other concepts (or selected dimensions), and the weighting of dimensions. In addition, the development of this taxonomy for this thesis (the second aim) led to an academic publication (i.e. Farquhar, 1995b) thus contributing directly to the existing body of knowledge on quality of life definition.

Aim (iii): Definitions of quality of life among older people living at home:

The third aim of the thesis was the identification of lay definitions of quality of life among people aged 65 and older living at home. It was proposed that some of the problems of defining and measuring quality of life, outlined in chapters 1 through 4 (and particularly within the taxonomy), could be addressed by asking older people to describe the quality of their own lives, in their own words, using their own frames of reference (Farquhar, 1994).

Thus Chapter 5 described the three established samples of older people living at home in Hackney and Braintree, on which the empirical study was based, together with the methods and rationale for data collection, coding and analysis of each the stages of the study: Stage Ia ('quality of life' scales), Stage Ib (the Quality of Life Questions), and Stage II (in-depth interviews). In Stage Ia respondents were asked to complete two out of six established and accepted 'quality of life' scales, in Stage Ib a sub-sample were asked to respond to a brief set of open questions on quality of life, and in Stage III 40 respondents participated in in-depth interviews on quality of life.

The high response rates to each of the stages of the study combined with the description of the demography of the samples, as reported in Chapter 6, suggests the representativeness of the various samples in relation to the older population living at home in the localities, and therefore the generalisability of the findings of the study to other populations of older people

living at home in inner city and semi-rural areas of south east England.

Analysis of the responses to the Quality of Life Questions at Stage Ib, as presented in Chapter 8, revealed that although the majority of respondents described the quality of their lives in positive terms, there were differences by age group and area. The very elderly sample in Hackney were the most likely to describe their quality of life in very negative terms. As there was no very elderly sample in Braintree with which to compare this finding, it could be argued that this is purely a reflection of their area of residence. However, if this were so, then one might also have expected a higher percentage of the younger elderly sample living in Hackney to have described the quality of their lives in this way. This may, in some way, be linked to the inevitable gender differences between the samples. This finding is in contrast to that of Bury and Holme (1991) in their study of quality of life among people aged 90 and over cited in Chapter 2: their main conclusion was that life after age 90 was compatible with a good quality of life.

In addition, it appears that those living in a semi-rural area are more likely to describe the quality of their lives in a very positive way than those living in an inner city. Again, it could be argued that this is a reflection of the fact that the semi-rural Braintree sample was comprised of only the younger elderly, however the differences were apparent even when comparing only the two younger samples in each area. This may, in some way, be linked to social class differences, and thus the material circumstances, of the samples. Environmental factors are also likely to have played a part.

Social contacts (including family), functioning (health, activities, mobility, ability) and outlook were among the recurring themes identified by the Quality of Life Questions when used with each of the samples. Age and functioning and social contact all interact and it is the loss of these that these older people indicated would reduce their quality of life. In addition, material circumstances seemed to be important. Those with secure and higher incomes, and better housing conditions described their quality of life in more positive terms, but this again appears to interact with age: the very old were not as concerned about their material possessions. This latter finding has parallels with Vetter et al's finding that the importance of finances to quality of life declined over a two-year period for a sample of respondents aged 70 and over (Vetter et al, 1988). In addition these findings confirm the views of Grimley Evans (1992) and others cited in Chapter 1, that 'older people' are not a homogenous group, and so can not be grouped together for the purposes of analysis. The interaction of this homogeneity with other social dimensions and its impact on quality of life was discussed in Chapter 1.

There were reassuring consistencies between these findings and the responses to the 40 in-depth interviews conducted at Stage II and reported in Chapter 9. Themes identified through the interviews included: activities, material circumstances, health, family, location, social contacts, society, services, feelings, the past, control, working and retirement, old age, transport, crime, tasks, independence, and personality. Most important were health, family (including marriage), social contacts (including companionship), financial security, environment (home and surrounding area) and happiness. Of all the themes mentioned, families were perhaps the most unchanging factor in these respondents lives (beyond

individual births, deaths and marriages) i.e. even if respondents' health or material circumstances changed for the worse, a supportive family could be reasonably expected to remain a supportive family.

Chapter 9 also reported that some respondents spontaneously provided a definition of quality of life: some acknowledged that quality of life meant different things to different people and some described it as a nebulous and multifaceted concept. In addition, just as the analysis of the professional, or 'expert', definitions for the development of the taxonomy lead to the identification of factors influencing their definitions in Chapter 1, so the analysis of respondents' thoughts on quality of life lead to the identification of possible factors influencing lay definitions and valuations of quality of life; principally their social histories (Chapter 9).

Thus Chapters 8 and 9 demonstrated that older people can talk about quality of life, are able to describe their quality of life, identify components of a good and bad quality of life and describe ways in which their lives could be improved or made worse. Although health was deemed an important component of quality of life at both of the qualitative stages of the study (Stage Ib and II), these stages showed that there was more to quality of life than health: for these respondents family and social contacts appeared to be as valued components. This finding adds significant weight to the small but growing unease emerging in the health-related literature (as described in Chapters 1, 2 and 4) regarding the trend to equate 'quality of life' with 'health'.

Aim (iv): The relevance to older people of 'quality of life' scales:

The final aim of the thesis was the examination of the relevance to older people of scales commonly used to measure quality of life. Chapter 3 had described the set of scales identified as having previously been used, or recommended for use, with older people to measure quality of life. Chapter 7 described the results of the administration of these scales to the three established samples of older people.

Administering the scales at Stage Ia was not straightforward: members of all three samples experienced some degree of difficulty in completing each of them. In addition, significant differences were found between the samples regarding their need for assistance with completing the various scales, with the very elderly respondents being the more likely to require help. Problems included: print size/font and line spacing; clarification of item meaning due to ambiguity of language, Americanisms and the irrelevance of examples to older people; loss of the temporal context of questions; repetitiveness of scales; length of scales; difficulty following filter questions and interpreting visual analogue scales; a typing error transferred from an original publication; responses being given 'openly' rather than selecting from a fixed choice; and visual confusion.

By contrast, the respondents had had far less difficulty with the qualitative methods of data collection used in the study: the open Quality of Life Questions (Stage Ib) and In-depth interviews on quality of life (Stage II). Nord et al (2001) suggest that 'to most people "quality of life" refers to how good, desirable and enjoyable life as a whole is felt by the person in

question [...] overall feeling can only be communicated in non-standardised language chosen by the patients themselves'. This certainly appeared to be the case with regard to these respondents. There appeared to be far fewer difficulties in responding to the Quality of Life Questions (Stage Ib) and in-depth interviews (Stage II) than there were with completing the scales (Stage 1a). It should be recalled, however, that the scales were written forms requiring an ability to read and write, whereas the Quality of Life Questions were verbal (although some of those completing the scales verbally still appeared to have difficulties with comprehension). In addition, the Quality of Life Questions were administered by the researcher alone, who was highly motivated, rather than by the other interviewers who may not have been so motivated.

Thus this thesis has found that these selected scales, all of which had either been previously used to measure the quality of life of older people, or had been recommended as measures of quality of life in older people (as described in Chapter 3), were in fact unsuitable for such use. In addition, this thesis can not recommend these scales for postal use, nor for unassisted self-completion in an interview setting with older people. The presence of an interviewer is frequently required for assistance with their completion, particularly with respondents aged 85+, but the effects of that assistance on the responses given is unknown.

The achievement of this fourth aim, and the reporting of its findings, represents a significant contribution to the knowledge base on the measurement of quality of life among older people: nowhere in the published literature is a critique of the use of such scales with older people, based on empirical findings, reported.

Conclusions about the research problem

Having summarised the findings of this thesis in relation to each of its aims, this section will now examine the implications of the findings for furthering understanding of the research problem. It will focus on insights discovered using the qualitative methods, but rarely considered by the literature reviewed, so further developing the contribution of this thesis to the existing body of knowledge.

Problems with the definition and established measurement techniques of the quality of life of older people living at home identified by this thesis led to the exploration of lay definitions and qualitative, lay-based, measurement of quality of life. Contrary to the critics of such techniques, responses to the brief Quality of Life Questions at Stage Ia demonstrated that older people could talk about quality of life, indicating that in-depth interviews about quality of life would be possible, which was confirmed in Stage II of the empirical study. This refutes the critics and confirms the findings of Andrews (1974) who concluded that people have given thought to such matters. Indeed a few respondents mentioned the term 'quality of life' during the parent study interview before they were asked the Quality of Life Questions or invited to complete the scales, and others indicated that it was something they had thought about previously. As one 91 year old lady from Hackney said:

'it's surprising how you get used to things... that's why, Morag, make the most of your youth. I didn't think my retirement would be like this... I thought I would be baking and on holiday. I used to keep my wardrobes tidy, but I don't now. It's very

sad.'

When using the term 'quality of life', respondents were not simply talking about the good things in their lives, they were talking about the bad things too. When asked to describe the quality of their lives they gave an adjective such as 'good' or 'bad'; they talked about the nature of their lives, not just its attributes. However a few respondents did answer by saying that their lives had 'no quality'. As the same 91 year old from Hackney said:

'once you get beyond a certain age there is no quality, that's my view... I don't suppose the Queen Mother would say that.'

Both the Quality of Life Questions and the in-depth interviews generated the discussion of a surprisingly consistent series of broad themes in relation to quality of life: activities, material circumstances, health, family, location, social contacts, society, services, feelings, the past, control, working and retirement, old age, transport, crime, tasks, independence, and personality. Indeed the consistency of responses between both the Quality of Life Questions and the in-depth interviews, and between the Quality of Life Questions and data from the parent study, was reassuring. In addition, in Bowling's later national survey of adults (including both pre and post retirement age) which asked people open questions about important areas of their lives, respondents prioritised relationships with family/relatives, their health, the health of close others, their finances, followed by social life/leisure activities (Bowling, 1995b), thus confirming the earlier findings reported here.

Themes referred to in relation to a good quality of life (i.e. in response to questions relating to

the best time of their lives, people with a better quality of life than them, and factors that would make their quality of life better) repeatedly included their families, being still married, the companionship of friends, being financially secure with a comfortable home and pleasant and safe surroundings, having few responsibilities and maintaining independence, with an adequate level of freedom and flexibility in their daily lives.

Themes referred to in relation to a poor quality of life (i.e. in response to questions relating to the worst time of their lives, people with a worse quality of life than them, and factors that would make their quality of life worse) repeatedly referred to the War years (with women specifying the difficulties of bringing up children alone whilst husbands were away fighting, and coping with blackouts, air raids and rationing) and also included reference to ill health, reduced functional ability, loss of independence, being alone (including loss of friends and family), taking on a caring role and personality traits.

Thus the results show that, for older people living at home, there is more to quality of life than health. Indeed it appears that family relationships, social contacts and activities are as valued components of a good quality of life as general health and functional status. This finding also compares well with the earlier findings of Hall (1976) who found that the largest single category referred to was the family, home life and marriage, followed by happiness and health. As Faden and Leplege (1992) state 'although health states, and the interventions that produce them, can have a significant impact on life quality, they are among many factors determining a person's quality of life'. However, some caution is required here as social contacts and activities are to a certain extent dependent on a reasonable state of health and

functioning. The broad themes identified by respondents were therefore not independent or distinct, but interconnected. Just as Vetter et al reported that respondents (aged 70 and over) who became more dependent over a two-year period had an increased level of satisfaction with their family relationships (Vetter et al, 1988), so connections between the themes identified within this thesis can be described.

Word limits do not permit the discussion of the interconnectedness of each of the themes individually, however taking the example of 'Activities' it can be demonstrated that each of the other 17 themes could have a positive or negative impact on this theme. For example, a negative assessment of 'Activities' could in part be caused by: low income (the 'Material circumstances' theme, which may in turn be influenced by the 'Working and Retirement' theme); health problems reducing mobility ('Health' theme); lack of access to a supportive family or other social contacts for transport to, or companionship at the activities ('Family' and 'Social Contacts', the latter also being closely linked to 'Health'); the needs of a dependent family or family member ('Family'); the distance from home to the activities ('Location', which may itself be influenced by 'Material Circumstances'); societal changes reducing access to activities such as closure of local clubs, decline of local Christmas bazaars, discontinuation of council holidays, lack of neighbourliness inciting a reluctance to go out ('Society', which is linked to 'Crime'); lack of services such as health and social care which could limit health and functional ability so that access to activities was reduced ('Services', which themselves could be influenced by 'Location' and 'Society'); negative feelings such as spiralling loneliness and unhappiness may make individuals reluctant to seek entertainment and the companionship of others, or the impact of a particularly cold spell of weather could

restrict the amount of time individuals spend outdoors accessing activities thus leading to boredom and loneliness ('Feelings'); lack of relevance to the individual of the activities available ('The Past' and 'Old Age'); the cyclical effect of the fateful acceptance of a lack of access to activities and individuals' loss of confidence in their ability to attend or carry out activities ('Control', which may be influenced by 'Health', 'Personality', 'Feelings', 'Independence' and 'Society'); the financial effects of retirement or the loss of work related activities such as work social events ('Work and Retirement', which may also be influenced by 'Health' and 'Old Age'); lack of, or expense of, or physical inability to access personal or public transport to the activities, or as an activity in itself ('Transport', which in turn may be influenced by 'Material Circumstances', 'Health', 'Location', 'Services' and 'Society'); fear of going out alone ('Crime', which may be linked to 'Location', 'Society' and 'Old Age' (as in potentially increased vulnerability)); limitations on time and energy to attend activities due to the increased time and effort taken to complete basic tasks of daily living ('Tasks', which may be influenced by 'Health'); limited ability to attend activities unaided, in terms of the physical and financial resources required ('Independence', which may be influenced by 'Health', 'Control', 'Services', 'Material Circumstances'); and finally, the potential effect of negative outlook on ability to participate in activities with others ('Personality', which in turn may influence 'Feelings').

Thus the hypothetical example above illustrates the interconnectedness of the broad themes but also highlights the multidimensionality of the concept of quality of life which was noted by the respondents themselves. By contrast, Fletcher, Dickinson and Philp (1992) have recommended that 'when resources are limited, the use of a brief unidimensional instrument

to measure quality of life may be the best approach, particularly in the context of health-care decision making' (p149). However, a fundamental problem underlies this approach: where unidimensional measures are used in isolation, they tell us nothing about which aspects of quality of life could or should be improved. Vetter et al (1988) have described unidimensional measures of quality of life as 'meaningless'. This has parallels in patient satisfaction research where the sole use of global patient satisfaction questions are meaningless as they do not inform what alterations are required to a service in order to improve its quality (Farquhar, 1994).

As an alternative, Bernheim (1997) suggests using global assessments but with the inclusion of items, whereas Bowling (1994) recommends questionnaires that independently measure and reflect each construct. The problem with this latter suggestion is the unwieldy nature of the resulting battery of instruments, which is of a particular concern if used for samples of older people given the findings of this thesis (both empirically and from the literature review) on the difficulties faced by older people with uncensored survey methods. Where items are included (as in the former method proposed by Bernheim (1997)), Tantam (1988) states that subsequent aggregation of items into single score may lead to the over-simplification of quality of life but also suggests that it enables the benefits in one domain to be weighed against the deficits in another. However, Fitzpatrick et al (1992a) state that summing disparate dimensions is not recommended because contradictory trends for different aspects of quality of life are missed (Fitzpatrick et al, 1992a).

A solution to this is presented in Simmons' useful review of quality of life in community

mental health care (Simmons, 1994). In suggesting certain features crucial to the assessment of quality of life of those with long-term psychiatric illness, Simmons considers that assessments should be based on self-reports which include some element of the person's global satisfaction with life in general, and specific features of it in particular, and use methods providing some guidance through a semi structured interview but not constraining the respondents' opportunities to talk about areas of importance and concern to them. She goes on to suggest that information derived from interviews should be translated into scores by the interviewer, or recorded verbatim and analysed qualitatively using content analysis, and that there should be some assessment of the person's welfare (as opposed to satisfaction with life) which might take the form of more objective measures. In short she advises a combination of measures, structured and semi-structured, quantitative and qualitative, gathering both subjective and objective ratings (Simmons, 1994). Perhaps with the exception of the translation of responses into scores (due to issues of validity and reliability), the findings of this thesis endorse Simmons' suggestions: 'only then may we more fully develop our understanding of such a complex and elusive phenomenon' (Simmons, 1994).

One of the other dilemmas the multidimensionality of quality of life presents is that many of the dimensions of quality of life identified here have little to do, directly, with health care. If we are truly using 'quality of life' as a measure of the effects of health care interventions, then we cannot expect our interventions to make much of an impact on an overall assessment of quality of life, given the diversity of dimensions it includes beyond health. For example, health interventions cannot be expected to have a direct impact on family, social contacts or crime.

The main impact of health interventions with regard to the dimensions of quality of life identified for this empirical study will be on the dimension of 'health' itself, with knock on effects on 'activities', 'independence', 'tasks', '(health related) services' and perhaps even 'control' and 'feelings'. This has been referred to by Lehman (1988) when he asks 'Is it fair to apply broad QoL outcome criteria to health care and social service interventions, which may target more narrow outcomes?'. Similarly, Bunker, Frazier and Mosteller (1994) refer to the relief of pain and suffering and of physical, social and mental dysfunction as being the main impact of health care. This is one of the principal reasons for the trend of quality of life in health care being measured primarily in terms of health.

This 'medicalisation' of quality of life was noted by Hunt, McEwen and McKenna (1986) as having parallels with the medicalisation of the human condition as described by, amongst others, Illich (1976):

'This process may take various forms and appear sinister or humanitarian depending upon one's own set of values, but it is said to manifest itself in the tendency to bring fairly common human problems such as drunkenness, crime, infertility or obesity within the province of medicine or to make normal human events such as birth and death into medical issues. The repercussions of this are the conversion of moral dilemmas into technical problems to be treated from the armamentarium of medical technology; the transformation of natural experiences into tasks for medical management; the erosion of individual responsibility and the encouragement of the idea that almost any human experience which gives rise to distress can be conceptualised as a health or medical matter' (Hunt, McEwen and McKenna, 1986).

However the truth of the matter is that there really is very little that health care can do directly to many of the domains of quality of life, as identified by the respondents to this empirical study.

The findings of this thesis suggest that there are two potential solutions to this within empirical research. One is to establish a finite definition of ‘quality of life’ (based on both lay and expert opinion) and encourage the measurement of the concept using all the dimensions identified, accepting that health interventions can have only a limited impact in terms of the number of dimensions it can affect. The other is to continue focusing our measurements on health but to be explicit about this by ceasing to use the term ‘quality of life’ and using the terms ‘health’ or perhaps ‘wellbeing’ instead. At the very least we should be using the term ‘health-related quality of life’ in place of ‘quality of life’ when we focus our definitions and measures on health.

Within the qualitative components of the empirical study, behind the different dimensions or themes of quality of life mentioned, there was a continual reference to context: both the here and now context, and the broader context of a life that had been lived. Respondents spoke about their current quality of life and their quality of life in the past. It appeared, therefore, particularly in the in-depth interviews, that there were factors that influenced quality of life beyond respondents’ immediate circumstances i.e. their social histories. The most comprehensive event amongst these histories was World War II.

This finding of the importance of such an event in forming values and attitudes is not unique. Hall’s work, cited in Chapter 4, described older peoples’ references to values and to the past (Hall, 1976), and Bury and Holme noted the shared sense of generation among their sample of people aged 90 and older, in the shape of common experiences and attitudes (Bury and

Holme, 1990). More recently, Field (2000) analysed data from the April 1994 directive on personal experiences of death and bereavement held in the Mass Observation Archive at the University of Sussex. The Archive seeks to involve members of the public in the recording of every day life by inviting a panel of around 500 people to respond regularly to open-ended 'directives' on various themes or topics of contemporary interest. The April 1994 directive led to a sample of 55 correspondents in the 65-80 year age range being selected for detailed analysis of their personal experiences. Field reported that 'preliminary analysis found that among this age category experiences of the Second World War appear to have been of particular importance in shaping personal responses and attitudes towards death and dying', he goes on more generally to suggest that the war 'clearly played a significant role in shaping their lives and, for many, quite evidently continued to exert an important influence throughout their lives' (Field, 2000).

Expectations governing individual estimations are socially produced. Thus the experience of a world war undoubtedly influenced the expectations of life of the cohort studied for this thesis. The realities of living through such an event would have meant having to aspire to less, and so accepting lower standards. This has been demonstrated by Amos et al (1982) who compared responses to questions on life satisfaction of those living in 22 less economically developed counties in Oklahoma, with the responses of those living elsewhere in the state: no difference was found between the two groups except for 'satisfaction with health'. Similar findings have been reported by Simmons et al (1977) when comparing cancer survivors to the general population: contrary to the authors' expectations the survivors were more satisfied with life as a whole. Schuessler and Fisher (1985) suggest that these

findings demonstrate the link between satisfaction and aspiration, with a 'mental rescaling of aspiration' producing these unexpected results, bringing 'perceptions of life quality in line with social reality'.

The importance of the temporal context in influencing valuations was alluded to by Nord et al (2001). They discussed the dearth of measures of overall feeling, or enjoyment of life as a whole, in clinical instruments of quality of life. They reported that those which did refer to subjective feelings often only referred to short term mood, such as mood on the day of measurement or in the week or two preceding it: 'our short term mood does not necessarily reflect our overall view of the desirability of the life we are living, viewed as a long sequence of years with ups and downs, strengths and weaknesses, hopes and challenges, frustrations and rewards' (Nord et al, 2001). Thus, to incorporate an element of context into the measurement of quality of life a more flexible, narrative method is once again required than the established, more structured methods of quality of life measurement might suggest. In addition, it is worth considering that if an older person is unable to recall how good or bad life was in the past (autobiographical memory) this may affect how they evaluate their quality of life at the present time. Some form of assessment of individuals' autobiographical memory may therefore be pertinent in studies of the quality of life of older people.

Thus this thesis has contributed to the further understanding of the research problem presented here of defining and measuring quality of life in older people by: (i) clearly establishing the breadth of the problems that exist by identifying the inconsistencies of definitions (as uniquely demonstrated by the taxonomy) and inadequacies of measurement in

terms of the content of measures (i.e. their focus on health and functional ability or psychological wellbeing) and their style (i.e. the unsuitability of the uncensored use of the survey method); (ii) making a case for the use of alternative, qualitative, lay-based methods; (iii) providing evidence that such methods can be successfully used with older people living at home and that such methods appear more acceptable than the established structured methods; (iv) identifying variations in the quality of life of older people living at home by age group and area of residence, as assessed by these methods; (v) confirming the multidimensionality of the concept, thus questioning the trend of focusing definitions and measures of quality of life on the dimensions of health and functional ability; and (vi) identifying the importance of the role of temporal context in influencing valuations of life.

Implications for theory

Having summarised the findings of this thesis in relation to its aims and examined the implications of the findings for furthering understanding of the research problem, this section will set out the implications of the thesis for the wider body of knowledge through related disciplines, and will summarise its dissemination to date.

The usefulness of this research for other disciplines is considerable given the multidisciplinary (as well as international) use of the concept of quality of life. Chapter 1 had highlighted the broad appeal of 'quality of life' beyond health and social care (including psychology, medical and nursing science) to the wider realms of sociology, economics, political science, philosophy, history and geography (Schuessler and Fisher, 1985; Hanestad

1990; Farquhar, 1995). George and Bearon (1980) suggested that the broad appeal of the concept could help facilitate communication between knowledge-oriented and action-oriented professionals. However communication relating to quality of life can only be facilitated between these groups and between (and within) the disciplines outlined above if those professionals and disciplines are communicating about the same thing. A term in such multidisciplinary usage requires clarity and consistency of definition.

This thesis, however, identified inconsistencies of definitions. The discussion of these was focused principally within the field of health services research (as uniquely demonstrated by the taxonomy). Whether this problem exists within other disciplines, or between disciplines (i.e. there may be consistency within other individual disciplines but not when disciplines as a whole are compared e.g. an agreed and accepted economic definition may differ from an agreed and accepted historical definition) is unknown, although the existence of discipline-dependent definitions was alluded to in Chapter 1 suggesting that this may be a multidisciplinary problem. This could be confirmed or refuted by other disciplines following the model of the development of the taxonomy of quality of life definitions, as described in Chapter 1, using the literature from within their discipline.

As noted earlier, the knock-on effect of inconsistent and inadequate definition is inadequacy of measurement. This thesis found the accepted and recommended techniques and tools of measurement of quality of life among older people to be inadequate in terms of the content of measures (i.e. their focus on health and functional ability or psychological wellbeing) and their style (i.e. the unsuitability of the uncensored use of the survey method). Measures

developed, or used, by other disciplines are likely to be similarly flawed if their definitions are so flawed. For example, a measure of quality of life within the discipline of geography is likely to focus on dimensions that have geographical relevance (e.g. housing, environment, pollution, physical access to services) rather than consider an all-encompassing broader definition of quality of life. Just as this thesis has recommended the use of the term 'health-related-quality of life' (where researchers feel the term 'quality of life' must be incorporated), so it advises the use of other discipline-dependent terms e.g. 'geographically-related-quality of life', 'geographically-based-quality of life' or 'geographical-quality of life'. In addition, whatever the discipline, this thesis does not recommend the uncensored use of the survey method with older people.

By contrast, the recommendation, based on the findings reported here, is that alternative, qualitative, lay-based methods of assessing quality of life must also be considered by other disciplines. This thesis provided evidence that such methods can be successfully used with older people living at home and that such methods appear more acceptable than the established structured methods. Both the literature reviewed and the empirical study demonstrated the advantages of these methods in terms of reliability and validity. Thus the use of such alternatives should be explored by other disciplines particularly when the focus is on older people.

The finding that the quality of life of older people living at home varied by age group and area of residence also has relevance to other disciplines. Regardless of discipline, variable data should be collected in relation to area of residence and age (group) in such a way that it can

be readily utilised in analyses (qualitative or quantitative). In addition, this suggests that other variables may also be important for which testing was not possible within the quantitative elements of this thesis due to small sample sizes e.g. gender. Thus other variables too should be considered.

This thesis confirmed the multidimensionality of the concept quality of life, thus questioning the trend within health care of focusing definitions and measures of quality of life on the dimensions of health and functional ability. There is a need, therefore, to establish whether similar discipline-dependent trends have occurred elsewhere. If this proves to be the case, then these trends need to be clearly and explicitly flagged by locating the resulting definition and measures as being firmly within the parent discipline (e.g. using terms such as ‘geographical-quality of life’ as described earlier), or re-labelled without the use of the term ‘quality of life’ at all (e.g. as measures of the ‘acceptability of the geographical environment’). Alternatively, the content of measures should be re-considered to be more all-encompassing of the broader definition of quality of life. The choice of these options depends on the exact purposes of the research and whether or not the aim is truly to measure ‘quality of life’ or whether the phrase ‘quality of life’ is simply, but misleadingly, being used because it is in vogue.

The identification of the importance of the role of temporal context in influencing valuations of life also has relevance to other disciplines. In terms of the measurement of quality of life, just as it did within health services research, this thesis recommends testing the flexibility of a qualitative method by other disciplines and the use of laymen’s own language to express and

locate valuations. For example, within economics, who, other than the individual respondents themselves who have lived and are living their lives, are to know what factors are important or what priority order they might place their material needs and desires in relation to their quality of life. In addition, for the older generations studied here, the role of the war years had undoubtedly been influential on their valuations of past and present life, thus the consideration of cohort effects by other disciplines is therefore recommended.

In addition to these broader considerations there may be particular implications for the closer field of social gerontology. These findings may contribute to the evidence base for notions of coherence, memory and the ability to reshape experience.

Regardless of the actual contributions to other disciplines identified and outlined here, the broadcasting of findings and their implications is vital if a contribution to wider knowledge is to be truly realised. This can only be achieved through effective, timely and broad dissemination. Thus, whilst preparing this thesis, considerable efforts were made to ensure contribution to a wider body of knowledge beyond that of health services research. This was actively conducted by means of peer-reviewed publication and presentation to a wider academic audience (both in terms of discipline and location) before the completion of the thesis. For example, as well as publishing ongoing findings in peer reviewed journals within, or close to the discipline of health services research (i.e. Farquhar, 1992 (*Journal of the Royal Statistical Society*); Farquhar, 1995a (*Social Science and Medicine*); and, Farquhar, 1995b (*Journal of Advanced Nursing*)) and contributing a book chapter to a medical sociology volume (Farquhar, 1994), an abstract was published in *Bulletin*, the journal of the Social

History Society (Farquhar, 1993) following the presentation of a paper at the Annual Social History Society conference (London: January, 1993) which focused on the thesis' finding of the importance of the role of temporal context to valuations of quality of life. Further conference presentations addressed sociologists (British Sociological Association Conference, Manchester: March, 1991), medical sociologists (BSA Medical Sociology Group's Annual Conference, Edinburgh: September 1992), and nurses (Royal College of Nursing Research Advisory Group Conference, Birmingham: April, 1992). A wider European audience was also addressed (Third European Conference on Health Services Research and Primary Health Care, London: December, 1991).

Thus this discussion has summarised the findings of this thesis in relation to each of its aims, examined the implications of these for furthering understanding of the research problem and set out the implications of the thesis for the wider body of knowledge.

Chapter 11: Conclusion

In this final chapter I shall consider the practical implications of the thesis ('Implications for policy and practice'), discuss limitations that became apparent during the progress of the research ('Limitations of the thesis'), and identify areas for further research based on the process and outcome of the thesis, in terms of both topics and methodologies ('Implications for further research').

Implications for policy and practice

Evidence-based medicine is the gold standard within modern health care. Sources of such evidence are usually randomised controlled trials and tend to relate to interventions such as new drug regimens. Measures of outcome within such trials may take the form of survival data or clinical outcome measures, but increasingly (as was demonstrated in Chapter 1) routinely include 'off the shelf' measures of 'quality of life'.

This thesis has clearly established inconsistencies in the definition of quality of life and inadequacies in the measurement of the concept with regard to older people both in terms of the content of measures and their style. The implication of these findings for policy and practice initiatives that are evidence-based is that 'quality of life' data may not truly represent quality of life, but a selection of dimensions of the concept. Such selection can lead to biased results if respondents' ratings on the selected dimensions are more or less favourable than their assessments of their overall quality of life. This may be particularly pertinent to older

people whose health and functional ability may be expected to be lower than those of the younger adult population. Unfavourably negative ratings of quality of life may therefore result from measures which are focused on these dimensions only.

Beyond the realms of the RCT, surveys are also a source of evidence. Given this thesis' critique of the uncensored use of the survey method with older people (following the review of the literature and empirical testing of 'quality of life' scales) close attention should be paid to the methodology and interpretation of findings of surveys of older people, regardless of their subject. Surveys of older people should only be used as an evidence base where authors have demonstrated a clear understanding of the particular needs of this group and designed or adapted their methods accordingly; indeed a checklist of requirements or set of criteria for assessing such surveys of older people could be developed on the basis of the findings of the literature review and empirical study presented here. In addition, studies using alternative, qualitative, lay-based methods should be considered as a source of evidence.

With regard to the empirical findings of this thesis, the identification of variation in the quality of life of older people living at home by age group and area of residence has implications for policy and practice. Policies and practice initiatives aimed at maintaining or improving the quality of life of older people living at home need to be both age and area sensitive. For example, although the maintenance of social contacts was important for maintaining a good quality of life for most respondents, those respondents living in Hackney were more concerned with their generally poorer material circumstances than those living in Essex, and respondents from the very elderly sample were more concerned with their health

and reduced functional ability than those from the two younger samples. Thus, initiatives aimed at improving the quality of life for older people living in Hackney should seek to maintain their social contacts and address their material circumstances, however for the very elderly living in the area efforts should be focused on improving their health and functional ability.

The empirical study identified the multidimensional meaning of 'quality of life' to two samples of older people living at home in the south east of England. The dimensions identified were not a comprehensive list of items to be covered in any assessment of quality of life, but they do suggest factors that should perhaps be considered in a model of quality of life for older people that may also be relevant to policy and practice initiatives. However, Lehman (1988) has questioned how patient-derived quality of life data be translated into policy and how such data can be weighed in relation to other policy-relevant information, including expert opinion, community needs, and government priorities. In addition the finding referred to earlier of variation in the relative importance of various factors by age group and area adds to this problem. Together, the findings of this thesis suggest that initiatives should be locally led and flexible, targeting dimensions that are likely to have the widest impact and based on consultation with both lay and expert opinion. Indeed, the central message of a recent Joseph Rowntree Foundation report, 'Older People Shaping Policy and Practice', suggests that older people must be involved in planning the policies and services that affect them in order to make an enduring contribution to improving quality of life in old age (Joseph Rowntree Foundation, 2004).

With this multidimensionality came interconnectedness. Themes described by respondents in relation to their quality of life were not isolated, but overlapped and impacted upon one another. The discussion in Chapter 9 provided a detailed description of how the theme of ‘Activities’ could hypothetically be affected by each of the other themes. Thus, the target of initiatives aimed at improving aspects of quality of life may not necessarily need to be directed at those aspects themselves. For example, the provision of easy access buses on relevant routes may lead to an increased use of the public transport system by older people, providing them with better access to activities and health care services, and easier completion of tasks such as shopping. The knock-on effects of this might in turn be more positive feelings, increased independence, freeing up family members from some of their care-giving role and improvements in health associated with increased exercise (due to walking to the bus stop and carrying shopping, as opposed to being picked up from the front door, or having the entire task taken over by someone else). Thus, where little can be done directly about one aspect of quality of life, other aspects should be considered as alternative indirect targets.

Finally, the identification of the importance of the role of temporal context in influencing valuations of life suggests that there may be a cohort effect. Thus initiatives aimed at improving the quality of life of older people living at home in the 1990s may need to be different to those in, for example, the year 2030. These latter initiatives will be aimed at a largely post-war generation born in the 1960s and earlier. Their experiences and valuations of life may therefore be very different from the survivors of a world war. Thus timely repetition of studies, such as that presented in the empirical part of this thesis, will be required to test for this effect and provide a new and relevant evidence base for future policy

and practice.

Limitations of the thesis

Having considered the implications of the thesis for policy and practice, limitations which became apparent during the progress of the research will now be described.

A number of limits were defined at the outset regarding the scope of this thesis for reasons of manageability, relevance and adherence to word counts. These limits were explicitly described in the earlier chapters e.g. due to the timing of the fieldwork for the empirical study, only those 'quality of life' measures recommended for use, or previously used, with older people up to the year 1990 were sought (Chapter 3). However, further limitations always become apparent during the progress of research, particularly when the researcher comes to consider the implications of findings and their generalisability.

This study justifiably focused only on older people, and specifically on older people living at home. In addition, despite the valuable contrast of an inner city and semi-rural area, this study was firmly located in the south east of England, and in the developed world. The relevance of the findings to younger adults, to institutionalised older adults, to other parts of the developed world (including other parts of England), and to the developing world is unknown.

Beyond sampling there were some methodological limitations at each of the stages of the

study which became apparent during the progress of both the fieldwork and the analyses. With regard to Stage Ia and the administration of the 'quality of life' scales, the researcher became aware of the lengthiness of one of the pairings of scales in particular, following a long interview for the parent study i.e. the combination of the McMaster Health Index Questionnaire (MHIQ) with the Self Evaluation of Life Function (SELF). In addition, this pairing produced a difficult combination of scales due to the complexity of these two particular measures. Some process of randomising the pairings of scales might have helped to overcome this issue, however the logistics of this would have been complex given the employment of a team interviewers to administer the scales, rather than the researcher working alone. An alternative would have been to request randomisation within the pairings e.g. administration of the MHIQ followed by the SELF to one respondent then administration of the SELF followed by the MHIQ to the next respondent to whom this pairing had been allocated. This would also have allowed for the identification of any order effects of scale administration (i.e. the content of the first scale in some way influencing responses to the second).

To ease the administration of each of the paired scales, the two scales within each pairing were printed on matching coloured paper (pale yellow, pink or blue). The effects of the paper colour on, for example, face validity and therefore responses, are unknown; readability is certainly known to be effected by background colour. It would have been better to have had all the scales printed on the same colour of paper. In addition, use of the same font style and size throughout the scales might have eased comparison of respondents' and interviewers' reactions to them.

The assessment of the ease of administration of scales was not formalised or systematic. Although a series of regular, scheduled debriefing sessions with interviewers was held and proved effective at providing insights into the process of administration and respondent reaction to scales, interviewers were not asked to formally report their findings in written form in response to a set of pre-defined evaluation criteria. In addition, respondents themselves were not directly asked their opinions of the scales or their views on the relevance of the scales to their quality of life. Systematically asking the respondents their views would have been particularly valuable. To have done so at Stage Ia, however, would have increased the length of this interview still further. An alternative might have been to incorporate discussion of the scales completed by individual respondents into the in-depth interviews conducted at Stage II. However, this would have tapped the views of only a small sub-sample of respondents who completed the scales. A further alternative might have been to have convened focus groups in each area, and for each age group, to discuss the content and style of each of the scales.

The location of the 'quality of life' scales and Quality of Life Questions at the end of the structured interview for the parent study proved valuable in terms of recruiting respondents to these stages of the study (Stage Ia and Ib) but inevitably meant that the length of the interview, in its entirety, was very long. The affects of this on the respondents, and on the responses given, is unknown. Interviewers were trained to be aware of the needs of respondents and to remind them that they were free to withdraw from the study at any time. An alternative might have been to have invited respondents to participate in a separate

‘quality of life study’ to be conducted on a separate occasion. This might have achieved different responses but at the expense of potentially lower recruitment rates. In addition the economic and temporal impact of this on the researcher would have been considerable.

Due to the established samples from which respondents were drawn, analysis of the findings of the Quality of Life Questions asked at Stage Ib, focused on differences by age group and area. These were useful and informative variables to analyse the data by, however further refining the age groups from 67<87 and 87+ to 67<77, 77<87 and 87+, may have been more informative. In addition, it would have been useful to have analysed the data by gender. However both of these refinements to the quantitative analyses were precluded by the sample sizes.

At both Stage Ib and Stage II, the two qualitative stages, analysis of the data was conducted by the researcher (MF) alone. Some form of inter-rater testing would have been beneficial to examine the reliability and validity of the analyses conducted, particularly in relation to the development of themes or categories that emerged from the very rich data. However, this was not possible due to the self-funded nature of this thesis.

Implications for further research

Finally, having considered the implications of the thesis for policy and practice and the limitations of the research which became apparent during the progress of the research, areas for further research based on the process and outcome of the thesis will now be described.

Further research may take the form of new topics or new methodologies.

The findings of the literature review reported in this thesis suggest that quality of life research, if it is to continue under this rubric, is still in its infancy. There are a number of authors, however, who would most probably disagree with this sentiment. Repetition of the empirical study described here, but without the limitations outlined earlier in this and in other chapters, would be an obvious place for further empirical research to commence. For example, the use of these methods with samples of older people living in institutional care, with younger adults, with larger sample sizes to allow for analysis of the quantitative data by gender and smaller age groups, beyond south east England, beyond England and within the developing world.

There remains a dearth of research on the processes involved in individual quality of life evaluation. This thesis has identified the potential contribution of the temporal context to valuations of life, however further exploration of this is warranted. Thus studies might incorporate some form of assessment of individuals' autobiographical memory and exploration of the impact of their recall on their valuations. In addition, understanding how, where and from what basis our values and expectations develop might enlighten policy and practice initiatives aimed at improving quality of life. Thus repetition of this study with new cohorts of older people would also be valuable.

Chapter 1 referred to the growing number of disease specific 'quality of life' scales. A further area for research may therefore be the exploration of the relevance of these scales to the

quality of life of the relevant samples (i.e. those within the disease group). It is highly likely that the scales will be relevant to their disease, but the relevance of the scales to overall quality of life may require testing using the qualitative, lay-based methods developed and employed here.

For the administration of the 'quality of life' scales at Stage Ia, a traditional survey method was used. By contrast, the structured open Quality of Life Questions at Stage Ib, and the unstructured In-depth Interviews at Stage II, utilised qualitative methods. Each of these methods was well suited to the purpose for which it was chosen. However to address the research questions that have arisen from this thesis, the adoption of different techniques, such as the focus group method, may be productive.

As alluded to earlier, focus groups of older people could be invited to discuss the content and style of various scales used to measure quality of life. Given the lapse of time since the data collection for this study, a new search of the literature to identify 'quality of life' scales more recently used, or recommended for use, with older people should be conducted and might include the Patient Generated Index (Ruta et al, 1994) or the SEIQoL (O'Boyle et al, 1993). Once identified, the scales could be administered to suitable samples of older people, ideally with a range of ages and adequate numbers to allow for quantitative analyses of responses. In addition, quantitative analyses of ease of administration and completion could be conducted by age group and gender. The results of this could be presented to the focus groups as a classic warm up exercise on which discussions of the various scales could then be based.

Focus groups could also be used to discuss the findings of the In-depth Interviews. Groups could be asked to prioritise the dimensions identified through the interviews. What would undoubtedly be of value here would not be the resulting priority listing of dimensions, but the discussion that lead to the production of the list. Indeed, the list itself may, in fact, be counterproductive given the individual, or subjective, nature of quality of life supported by this thesis.

End note

This thesis was commenced in 1990 at a time when quality of life, although not new to the fields of health and social research, was certainly achieving a meteoric rise in popularity. It was the new 'buzz word'; the key phrase to include in the titles or, at the very least, the discussion section of papers. Due to personal circumstances this thesis was subjected to several periods of interruption to its registration and has subsequently taken substantially longer to complete than originally planned. Throughout this extended period quality of life methodology has undoubtedly moved on a little, but the concept is no less popular and its misuse continues. Indeed the phrase 'quality of life' has been further subsumed into every day speech and research contexts, particularly within biomedicine. There remains no gold standard but perhaps, given the very nature of the concept, this will always be the case. What is of greater concern though is the continued dearth, until very recently, of research on the concept in terms of its basic meaning to individuals and amongst older people in particular.

As we entered the year 2000, the Economic and Social Research Council (ESRC) launched the Growing Older research programme described by its director (Alan Walker) as:

'an ambitious programme of research which aims to examine the factors which influence quality of life in old age. A key function of such a research programme is to generate new knowledge and this is a topic that has been neglected by social scientists [...] The Growing Older Programme brings together many of the UK's leading social science researchers on one of the most important topics of the new millenium' (Walker, 2000).

The programme comprised 24 projects over six themes: defining and measuring quality of life; inequalities in quality of life; technology and the built environment; healthy and

productive ageing; family and social support networks; and participation in activity and later life (Walker 2000). The 'defining and measuring quality of life' theme is one of the two largest. Thus this thesis, at its inception, a decade before this programme, was pioneering¹⁷ and yet, despite its longevity, is still highly relevant to today's ongoing debate on quality of life, particularly with regard to older people.

This thesis has addressed some of the problems of defining and measuring quality of life amongst older people. It has not been an attempt to produce yet another 'quality of life' measure, but uniquely asked older people to describe the quality of their own lives, in their own words, using their own frames of reference, in an attempt at Hunt's 'pure research': '...to define, refine and understand the concept of "quality of life", in order to ascertain if it could meaningfully be measured' and, if so, how valid existing 'measures' are (Hunt, 1997a). In response to this it has shown that, among older people living at home, quality of life can be meaningfully measured and suggests that measures in use at the time of the data collection were biased towards the dimensions of health, functional ability and psychological wellbeing and were based on an uncensored survey method; thus they may, therefore, be invalid.

At the end of the twentieth Century we became accustomed to hearing the phrase 'quality of life' throughout our everyday lives. Embarking on the twenty-first Century its popularity shows no sign of abating, yet it is unclear if we are any closer to understanding the conceptual meaning of the phrase. Progress has been made yet we should not be complacent. The development of the Internet has provided a new locus for the unchecked proliferation of the

¹⁷ As a result of work published in the mid 1990s from this thesis the research (MF) was invited to be a referee on this ESRC programme.

'quality of life' concept, with websites devoted to the topic and databases of instruments being readily available (e.g. QOLID's Quality of Life Instruments Database: www.QOLID.org (Emery, Tamburini and Pasquier, 2002)). Few sites are subject to peer review, but as the review of the paper literature demonstrated, peer review itself is by no means infallible.

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Appendix I: 'Quality of life' scales

Nottingham Health Profile

Affect Balance Scale

General Well-being Schedule

McMaster Health Index Questionnaire

Self-Evaluation of Life Function

Dartmouth Co-operative Chart for Quality of Life

The Faces Scale for Quality of Life

Appendix II: Quality of Life Questions

QUALITY OF LIFE

1. How would you describe the quality of your life?

Why do you say that?

2. What things give your life quality?

3. What things take the quality away from your life?

4. What would make the quality of your life better?

5. What would make the quality of your life worse?

		1-2
		3-4

NOTTINGHAM HEALTH PROFILE

Listed below are some problems people may have in their daily life.

Look down the list and put a tick in the box under yes for any problem you have at the moment. Tick the box under no for any problem you do not have.

Please answer every question. If you are not sure whether to say yes or no, tick whichever answer you think is more true at the moment.

	Yes	No	
I'm tired all the time ()	()	()	<input type="checkbox"/> 5
I have pain at night ()	()	()	<input type="checkbox"/> 6
Things are getting me down ()	()	()	<input type="checkbox"/> 7
	Yes	No	
I have unbearable pain ()	()	()	<input type="checkbox"/> 8
I take tablets to help me sleep ()	()	()	<input type="checkbox"/> 9
I've forgotten what its like to enjoy myself ()	()	()	<input type="checkbox"/> 10
	Yes	No	
I'm feeling on edge ()	()	()	<input type="checkbox"/> 11
I find it painful to change position ()	()	()	<input type="checkbox"/> 12
I feel lonely ()	()	()	<input type="checkbox"/> 13
	Yes	No	
I can only walk about indoors ()	()	()	<input type="checkbox"/> 14
I find it hard to bend ()	()	()	<input type="checkbox"/> 15
Everything is an effort ()	()	()	<input type="checkbox"/> 16

I'm waking up in the early hours of the morning () ()

I'm unable to walk at all () ()

I'm finding it hard to make contact with people () ()

Yes No

The days seem to drag () ()

I have trouble getting up and down stairs
or steps () ()

I find it hard to reach for things () ()

Remember if you are not sure whether to answer yes or no to a problem tick whichever answer you think is more true at the moment.

Yes No

I'm in pain when I walk () ()

I lose my temper easily these days () ()

I feel there is nobody I'm close to () ()

Yes No

I lie awake for most of the night () ()

I feel as if I'm losing control () ()

I'm in pain when I'm standing () ()

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	Yes	No	
I find it hard to dress myself	()	()	<input type="checkbox"/> 29
I soon run out of energy	()	()	<input type="checkbox"/> 30
I find it hard to stand for long (e.g. at the kitchen sink, waiting for a bus)	()	()	<input type="checkbox"/> 31
	Yes	No	
I'm in constant pain	()	()	<input type="checkbox"/> 32
It takes me a long time to get to sleep	()	()	<input type="checkbox"/> 33
I feel I am a burden to people	()	()	<input type="checkbox"/> 34
	Yes	No	
Worry is keeping me awake at night	()	()	<input type="checkbox"/> 35
I feel that life is not worth living	()	()	<input type="checkbox"/> 36
I sleep badly at night	()	()	<input type="checkbox"/> 37
	Yes	No	
I find it hard to get on with people	()	()	<input type="checkbox"/> 38
I need help to walk about outside (e.g. a walking aid or someone to support me)	()	()	<input type="checkbox"/> 39
I'm in pain when going up and down stairs or steps	()	()	<input type="checkbox"/> 40
	Yes	No	
I wake up feeling depressed	()	()	<input type="checkbox"/> 41
I'm in pain when I'm sitting	()	()	<input type="checkbox"/> 42

Now we would like you to think about the activities in your life which may be affected by health problems.

In the list below, tick yes for each activity in your life which is being affected by your state of health. Tick no for each activity which is not being affected, or which does not apply to you.

Is your present state of health causing problems with:	Yes	No	
Looking after the home (Examples: cleaning & cooking, repairs, odd jobs around the home)	()	()	<input type="checkbox"/> 43
Social life (Examples: going out, seeing friends, going to the pub etc.)	()	()	<input type="checkbox"/> 44
Home life (That is: relationships with other people in your home)	()	()	<input type="checkbox"/> 45
Interests and hobbies (Examples: sports, arts and crafts, do-it-yourself etc.)	()	()	<input type="checkbox"/> 46
			<input type="checkbox"/> 47
			<input type="checkbox"/> 48
			<input type="checkbox"/> 49
			<input type="checkbox"/> 50
			<input type="checkbox"/> 51
			<input type="checkbox"/> 52
			<input type="checkbox"/> 53
			<input type="checkbox"/> 54
			<input type="checkbox"/> 55

The General Well-Being Schedule

READ This section contains questions about how you feel and how things have been going with you. For each question, mark (X) the answer which best applies to you.

1. How have you been feeling in general?
(During the past month)

1 In excellent spirits

2 In very good spirits

3 In good spirits mostly

4 I have been up and down in spirits a lot

5 In low spirits mostly

6 In very low spirits

2. Have you been bothered by nervousness or your "nerves"?
(During the past month)

1 Extremely so -- to the point where I could not work or take care of things

2 Very much so

3 Quite a bit

4 Some -- enough to bother me

5 A little

6 Not at all

3. Have you been in firm control of your behaviour, thoughts, emotions OR feelings? (During the past month)

- 1 Yes, definitely so
- 2 Yes, for the most part
- 3 Generally so
- 4 Not too well
- 5 No, and I am somewhat disturbed
- No, and I am very disturbed

4. Have you felt so sad, discouraged, hopeless, or had so many problems that you wondered if anything was worthwhile? (During the past month)

- 1 Extremely so -- to the point that I have just about given up
- 2 Very much so
- 3 Quite a bit
- 4 Some -- enough to bother me
- 5 A little bit
- 6 Not at all

5. Have you been under or felt you were under any strain, stress, or pressure? (During the past month)

- 1 Yes -- almost more than I could bear or stand
- 2 Yes -- quite a bit of pressure
- 3 Yes -- some - more than usual
- 4 Yes -- some - but about usual
- 5 Yes - a little
- 6 Not at all

<p>6. How happy, satisfied, or pleased have you been with your personal life? (During the past month)</p>	<p>1 <input type="checkbox"/> Extremely happy - could not have been more satisfied or pleased</p> <p>2 <input type="checkbox"/> Very happy</p> <p>3 <input type="checkbox"/> Fairly happy</p> <p>4 <input type="checkbox"/> Satisfied -- pleased</p> <p>5 <input type="checkbox"/> Somewhat dissatisfied</p> <p>6 <input type="checkbox"/> Very dissatisfied</p>	<input type="checkbox"/> 61
<p>7. Have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel, or of your memory? (During the past month)</p>	<p>1 <input type="checkbox"/> Not at all</p> <p>2 <input type="checkbox"/> Only a little</p> <p>3 <input type="checkbox"/> Some -- but not enough to be concerned or worried about</p> <p>4 <input type="checkbox"/> Some and I have been a little concerned</p> <p>5 <input type="checkbox"/> Some and I am quite concerned</p> <p>6 <input type="checkbox"/> Yes, very much so and I am very concerned</p>	<input type="checkbox"/> 6
<p>8. Have you been anxious, worried, or upset? (During the past month)</p>	<p>1 <input type="checkbox"/> Extremely so -- to the point of being sick or almost sick</p> <p>2 <input type="checkbox"/> Very much so</p> <p>3 <input type="checkbox"/> Quite a bit</p> <p>4 <input type="checkbox"/> Some -- enough to bother me</p> <p>5 <input type="checkbox"/> A little bit</p> <p>6 <input type="checkbox"/> Not at all</p>	<input type="checkbox"/> 6

9. Have you been waking up fresh and rested?
(During the past month)

- 1 Every day
- 2 Most every day
- 3 Fairly often
- 4 Less than half the time
- 5 Rarely
- 6 None of the time

10. Have you been bothered by illness, bodily disorder, pains, or fears about your health?
(During the past month)

- 1 All the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

11. Has your daily life been full of things that were interesting to you?
(During the past month)

- 1 All the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

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12. Have you felt
down-hearted and blue?
(During the past month)

- 1 All the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

13. Have you been feeling
emotionally stable
and sure of yourself?
(During the past month)

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

14. Have you felt tired,
worn out and used-up,
or exhausted?
(During the past month)

- 1 All of the time
- 2 Most of the time
- 3 A good bit of the time
- 4 Some of the time
- 5 A little of the time
- 6 None of the time

For each of the four scales below, note that the words at each end of the 0 to 10 scale describe opposite feelings. Circle any number along the bar which seems closest to how you have generally felt DURING THE PAST MONTH

15. How concerned or worried about your HEALTH have you been?
(During the past month)

0	1	2	3	4	5	6	7	8	9	10
Not Concerned at all					Very Concerned					

70

16. How RELAXED or TENSE have you been?
(During the past month)

0	1	2	3	4	5	6	7	8	9	10
Very relaxed					Very tense					

71

17. How much ENERGY, PEP, VITALITY have you felt?
(During the past month)

0	1	2	3	4	5	6	7	8	9	10
No energy AT ALL Listless					Very ENERGETIC, dynamic					

72

18. How DEPRESSED or CHEERFUL have you been?
(During the past month)

0	1	2	3	4	5	6	7	8	9	10
Very depressed					Very Cheerful					

73

74 75

76 77

(78 BLANK)

CARD NO.

2	1
79	80

		1-2
		3-4

AFFECT BALANCE SCALE

During the past few weeks, did you ever feel _____

- A. Particularly excited or interested in something?
- B. Did you ever feel so restless that you couldn't sit long in a chair?
- C. Proud because someone complimented you on something you had done?
- D. Very lonely or remote from other people?
- E. Pleased about having accomplished something?
- F. Bored?
- G. On top of the world?
- H. Depressed or very unhappy?
- I. That things were going your way?
- J. Upset because someone criticized you?

YES	NO
—	—
—	—
—	—
—	—
—	—
—	—
—	—
—	—
—	—
—	—
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	18
	19
	20

M.H.I.Q.

- A) Often peoples' health affects the way they feel about life.
 For these next questions, please circle the choice that is closest to the way you feel about each statement.
 If you STRONGLY AGREE, circle 1
 If you AGREE, circle 2
 If you are NEUTRAL, circle 3
 If you DISAGREE, circle 4
 If you STRONGLY DISAGREE, circle 5

	STRONGLY AGREE				STRONGLY DISAGREE	
1. I sometimes feel that my life is not very useful.	1	2	3	4	5	<input type="checkbox"/> 21
2. Everyone should have someone in his life whose happiness means as much to him as his own.	1	2	3	4	5	<input type="checkbox"/> 22
3. I am a useful person to have around.	1	2	3	4	5	<input type="checkbox"/> 23
4. I am inclined to feel that I'm a failure.	1	2	3	4	5	<input type="checkbox"/> 24
5. Many people are unhappy because they do not know what they want out of life.	1	2	3	4	5	<input type="checkbox"/> 25
6. In a society where almost everyone is out for himself, people soon come to distrust each other.	1	2	3	4	5	<input type="checkbox"/> 26
7. I am a quick thinker.	1	2	3	4	5	<input type="checkbox"/> 27
8. Some people feel that they run their lives pretty much the way they want to and this is the case with me.	1	2	3	4	5	<input type="checkbox"/> 28
9. There are many people who don't know what to do with their lives.	1	2	3	4	5	<input type="checkbox"/> 29
10. Most people don't realize how much their lives are controlled by plots hatched in secret by others.	1	2	3	4	5	<input type="checkbox"/> 30
11. People feel affectionate toward me.	1	2	3	4	5	<input type="checkbox"/> 31
12. I would say I nearly always finish things once I start them.	1	2	3	4	5	<input type="checkbox"/> 32
13. When I make plans ahead, I usually get to carry out things the way I expected.	1	2	3	4	5	<input type="checkbox"/> 33
14. I think most married people lead trapped (frustrated or miserable) lives.	1	2	3	4	5	<input type="checkbox"/> 34

	STRONGLY AGREE					STRONGLY DISAGREE					
15. It's hardly fair to bring children into the world the way things look for the future.	1	2	3	4	5						<input type="checkbox"/> 35
16. Some people feel as if other people push them around a good bit, and I feel this way too.	1	2	3	4	5						<input type="checkbox"/> 36
17. I am usually alert.	1	2	3	4	5						<input type="checkbox"/> 37
18. Nowadays a person has to live pretty much for today and let tomorrow take care of itself.	1	2	3	4	5						<input type="checkbox"/> 38
											<input type="checkbox"/> 39
											<input type="checkbox"/> 40

B) This section contains some questions on general health and on your social activities.

19. How would you say your health is today? Would you say your health is (Circle your answer)
- 1 VERY GOOD
 - 2 PRETTY GOOD
 - 3 NOT TOO GOOD
- 41
20. Taking all things together, how would you say things are today? Would you say you are
- 1 VERY HAPPY
 - 2 PRETTY HAPPY
 - 3 NOT TOO HAPPY
- 42
21. In general, how satisfying do you find the way you're spending your life today? Would you call it
- 1 COMPLETELY SATISFYING
 - 2 PRETTY SATISFYING
 - 3 NOT VERY SATISFYING
- 43
22. How would you say your *physical* functioning is today? By this we mean the ability to move around
- 1 GOOD
 - 2 GOOD TO FAIR
 - 3 FAIR
 - 4 FAIR TO POOR
 - 5 POOR
- 44
23. How would you say your *social* functioning is today? (By this we mean your ability to work, to have friends, and to get along with your family.)
- 1 GOOD
 - 2 GOOD TO FAIR
 - 3 FAIR
 - 4 FAIR TO POOR
 - 5 POOR
- 45
24. How would you say your *emotional* functioning is today? (By this we mean your ability to remain in good spirits most of the time and to be usually happy and satisfied with your life.) (Circle your answer)
- 1 GOOD
 - 2 GOOD TO FAIR
 - 3 FAIR
 - 4 FAIR TO POOR
 - 5 POOR
- 46

(461 - 78 BAWW)
 CARD NO.
 2 2

S.E.L.F. SCALE

Directions:

Please show how much the following symptoms have bothered you in the *past month* by circling the appropriate number to the right of each symptom.

	Not at all	A little	Quite a bit	Extremely
Nervousness or shakiness inside	1	2	3	4
Feeling low in energy or slowed down	1	2	3	4
Trembling	1	2	3	4
A feeling of being trapped or caught	1	2	3	4
Feeling lonely	1	2	3	4
Heart pounding or racing	1	2	3	4
Trouble getting your breath	1	2	3	4
Feeling blue	1	2	3	4
Soreness of your muscles	1	2	3	4
Numbness or tingling in parts of your body	1	2	3	4
Heavy feelings in your arm or legs	1	2	3	4
Feeling hopeless about the future	1	2	3	4
Weakness in parts of your body	1	2	3	4

QUALITY OF LIFE

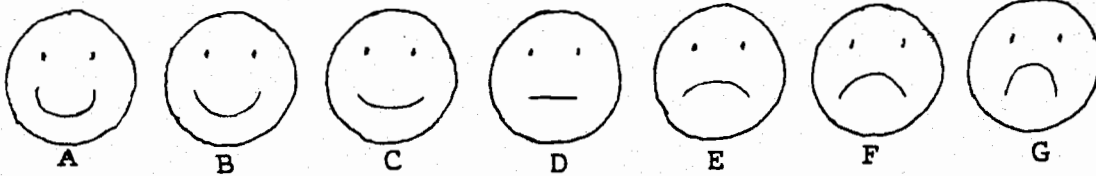
How has the quality of your life been during the past 4 weeks? i.e. How have things been going for you?

Very well: could hardly be better	1
Pretty good	2
Good & bad parts about equal	3
Pretty bad	4
Very bad: could hardly be worse	5

44.

"FACES" QUESTIONS

Here are some faces expressing various feelings. Below each is a letter



a. Which face comes closest to expressing how you feel about you life as a whole now?

_____ write letter on line

41

b. Which face comes closest to expressing how you feel about living here (your accommodation)?

42

c. Which face comes closest to expressing how you feel about your activities?

43

d. Which face comes closest to expressing how you feel about your independence or freedom - the chance you have to do what you want?

44

e. Which face comes closest to expressing how you feel about the control you have over your life?

45

f. Which face comes closest to expressing how satisfied you are with your social contacts?

46

g. Which face comes closest to expressing how you feel about your health?

47

h. Which face comes closest to expressing how you feel about the quality of your life?

48

Appendix II: Quality of Life Questions

QUALITY OF LIFE

1. How would you describe the quality of your life?

Why do you say that?

2. What things give your life quality?

3. What things take the quality away from your life?

4. What would make the quality of your life better?

5. What would make the quality of your life worse?