ADEQUACY OF THREE QUALITY OF LIFE MEASURES FOR DEMENTIA:
PATIENT AND FAMILY INPUT

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in partial fulfillment of the requirements for the degree of Master of Science.

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Adequacy of three Quality of Life Measures for Dementia: Patient and Family Input

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Background: New dementia treatments are currently under investigation. Assigning value to treatments is a difficult enterprise. Ethical clinical trials would likely yield null results that could obscure meaningful differences. On the other hand, statistically significant differences may be obtained even when symptomatic improvement is negligible from a clinical perspective. When comparing treatments, utility-based quality of life assessments can be useful in creating a ‘value space’ around the treatments. Objectives: 1) To obtain a baseline profile of the opinions and experiences of patients and family members about aspects of quality of life which may be important to them. 2) To assess the opinions of patients and family members on the feasibility of using utility-based instruments (European Quality of Life Instrument, Health Utilities Index, Quality of Well-Being Scale) to measure the quality of life of patients diagnosed with dementia. Method: Forty subjects (20 mild dementia patients and 20 family members) were included in the study. 1) A semi-structured interview was conducted to determine which aspects of quality of life the subjects consider important, and whether or not these attributes are included in the measures. 2) After the respondents had completed each of the measures, they were provided with a questionnaire to assess their opinions on the relevance, acceptability, and sufficiency of these measures. Analysis: 1) The data derived from the interviews was analyzed using content analysis techniques. 2) Differences amongst the measures on the dimensions of relevance, acceptability and sufficiency were analyzed with ANOVA procedures. Results: 1) Essential attributes of quality of life for the respondents were missing in the three measures selected for the study. 2) The three measures were indistinguishable in terms of the subjects’ assessments of their relevance, acceptability and sufficiency. Conclusions: 1) Mild dementia patients are able to provide useful descriptions of their quality of life; 2) The quality of life perspective provided by patients and family members is broader in scope than that contained in the measures; 3) Null results in the quantitative analysis suggest that neither patients nor family members are able to distinguish between the measures; 4) All measures present serious shortcomings in content validity according to the respondents.
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1. LITERATURE REVIEW

1) WHAT IS QUALITY OF LIFE?

This section will review some philosophical theories that offer a broad conception of a good life. Scanlon (1993) suggests that the subject of quality of life might be associated with three related questions: 1) What are good conditions under which to live?; 2) What makes life a good one for the person who lives it?; 3) What makes a life a valuable one?. Since each of these questions requires a different set of answers, and each one also admits a variety of interpretations, the field of quality of life “suffers from an embarrassing richness of possibilities” (Scanlon 1993 p.185). The complexity of the subject is further increased depending on whose perspective is being engaged.

The following review begins by restricting the scope of the subject to the second question, which is closely associated to the first. The scope will be restricted further when accounts of quality of life are needed to deal with evaluation measures for health care outcomes. The third question touches the scope of moral theories, questions related to life-sustaining treatment decisions, end-of-life care, euthanasia, and the like. This question has no direct bearing to this study.

From a utilitarian perspective, there are three broad types of theories that address what makes a life a good one for the person who lives it. Utilitarian theories lie within a consequentialist framework. In utilitarian terms, well being or quality of life is understood in terms of the presence of pleasure and the absence of pain. Theories within this framework are distinguished depending on how broadly the terms pleasure and pain
are conceptualized. The distinctions include hedonistic theories, desire fulfillment or preference satisfaction theories, and objective list, substantive good or ideal theories.

1.1) Hedonist Theories

Hedonist theories hold that quality of life can only be judged from the experience of living that life. This experience is accounted for by specifying certain subjective states, happiness or pleasure, which make life better or worse. What would be best for someone or what would make a person's life be as good as possible is what would make his life happiest (Parfit 1984). Particular states such as being healthy or ill are part of a good life only to the extent they produce happiness for that particular individual. This notion of utility as a pleasurable mental state provides a dominant end or substantive value (happiness) and a principle of choice by which conflicts between all other subordinate ends can be resolved. Hedonistic theories do not admit pluralism of intrinsic values.

    Hedonist theories assume there is a single homogeneous mental state: a continuum that goes from pleasure to pain, each on a same scale but in opposite directions. The assumption is made that different experiences such as eating, listening to music, or studying philosophy, have a unified character, a common element that allows proper comparisons amongst them in terms of the amount of happiness or pleasure they produce. There is one ultimate good, happiness, which it is claimed makes sense at an intuitive level.

    The basic assumption of hedonism is contentious. People can value many types of things other than happiness (Griffin 1986). Consider the case of a terminally ill patient who decides to avoid pain-killers because he prefers to face the terminal stages of his
illness while being alert rather than overly sedated. A narrow hedonistic theory would claim that this patient’s choice far from being legitimate is misled, since pain-killers offer a better quality of life because the amount of “pleasure” is greater (or more appropriately, the amount of pain is less). This example shows there may be exceptions to a single valued mental state. There are other criteria of quality of life by which to rank options.

Hedonistic theories are too narrow as they exclude things that should count to well being. Parfit (1984) questions the plausibility of these theories because they only include those present preferences that are consciously accessible to the individual at the time they produce pleasure. The “experience requirement” would disregard important events that are outside the awareness of the person but are still relevant to his quality of life. For instance, someone may be unaware that something bad has happened to his children, but this remains important to his quality of life whether or not that knowledge has entered his conscious experience. If one’s children are a part of one’s life-plan, one would rather know of their mishaps than remain unaware and comfortably deceived. Despite having the option of being deceived many confront reality and risk happiness for truth.

1.2) Desire or Preference Theories

Another variant of the hedonist theories contends that what unifies apparent disparate experiences is their relation to desires. Preference theories hold that a good life consists in the satisfaction of people’s desires or preferences. This is measured in terms of the person’s success in having their preferences met (Brock 1993). What is good for people is that they should get what they most want. Therefore, the quality of a person’s
life at a given time is measured by the degree to which the preferences are fulfilled (Scanlon 1993). Preference theories put a premium on individual self-determination. In deciding what is good and what is bad for a given person, the ultimate criterion can only be the person’s own preferences (Harsanyi 1976). Going back to the example of the terminally ill patient, the preference account would say that his life was better because he chose the option he preferred.

The preference account sees utility as a collection of values thereby introducing the notion of ‘more and less’ valuable (Griffin 1986). Utility is related to a set of values: accomplishment, pleasure, autonomy, loving relationships, etc. This permits a pluralism of values because each one could potentially be preferred. The preference account assumes that there is a discrete set values that are relevant for everyone, but each person decides which value has more weight when values are in conflict.

The simplest and broadest account is the actual desires theory, which states that utility is the fulfillment of actual desires. This is appealing because actual desires are often revealed in choices that are observable and amenable to empirical confirmation. In its ideal frame, persons operate like autonomous agents (Griffin 1986). The actual desires theory claims there are no instances when we are not better off when our desires are fulfilled. Regardless of the outcome, we are better off by virtue of having exercised our choice. When considering desires that are trivial, abnormal, irrational, or immoral the theory does not offer distinguishing criteria.

The actual desires theory in order to be plausible needs preferences to be corrected. The informed desire account says that utility is the fulfillment of only those desires that people have when they realistically appreciate the nature of the given object
of desire (Griffin 1986). In this account, only those desires that are rational or informed count. The informed desire account departs from the actual desires accounts in recognizing that actual desires can be flawed. One flaw stems from lack of sufficient information. A patient may agree to undergo a risky operation not knowing that a medication could be just as effective. Another flaw can result from making 'logical' errors. Reasoning may be confused or irrelevant. Only reasoned, informed desires, have utility.

Regardless of how the theory is presented, there are some problems that arise. If we had a set of immutable preferences, a sort of preference framework, it would be plausible to measure the degree to which those preferences are met. The problem is that desires or preferences change over time in a way that does not permit past preferences to be discounted or subtracted from present ones. Persons can hold both current and past preferences simultaneously. A dramatic instance arises in a medical ethical problem: should the present preferences of a severely demented patient outweigh his past preferences that he held all his life? There is controversy in the ethical and legal literature as to whether or not the demented self is the same person as the one prior to illness. If not, it may be that at different stages in the progression of dementia patients may hold different values.

Another problem is that the theory is too broad. This makes the theory appealing but it is also its greatest flaw. By dropping the experience requirement, the theory includes considerations that are not relevant to well being, including the desires of the dead. This is not to say that the wishes of the dead are unimportant. There is a legitimate interest in fulfilling them, as in inheritance matters. However, it is another matter to claim
that these wishes have a bearing to the well being of the person now deceased. Griffin provides two examples to this point. 1) Leonardo wanted humans to fly, an informed desire, but it is highly unlikely that his life was improved because centuries later humans were able to fly. 2) One may want people on the twenty-second century to prosper, but one’s life will not be better if they do. It does not make any difference to the life of Van Gogh that centuries later his paintings are selling at astronomical prices. Clearly, the fulfillment of some informed, reasoned desires does not affect well being. One way to salvage the theory is to consider only those desires that are a part of the central aims of our life plans. In this regard, the difference between wanting a stranger to prosper or our children to succeed is that the former is not a central end while the latter is.

In sum, hedonistic accounts are too narrow by excluding things that do not enter the conscious experience. On the other hand, the desire account is too broad, including things that are not relevant to well being.

1.3) Objective-list, substantive good, or ideal theories

These theories claim that quality of life is determined by the presence of certain substantive goods, conditions, and opportunities which can be specified and measured without depending on subjective experience (Scanlon 1993). For example, an important component of a good life is being an autonomous agent. It is of no import for this theory if the person is happier as a result of being autonomous, or even relevant that the person wants to be autonomous. A good life is pre-determined by certain essential conditions (based on general societal values), regardless of happiness or preferences. A plurality of conditions forms an objective-list known to contribute to or restrict a good life. Clearly,
what constitutes a good life may be in conflict with the views of the person whose quality of life is considered.

Brock (1993) questions the assumption that we are somehow forced to select only one of the competing theories of a good life. He argues against the notion of limiting our understanding of quality of life to either mental state(s) or conditions. Brock favors a more amalgamated view. His model presents the three components of a good life (happiness, preference satisfaction, and ideal conditions) as independent vectors that can be further subdivided. Differential weights can be assigned to vector components depending on their respective contribution to the overall assessment of quality of life.

Sen (1995) describes a conception of quality of life that is the basis for Brock’s belief that an amalgamated approach can work. Sen’s conception is very compatible with the efforts to measure quality of life in health care. This view of quality of life is described as capability: “Capability is concerned with the actual ability to achieve valuable functionings as a part of living.” (1995, p.30). This conception is very close to the ones already applied in health care, though Sen’s conceptualization has the advantage of “deliberate incompleteness” (1995, p.47). Deliberate incompleteness means that dimensions can potentially be included to incorporate virtually any quality of life consideration, giving the measure an infinite plasticity. Furthermore, Sen’s approach also includes individual effort and opportunity which are hard to assess (or never assessed) in a health care setting. Considering capability, it becomes important to distinguish between the state of a person; the commodities that help to generate that state; and the utilities generated by the state. Sen differentiates the capability approach from: 1) Personal utility - pleasure, happiness, or desire fulfillment; 2) Absolute or relative opulence - commodity
bundles, real income, real wealth; 3) Assessment of negative freedoms - procedural fulfillment of libertarian rights and rules of non-interference; 4) Comparisons of means of freedom- primary goods (Rawls); 5) Comparisons of resource holdings - Dworkin's equality of resources. For Sen, the “capability set” defines the freedom of opportunity associated with quality of life. Sen cautions: “Obviously this consideration would be of no direct relevance in the case of the mentally disabled.” (1995, p.44). For those that are mentally disabled, it is expected that they would have a much reduced capability set.

2) OBJECTIVE VS. SUBJECTIVE

Judgments about what constitutes a good life can be subjective or objective. Hedonist and preference theories are considered to be subjective because what makes a person happy or his desires fulfilled depend on a personal evaluation. On the other hand, substantive goods accounts are objective being justified by ideals regardless of people’s subjective experiences (Brock 1993).

An essential aspect of whether a judgment is objective or subjective depends on whether it is held by the individual or is shared by the community. According to Morreim (1986), objective quality of life consists of both a set of material facts and a shared societal evaluation of those facts. The material facts include those characteristics that describe someone’s life: facts about the body, mind, functional capabilities, and the environment. Therefore, health status measures attempt to provide more or less comprehensive lists of functions. It is not necessary to have a complete agreement on what is to be included or excluded from the list. It suffices to have a rough consensus on what is desirable and what is not. The second component is a normative evaluation of
these material facts as to the degree to which they are good or bad, desirable or undesirable from the perspective of the community. What it is taken to be a community becomes exceedingly relevant.

For subjective quality of life, the distinction between competent and incompetent persons becomes relevant. Competent persons make normative judgments based on their capacity to be autonomous agents. Even when there is little control over material conditions, an autonomous competent person still has choices to make the best of it. An objectively poor quality of life could be relatively better depending on the capacity to adapt to adversity. It is quite different when incompetent persons are involved. With incompetent persons, subjective determinations of quality of life and even objective ones are problematic. A severely demented patient who has lost any sense of biographical continuity is unable to conceptualize or communicate his mental life and cannot provide us with a personal account. Even in less severe cases, cognitive impairment may pose obstacles to obtaining a reliable subjective account. Furthermore, the objective conditions that contribute to quality of life for persons with that diagnosis cannot be established by a consensus of peers.

Depending on the evaluation program, the balance between objective and subjective could favor one or the other. There are programs aimed at society at large, other are designed to have an impact on individuals, and still others are focused on both. Programs aiming to improve the quality of life of society as a whole, such as public health programs, could be well served by an objective account. Public policy makers base their decisions on consensus or voting when public money is at stake. Programs designed to improve the quality of life of individuals focus on the perspective of the people who
are presumably going to benefit from the program (Morreim 1986). This is particularly acute for patients. A compromise recommended between subjective and objective evaluations would be to use patients' preferences to compare treatments within the same disease but to use the perspective of members of the broader community when comparing treatments across conditions (Gold, Patrick et al. 1996).

3) HEALTH RELATED QUALITY OF LIFE

Quality of life can be given a more or less broad interpretation depending on the type of decisions that need to be made. Health and medicine affect only limited aspects of people's lives. In this sense, health should not encompass everything we can think of as related to quality of life. It is commonly accepted that the main objective of medicine is to restore the patient to his pre-morbid level of functioning. Most measures of quality of life focus almost exclusively on patients' dysfunction in relationship to normal health.

The World Health Organization defines health-related quality of life "as an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns. It is a broad-ranging concept, incorporating in a complex way the person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationships to salient features of the environment" (Group 1994).

3.1) General Classification of Health-Related Quality of Life

Two basic approaches characterize the measurement of health-related quality of life: generic and specific instruments (Guyatt, Jaeschke et al. 1996).
Generic instruments attempt to measure all relevant aspects of health-related quality of life. The most important advantage of these instruments is that they apply to a variety of populations with a diversity of conditions. This in turn allows for comparisons across various health care programs. These generic instruments are less sensitive to changes in specific conditions.

On the other hand, specific instruments focus on health status variables particular to the disease under study. Only those aspects of health-related quality of life that are relevant to a population, disease, or function are included. The benefit of this approach lies in that it results in instruments which are more responsive and sensitive to mild changes within a specific condition. Disease-specific measures' increased responsiveness is particularly compelling in clinical trials (Guyatt, Jaeschke et al. 1996).

3.2) Utility-based instruments

Another important classification scheme refers to the distinction between utility-based measures and psychometric measures. Psychometric measures assign scores to individual components of health states (usually the severity of impairment) and then compute a total score. It is generally assumed that each item has equal weight. Where that is the case, psychometric measures are criticized. It is unlikely that people assign equal importance to each component of health. Psychometric measures leave out estimates of the extent to which health states are more or less desirable (Gold, Patrick et al. 1996). Utility-based instruments provide measures within specific domains and add how important these domains are to overall quality of life (Guyatt, Feeny et al. 1993). In that
way utility assessment provides information on quality of life that incorporates patients’ preferences.

Utility-based measures are anchored in the general belief that health related quality of life is a function of preference satisfaction. The preferences in these measures are for different health states. These preferences can be elicited by asking patients directly to rate the value of their health state compared to another or in isolation. The health status is converted to a utility score by applying a previously estimated scoring derived from the values elicited from the community at large (Guyatt, Jaeschke et al. 1996). The utilities are numeric values which usually fall between 0, representing death, and 1, representing perfect health (Gold, Patrick et al. 1996). In being able to provide a single numeric value or utility, the net effect of treatment-related benefits and complications can be evaluated at the same time (Feeny, Torrance et al. 1996). Utility based instruments are particularly useful in economic evaluations, such as cost-effectiveness analyses that show the relationship between resources used and health benefits achieved for one intervention compared to an alternative strategy (Neumann, Hermann et al. 1997).

Utility-based measures have rarely been used in dementia. Largely, the view of the public has predominated while the particular perspective of those directly affected by dementia is seldom elicited. The difficulty involved in eliciting preferences from cognitively impaired individuals seems to be the reason.

Deciding which dimensions are selected to characterize the health states affects the results (Megone 1990). The utilities elicited will depend on the public’s attitudes to the health states stipulated. The results may be different if the selected health states are different. One way to select the health states to be included is to ask experts in the field
for their input. Another way is to ask those affected by the particular disease. Empirical investigations can be made to accommodate these different vantage points.

The empirical determination of utilities poses a procedural dilemma. When preferences are elicited without pre-specified health states, it is unlikely that any meaningful comparison can result. Otherwise, the selection of health states and their dimensions can be pre-set requiring that the selection be defended. The latter appears to be a task that most researchers are reluctant to do. In the end, evaluative assumptions seem inescapable for any empirical method to determine quality of life.

Within a utility-based framework, preferences are assumed to remain stable over time. This is necessary if the measures are to be used to make comparisons over time. Even when large samples are surveyed, the stability of the results is not assured. Many would argue that preferences are in a constant process of revision. Furthermore, preferences may change in the process of obtaining them. There is no agreed system to weight preferences that change over time.

Nevertheless, utility based instruments combine a number of advantageous ingredients for the measurement of health related quality of life. In addition, they have been extensively employed. The advantages are: 1) A quantifiable subjective measure of intensity of preference for a given health state; 2) The use of ‘consensus’ weights to reflect an objective value for the particular health state; and, 3) A theoretically grounded method for combining and comparing the utilities obtained. This approach has yet to be used as an outcome for dementia treatments.
4) QUALITY OF LIFE IN DEMENTIA

The literature exploring the quality of life of older people is growing. This literature is relevant to quality of life in dementia because it shows the difficulties that have arisen. Raphael and colleagues (1995) have argued that the assessment of quality of life in older persons is overly focused on the negative aspects of aging. It has focused on physical illness and has ignored broader personal and social perspectives. This is seen in the narrowly defined measures of activities of daily living and functional dependence that have been used as quality of life indices (Buchner and Wagner 1992; Guralnik and Simonsick 1993). To overcome these limitations, Raphael and colleagues developed the Quality of Life Profile: Seniors Version (Raphael, Brown et al. 1995). It focuses on the self-reported quality of life of seniors living in the community. It contains three domains: Being (physical, psychological, and spiritual being), Belonging (physical, social, and community belonging), and Becoming (practical, leisure, and growth becoming).

In another attempt to overcome the limitations of current measures, Farquhar (1995) identified the definitions of quality of life among elderly people living at home. He concluded that elderly people are able and willing to talk about quality of life, confirming the findings of Andrews (Andrews 1974; Andrews and Withey 1976). It is possible to conduct in-depth, unstructured, interviews about quality of life with the elderly. To them, it appears that health status is only one of the many relevant aspects of quality of life. Family relationships, social contacts, and other activities appear to be as important as health.

Guyatt and colleagues (1993) developed and tested the Geriatric Quality of Life Questionnaire designed for the frail elderly in an attempt to include the perspective of
older people. One hundred patients over 65 years of age, living at home, but presenting enough functional impairment to compromise their ability to live independently were interviewed. Reports about their health problems were grouped into three domains: 1) activities of daily living; 2) symptoms; and, 3) emotional function. Although the questionnaire proved to be appropriate for the majority of the frail elderly, the questionnaire did not have any advantage over simpler measures of physical and emotional functions. Furthermore, the questionnaire proved to be too complex for the cognitively impaired elderly.

With respect to the cognitively impaired, Lawton (1994) points out that three domains are most often assessed in patients with Alzheimer's disease. These include cognitive function, competence in activities of daily living, and socially appropriate behaviors. This choice of domains suggests an assumption that the capacity to make subjective evaluations is lost with disease progression. Two domains Lawton considers are usually neglected are: 1) Engagement in positive activities, and, 2) Presence of positive and absence of negative affects. It is possible for a demented patient with severe cognitive dysfunction to engage in activities that create positive subjective states. Assessing the patient's engagement in positive activities could evaluate the effectiveness of pharmacological and social interventions. This effort would address the criticism that quality of life measures are only concerned with decrements in functional status. Along these lines, Rabins and Kasper (1997) propose the following domains should be included: social interaction, awareness of self, enjoyment of activities, feelings and mood, and response to surroundings. Ramsay and colleagues (1995) argue that the quality of life of demented persons is affected by a different set of factors from the quality of life of
cognitively intact adults. They suggest the inclusion of the following domains as outcome measures for patients with dementia: personal self-care, ADL, physical health, psychological well-being, cognitive decline, inappropriate behavior, social functioning and satisfaction. Finally, Pearlman and Uhlmann (1991) suggest the inclusion of the following general categories: memory, mood, physical health, functional ability, interpersonal relationships, psychological well-being, life satisfaction, participation in religious activities, environmental comforts, and physical discomfort.

4.1) Self-report vs. Proxy-report

It is usually assumed that patients with dementia are not able to report on their quality of life. Their self-reports have been considered suspect. Thus, the assessment of quality of life in dementia rarely includes the patient's perspective. However, there is increasing evidence suggesting that the patients' perspective needs to be included. Pearlman and Uhlmann (1988) found that elderly patients with chronic illnesses rated their quality of life significantly higher than did their physicians. It has been suggested that illness brings with it a rearrangement of a person's values (Lawton 1994). Cohn and Sugar (1991) studied quality of life assessments provided by nursing home residents, staff, and family members. They found that each group has a tendency to view quality of life in terms of how it validates their respective roles. For example, nursing aides will rate bathing the highest. For their part, family members undervalued the significance of non-family support. Patrick and colleagues (Patrick, Starks et al. 1994) studied the preference for life-sustaining treatments in a sample of well adults and nursing home residents. The methods to elicit preferences were rank order, category scaling, time trade-
off, and the standard gamble. The cognitive burden of giving preferences was assessed. The results showed that all well adults and 78% of nursing home residents were able to complete the measurement tasks. All nursing home residents found the tasks difficult and recommended that the cognitive burden should be reduced to adapt these methods for frail elderly patients in institutional settings.

Several researchers have begun to question the traditional view that dementia patients are not able to provide useful information about themselves. It appears that patients with mild and moderate dementia can provide valuable information about themselves. DeJong, Osterlund, and Roy (1989) report that patients with dementia often contributed their perceptions during interviews with caregivers. Grut, Jorm, and Fratiglione (1993) found that patients with mild and moderate dementia reported memory complaints which corresponded to the severity of dementia. Early-stage dementia patients can participate in focus groups, report feelings, and express concerns regarding the disease (David 1991; Foley 1992).

These previously mentioned findings have led to a series of nursing studies showing that it is possible to obtain relevant information directly from dementia patients. Parse (1996) successfully conducted a qualitative study to explore the meaning of quality of life with twenty-five patients diagnosed with mild to moderate Alzheimer’s disease. Burgener and Dickerson (1999) obtained qualitative and quantitative data from 84 patients with a diagnosis of AD, multi-infarct, or mixed dementia, to examine the impact of the disease on their everyday functioning. They found that patients were consistently able to identify relevant issues such as loss of independence (financial control and driving), loss of employment, and increased fear of social embarrassment. Patients
described being acutely sensitive to the reactions of others to their situation or behaviors. Some patients described distancing themselves from friends, and avoiding embarrassing social situations. Finally, loss of self-esteem was an essential complaint. Acton and colleagues (1999) conducted a qualitative analysis of 20 semi-structured interviews of patients with AD to determine to what extent meaningful communication could be achieved and to see which themes emerged as relevant. The findings indicated that individuals with impaired memory function are able to transmit meaningful information that could be interpreted by others. Reported inter rater reliability in coding (i.e. interpreting the meanings involved) between four raters was calculated to be 0.86. Intra rater reliability (re-coding two weeks later by the same rater) was calculated to be 0.89. The data showed that subjects could communicate about their needs, and that in some respects their concerns were different from the concerns of observers. For instance, 75% of patients reported awareness of cognitive limitations, but only 25% made mention of physical limitations. By contrast, all 20 caregivers reported limitations in activities of daily living. The authors concluded that subjects were less bothered by physical limitations than by cognitive ones.

Values and preferences are important outcomes for effectiveness research in dementia (Maslow and Whitehouse 1997). Lisa Gwyther (1997), using anecdotes from her work, proposed a number of patient-valued outcomes. These focus on the process of living with the disease rather than the outcome of the actual diagnoses. Examples include: a sense of normalcy, feeling useful, being involved in meaningful activities, experiencing self-defined pleasant events, having one’s symptoms recognized, receiving a diagnosis, knowing what to expect, knowing one will continue to receive appropriate medical care,
help with daily activities, and believing that one will not be abandoned as the disease progresses. Patients assign great importance to symptomatic relief from primary cognitive and emotional symptoms, such as feeling fatigued, feeling overwhelmed, inadequate, or frustrated.

4.2) Quality of Life in Anti-Dementia Drug Trials

Clinical trials should incorporate quality of life assessments. Ciampi and Till (1980) argue that in clinical trials null results often conceal what could be meaningful differences. They proposed that this issue be addressed by expanding the operational definition of success. It is clear that in the case of anti-dementia drug trials success cannot be defined in terms of cure. New treatments only claim to offer symptomatic relief or delay in disease progression. Therefore, outcomes have to be broadened to include the care dimension (amelioration of symptoms, reduction of side-effects, restoration of physical and/or psychosocial functions) and the cost dimension (economic efficiency).

The benefits of anti-dementia drugs include their impact on the quality of life. In a retrospective study conducted by Howard & Rockwood (1995) only a very limited number of anti-dementia drug trials included quality of life measures. These authors found that since 1989, only 36 out of 257 studies were randomized placebo controlled trials. Furthermore, only 5 studies used quality of life measures. None of these studies employed quality of life instruments as a primary outcome measure. To develop a valid quality of life measure for use in anti-dementia drug trials several questions had to be answered: who should participate in the assessment (patients vs. care-givers); which domains should be included (general vs. disease-specific); how to address the
heterogeneity of symptom manifestations; and, how to account for the lack of reversal in
treatment effects.

A wide consensus supports the use of disease-specific measures to evaluate the
effects of therapeutic interventions (Rabins and Kasper 1997). Whitehouse and colleagues
(1997) believe that it is precisely the breadth of the domains and the inclusion of the
patient perspective that makes this approach appealing as an outcome for clinical trials.

We have chosen three utility-based measures for this research (see method): The
European Quality of Life Instrument (EuroQol), The Health Utilities Index (HUI), and
the Quality of Well-being Scale (QWB). We chose these instruments because they have
been used extensively, for a variety of conditions, for a number of years. In addition,
these instruments can be readily incorporated into cost-effectiveness analyses and are
easy to administer.

The HUI and the QWB have been used in dementia research. The HUI was used
in a cost-effectiveness analysis of Donepezil (Neumann, R et al. 1999). The authors
estimated the cost-effectiveness of Donepezil when compared to no treatment in terms of
costs per quality-adjusted life-years gained. They concluded that Donepezil was
cost-effective only after two years of treatment. The limitations of this study included the
use of proxy respondents to fill out the HUI, and the use of preference weights obtained
from the general population.

One study assessed the validity of the QWB in patients with Alzheimer’s disease
(Kerner, Patterson et al. 1998). The study demonstrated that the QWB was strongly
correlated with measures of dementia, memory and behavioral problems, psychiatric
symptoms, and respite time. The authors concluded that the instrument could be used in cost-utility analyses. However, the study used patient-spouse dyads with caregiver proxy reports standing-in for the patients.

A modified QWB (the Index of Well-Being) has been used in a cost-utility analysis of group living for dementia care (Wimo, Mattson et al. 1995). The cost per gain in quality-adjusted life-year was calculated comparing three groups: 46 patients in group living, 39 patients living at home, and 23 institutionalized patients. The scores on the Index of Well-Being were converted mathematically from scores obtained from the Global Deterioration Scale. Patients’ and family members’ preferences for different caring alternatives were not included.

5) ETHICAL IMPLICATIONS OF SELECTING OF A QUALITY OF LIFE MEASURE

In medical decision making the doctrine of informed consent holds that individuals make their own informed, voluntary, capable choices amongst the treatments offered to them by the health care provider. The right of autonomous choice of the individual supports the moral stance that the individual is best equipped to judge his or her own quality of life. The doctrine of informed consent, as far as it promotes the well-being of patients by respecting their autonomous choices, is grounded in a preference or desire fulfillment account of a good life (Brock 1993).

The ultimate determinant of treatment choices is now widely accepted to be more than health promotion and the prolongation of life. Quality of life choices in health care can, and are, frequently based on other priorities. Furthermore, death is a preferred
outcome for some health states. Such quality of life considerations have an established place in medical decision making.

For comparisons between treatments to be ethical, the expected difference between treatments has to be relatively small so that no patients are deprived of a superior treatment (Clinical Equipoise). With the limited expectation of treatment differences in ethical trials, quality of life measures can help obtain a better information yield.

There are wide implications in choosing a quality of life measure. The quality of life measure should represent the viewpoints of both health care providers and consumers about what constitutes a 'good life' in the course of dementia. Agreement will ensure that the autonomous choices of affected individuals are represented in the quality of life measure used to evaluate treatments. Thus, it is contentious that the weights for scoring the items of these measures are usually derived from the general population and not from dementia patients or their caregivers. The population at large likely holds a different set of values from the values of the dementia population. Making decisions based on the results of these instruments on behalf of patients and family members would be the equivalent to making third party choices (Siegler 1992). It would be a surrogate decision based on other people’s values. This poses the risk of overriding the patients’ perspective by taking these measures as objective indicators of their quality of life.

Barry Brown (1988) argues that the common good of a disease community supports taking into account patients’ preferences seriously. Even though people suffering from dementia may have never explicitly associated with each other, they share common values, some of them being their loss of health and the remaining health they possess. They share common goals as well, for example, a common interest in finding a
cure, or relief from the disease. Dementia patients as a community should have a contribution in determining what’s best for them.

Clinical trials are ultimately aimed at changing clinical practices. Bioethicists like Kopelman (1995) and Lantos (1997) have criticized clinical equipoise for favoring the opinions of physicians and not including the patients’ perspectives. Quality of life measures that incorporate the patient’s perspectives in clinical trials would provide an answer to these criticisms.
II. METHOD

1) PARTICIPANTS

Two groups of volunteer subjects were sought: 1) Patients with an early diagnosis of dementia (MMSE: 16 - 26); and 2) Relatives of patients with dementia. A total of 40 subjects (20 patients and 20 family members) were recruited.

Inclusion criteria for the sample were as follows:

a) Patients had a diagnosis of dementia (any type).

b) Aged 60 and over.

c) Mini Mental Scores (Folstein, Folstein et al. 1975) falling between 16 and 26 points.

d) Patients had completed at least a grade 6 education and were fluent in English.

e) Patients’ ability to communicate was deemed to be relatively unimpaired.

Family members had to be involved in the care of a dementia relative. The two groups may or may not be associated.

Exclusion criteria:

a) Less than 60 years old.

b) Mini Mental Scores below 16 points or above 26 points.

c) Patients were not fluent in English.

d) Patients had communication difficulties.

Family members were not involved in the patient’s care.

The recruitment sites were Baycrest Center for Geriatric Care, Toronto East General Hospital, Beach Arms Lodge, Woodgreen Community Center, and Community Care East York. Referral sources included specialists (psychiatrists and neurologists) in
hospital settings, where the majority of patients were recruited (75% of the total sample), and general practitioners in the retirement home and community centers. These referral sources were asked to contact possible volunteers who matched the inclusion criteria and request their permission to be contacted by the investigator.

2) THE QUALITATIVE ANALYSIS

2.1) Objective

To obtain a baseline profile of the opinions and experiences of patients and family members about aspects of quality of life that may be important to them, and to determine whether or not these attributes are included in the three utility-based instruments (EuroQol, HUI, QWB. See appendices 1, 2, and 3).

2.2) Theoretical Background of the Qualitative Analysis

Qualitative research method is based on a belief that the investigator must communicate with his/her respondent. The relay of information plays a necessary role in the investigator’s achieving a convincing, sound result for the study. The research method has its origin in the ‘human science’ movement. Both Dilthey and Wundt claimed that the study of humans is distinct from the study of objects in the natural sciences.

The human science approach, in the form of qualitative research, relies on the recording of subjective experience (phenomenology) and its interpretation (hermeneutics). In recent years various models of qualitative research have emerged, such as narratology (Polkinghorne 1988; Mishler 1990), empirical phenomenology (Giorgi 1970), interpretative hermeneutics (Packer 1985), and grounded theory (Glaser and
Strauss 1967). All these approaches share a number of common features: data sources are in the form of natural language; reports are on subjective experience; the number of data sources is small; and the focus is on discovery/description, and interpretation.

The Grounded Theory Method (GTM) of analysis was originally developed and applied in sociology by Glaser and Strauss (1967). It provides the opportunity to access subject matters that are too complex to analyze using traditional research methods. It both describes and explains a phenomenon (Lincoln and Guba 1985). Becker (1993) in his review of studies using GTM, has found that while GTM was initially thought of as a discovery oriented approach, many grounded theory studies have been purely descriptive. These two modalities are quite different. Descriptive research provides a narrative report of categories or types, describing what is happening among a group of individuals. The discovery mode is a conceptualization of the relationships and commonalities among categories until a core category is developed. While discovery oriented analyses result in micro-theories, descriptive analyses tend to be used as a means to answer specific research questions. In addition, descriptive research uses selective sampling (the sample is determined prior to data collection), while the discovery mode uses theoretical sampling (the determination of the sample is an on-going process, depending on the emerging theory).

Both modalities of GTM require the investigator to stay close to the data by using a technique called the constant comparative method whereby he/she categorizes the data systematically and holds back from theorizing until all the data has been analyzed. Initially, open categorizing takes place. The text is broken into units of analysis called meaning units. A meaning unit is typically a line to half a page of text. It is represented
by a word or phrase, called a category or domain, based on the researcher's understanding of the meaning contained. As there may be several meanings in one statement, several categories may be assigned. These are compared within and between texts in search for shared meanings. These shared meanings are then given the label "descriptive categories". Descriptive categories are examined for commonalties. Redundant categories may be either pooled or subsumed under another category. If a new category(s) arises within a transcript, the preceding transcripts are searched to determine whether a newly developed category could be assigned to any of the meaning units in the previous transcripts. This searching process for commonalties goes back and forth until saturation has occurred - no new categories emerge.

2.3) The Qualitative Data Analysis

Data obtained in the interviews was analyzed following the Grounded Theory Method described above. This study used the GTM as a way to access descriptions and then contrast these with the items of the utility-based measures. In this respect the GTM modality used in this study was descriptive and not discovery oriented. The purpose was to contrast empirically determined domains with the external framework offered by the items of the instruments.

Stage 1: The investigator read the interview transcripts to determine meaning units (themes) referring to any aspect of quality of life (QoL). Then, categories or domains were assigned to these meaning units. Open coding of the names for the categories was tentative. These were reviewed as the data was being analyzed. The
breaking down of the transcripts into meaning units and assigning categories was carried out systematically with each transcript.

All statements referring to QoL in the subject’s past were purposely excluded as not relevant to the research question. The main objective of the interview was to elicit information about those aspects of the subject’s quality of life that have been affected by the experience of living with dementia. Accounts detailing the subject’s personal history were not considered relevant in the present context of living with the illness.

**Stage 2:** With each transcript category, the researcher attempted to find a match with the three utility-based measures (EuroQoL, HUI, and QWB) and with the two additional measures (DQOL, WHOQOL; see appendices 4 and 5).

**Stage 3:** The first validity check was a consultation with a team of three researchers (thesis committee) who conducted a random audit of the material. The members of the committee were all given four transcripts (two patients and two family members) which were picked at random. They were asked to underline all meaning units relevant to quality of life thereby giving independent open-coding to the transcripts. The committee was asked to ignore all themes that might refer to the subject’s past. The percentage of agreement was obtained by comparing each committee member’s meaning units with the investigator’s meaning unit, and then computing an average percentage of agreement. The final percentage of agreement is the average of all the matches for all four protocols. There is the possibility that there was a degree of incorporation bias because the thesis committee was familiar with the study. However, given that the analysis was descriptive rather than interpretative, it is unlikely that this had an effect on the final outcome.
Stage 4: The second validity check was a consensus meeting with the thesis committee to review two of the transcripts (one patient and one family member). The objective of this meeting was to reach a consensus as to: a) the final title of the domains; b) the concordance of the domain with the three utility based measures. When disagreements arose (the name for a domain or whether it matched with a measure) these were resolved by discussion and mutual agreement. The match between the interview’s domain and the measures were at times ‘limited’ (i.e. the items were too general to represent the domains as described by the subjects). This was noted on the tables and in the discussion.

Stage 5: The investigator engaged in a third validity check by auditing all transcripts and including the relevant changes that had resulted from the first audit (stage 3) and the consensus meeting (stage 4).

Stage 6: The last validity check of the material was conducted with only one of the committee members (advisor). The advisor reviewed all the meaning units, names of the domains, the groupings under the five main headings, and their match with the measures. This stage provided a test of the soundness of the interpretation. No major revisions resulted. These findings (included in the appendix 6) allow the reader to assess the validity of the interpretation, the correspondence between data, groupings, and measures.
3) THE QUANTITATIVE ANALYSIS

3.1) Objective

The objective was to assess the opinions of patients and family members on the feasibility of using utility-based instruments (EuroQol, HUI, and QWB) to measure the quality of life of patients diagnosed with dementia.

3.2) Hypotheses

3.2.1) Relevance hypothesis

The three QoL measures will differ in terms of the subjects' assessments of their relevance, as measured by the average of the responses to questions 1, 4 and 7 on the feasibility questionnaire (see appendix 7).

3.2.2) Acceptability hypothesis

The three QoL measures will differ in terms of the subjects' assessments of their acceptability, as measured by the average of the responses to questions 2, 5, 8, 10 and 11 on the feasibility questionnaire.

3.2.3) Sufficiency hypothesis

The three QoL measures will differ in terms of the subjects' assessments of their sufficiency, as measured by the average of the responses to questions 3, 6, and 9 on the feasibility questionnaire.

3.2.4) Completion time hypothesis

The three QoL measures will differ in terms of the time required for completion.

This hypothesis was required for two reasons: 1) Information about the time required for completion of these three measures for this particular population is not
available in the literature. 2) Completion time is an important feasibility indicator. Measures that are too long would not be practical because of the amount of time and resources they take, and the cognitive burden they may impose. Measures that are too short, although practical, would limit the collection of an appropriate amount of information. The ideal length of a measure would have to strike a balance between these competing interests.

3.3) The Quantitative Data Analysis

All the hypothesis will be tested using a two factor, mixed, repeated measures ANOVA. The between the subjects factor will be the distinction between patients and family members. The within the subjects factor will be the distinction between the quality of life measures (EuroQol, HUI, QWB).

4) PROCEDURE

Participants were contacted by telephone (following their permission to be contacted through their referral source) by the investigator. They were asked to participate in a study that involved an interview about quality of life and an evaluation of three quality of life instruments. They were told that they could meet the researcher at their treatment site or at their place of residence. Upon arrival, the interviewer spent the first ten to fifteen minutes introducing himself, developing rapport, answering any concerns the participant might have as well as obtaining informed consent (appendix 8). In the cases of patients, the interviewer reassured the participant that it was not a clinical diagnostic interview, and that he/she was not being assessed or evaluated in any way. The
The interviewer did not proceed with the interview until it was certain that the participant was comfortable with the arrangements, understood the purpose of the study, and had signed the consent form. The investigator administered the Mini-Mental State Examination and obtained demographic data. The interview protocol was open-ended with general questions designed to tap the person's experience of how dementia affects quality of life. Participants were asked the following nine specific questions (obtained from Parse, 1996).

1. - What is life like for you?
2. - What contributes to your quality of life?
3. - What may diminish your quality of life?
4. - What are your priorities right now?
5. - What changes in your routine or relationships might change your quality of life?
6. - How would you like to change your quality of life?
7. - What are your concerns?
8. - What are your hopes?
9. - Some people say that spirituality is important, is that a part of your life?

Often, prompts and probes ("Was that something that diminished your quality of life? Is that something you enjoy?") were necessary particularly with those participants who were less verbally productive or had a difficult time comprehending the questions. When participants were distracted or circumstantial the interviewer repeated the question.

The respondents were then provided with the three quality of life measures (EuroQol, HUI, QWB), one at a time in succession, and asked to fill them out. The
patients were asked to fill the measures out for themselves, and the family members were asked to act as proxy for their relative with dementia. The order of presentation of the measures was randomized. However, the randomization was not balanced since the expected sample size was not achieved. Considering that there were six possible orders in which the three instruments could be filled out, the sixty respondents (the expected sample size) were randomly allocated to one order of presentation. Accordingly, ten respondents (five patients and five family members) were to be assigned to each of the six possible orders. In this way control for the crossover effects was to be achieved. In addition, subjects were timed to determine how long it took them to fill out each QOL measure.

After the respondents had completed each QoL measure, they were provided with a questionnaire about the measures (see appendix 7). The questionnaires had a total of 11 statements about the relevance, acceptability, and sufficiency of the measures. Subjects responded to each statement on a visual analog scale (VAS) of 10 cm in length. Standard instructions to fill-out the VAS were given to all subjects: the investigator explained that the VAS was like a thermometer showing a continuum that went from strong agreement to strong disagreement.
5) INSTRUMENTS

5.1) The Three Utility-Based Measures

We have chosen three utility-based measures for this research: The European Quality of Life Instrument (EuroQol), The Health Utilities Index (HUI), and the Quality of Well-being Scale (QWB). We chose these instruments because they have been used extensively, for a variety of conditions, for a number of years. In addition, these instruments can be readily incorporated into cost-effectiveness analyses and are easy to administer.

5.1.1) The European Quality of Life Instrument (EuroQol)

The EuroQol is a generic utility based quality of life measure created by a consortium of investigators in five countries of Western Europe (Gold, Patrick et al. 1996). The initial version of the EuroQol instrument measured six domains (mobility, self-care, main activity, family/leisure activities, pain/discomfort, and anxiety/depression), with three domains having two levels of severity and the rest having three levels of severity. The most recent version (see appendix 1) combined the main activity and the family/leisure activities domains resulting in a total of five domains. In this latter version, the severity ratings for all domains include three levels of severity. In addition, the EuroQol includes two ratings of overall health. The first rating asks the respondents to compare their current general level of health with their general health over the past year. The second rating utilizes a visual analogue scale, similar in appearance to a thermometer, asking for the respondent’s evaluation of their overall health state. The combination of domains and levels of severity generates 245 different health states (Gold,
The preference weights for this instrument were originally derived through postal surveys using a self-administered visual analogue scale. A recent survey elicited time-trade off weights from a sample of 3000 adults in the United Kingdom (Williams 1995).

5.1.2) The Health Utilities Index (HUI)

The HUI is a multiattribute utility measure that uses a multiplicative scoring function and standard gamble weights derived from members of the general public in Hamilton, Canada. Since its first version (Mark I), the HUI has undergone two major revisions. The first version was based in part on the QWB system, and contains four domains: Physical function (mobility and physical activity), role function (self-care and role activity), social/emotional function (emotional well-being and social activity) and health problems (Gold, Patrick et al. 1996). The third version (Mark III), offers a health status classification system which includes eight attributes (vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain/discomfort). The latest version of this instrument (see Appendix 2) evaluates the health status of a person in terms of her/his ability to function on each of the above mentioned domains, and adds the dimension of self-care. It includes 15 items with a gradient from 4 to 6 levels of severity. The HUI adopts a less inclusive approach to health status than other measures. It focuses on a more narrow “within the skin” approach, including physical and emotional categories but excluding social interaction (Feeny, Furlong et al. 1995). This approach characterizes the HUI’s specific conception of health-related quality of life as opposed to a broader conception of quality of life.
5.1.3) The Quality of Well-Being Scale (QWB)

The Quality of Well-Being Scale (QWB) evaluates functional status based on individual’s performance on five domains (acute and chronic symptoms, self-care, mobility, physical activity, and usual activity). These domains list a number of ways by which a disease or injury can affect the person’s behavior or performance (Bowling 1997). The weights for the symptom/problems complexes and functional status scales were derived from population surveys in San Diego, California, and elicited using a rating scale technique and an additive scoring function. The QWB has been used extensively in clinical trials for a variety of conditions (Gold, Patrick et al. 1996). The QWB includes five sections. Part I is a comprehensive list of fifty seven items about acute and chronic symptoms. Part II includes two items about self-care. Part III includes three items about mobility. Part IV has eight items about physical activity and part V, three items on usual activities (see appendix 3).

5.2) Additional Measures Considered

The remaining two measures, the Dementia Quality of Life (DQOL) and the World Health Organization Quality of Life Instrument (WHOQOL) are included in the analyses because they offer broad guidelines as to which domains have been considered relevant in prior research. The DQOL offers a dementia-specific view and the WHOQOL is considered a comprehensive generic quality of life instrument. However, it should be noted that this analysis is limited in its validity because the original instruments were not available. The comparisons were made based on the published instruments found in Brod et. al. (1999) and in the WHOQOL working group (1994).
5.2.1) The Dementia Quality of Life Instrument (DQOL)

Until recently there was no disease-specific measure for dementia that met the standard of content validity. The only dementia-specific measure that has been published is the Dementia Quality of Life Instrument - DQOL (Brod, Stewart et al. 1999). This instrument is specifically designed to assess quality of life directly from dementia patients. The domains came from focus groups (1.5 hours each) with three groups of participants: patients, caregivers, and health professionals. It includes ten domains: physical functioning, daily activities, discretionary activities, mobility, social interaction, interaction capacity, bodily well-being, sense of well-being, sense of aesthetics, and overall perceptions (see appendix 4). The measure has adequate reliability and construct validity.

5.2.2) The World Health Organization Quality of Life Instrument (WHOQOL)

The WHOQOL (see appendix 5) is a measure developed within a cross-cultural project, including 15 field centres around the world. An important strength of this instrument is that it was created after several years of research based on the input of patients with a variety of illnesses, lay people, and health professionals from a variety of cultures. The WHOQOL was designed to be used in a variety of contexts: medical practice, assessment of the effectiveness and relative merits of different treatments, health services evaluation, research, and policy making. It is particularly appealing because it provides a holistic assessment of a person’s quality of life, and was developed taking into account patients’ input. It includes the following domains: overall quality of life and
general health, physical health, psychological state, level of independence, social relationships, environment, and spirituality/religion/personal beliefs.
III. RESULTS AND DISCUSSION

1) DEMOGRAPHICS

Age

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MMSE

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Gender

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Birthplace

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### Marital Status

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### Living Arrangements

<table>
<thead>
<tr>
<th>Group</th>
<th>Living Arrangement</th>
<th>Frequency</th>
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</tr>
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<tbody>
<tr>
<td>Patient</td>
<td>Private Accommodation</td>
<td>19</td>
<td>95</td>
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<tr>
<td></td>
<td>Retirement Home</td>
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<td>5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
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</tr>
<tr>
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### Living Alone?

<table>
<thead>
<tr>
<th>Group</th>
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<th>Frequency</th>
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</tr>
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<tbody>
<tr>
<td>Patient</td>
<td>Alone</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>With Others</td>
<td>17</td>
<td>85</td>
</tr>
<tr>
<td></td>
<td>Total</td>
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<td>100</td>
</tr>
<tr>
<td>Family Member</td>
<td>With Others</td>
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### Employment Status

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<td>Part Time</td>
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**Highest Level of Education Attained**

<table>
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<th>Education Level</th>
<th>Frequency</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Patient</td>
<td>Attended High School</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Graduated High School</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td>Attended College/ University</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Graduated College/ University</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td></td>
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</tr>
<tr>
<td>Family Member</td>
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<tr>
<td></td>
<td>Attended High School</td>
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<td>30</td>
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<tr>
<td></td>
<td>Graduated High School</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Attended College/ University</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Graduated College/ University</td>
<td>6</td>
<td>30</td>
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<tr>
<td></td>
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**Time Since Diagnosis was Made**

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<tr>
<td>&lt; 1 year</td>
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<td>10</td>
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<tr>
<td>1-2 years</td>
<td></td>
<td>45</td>
</tr>
<tr>
<td>2-3 years</td>
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**Family Member Relationship with Patient**

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<thead>
<tr>
<th>Relationship</th>
<th>Frequency</th>
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<tr>
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<tr>
<td>Child (Daughter/ Son)</td>
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<td>50</td>
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**Live with Patient?**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
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<tr>
<td>Not Living with Patient</td>
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<td>35</td>
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<td>Total</td>
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</tr>
</tbody>
</table>
Time Spend Caring for Patient

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>Percent</th>
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</thead>
<tbody>
<tr>
<td>24 hour Supervision</td>
<td>8</td>
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<tr>
<td>4-8 hours per day</td>
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<td>25</td>
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<td>1-2 hours per day</td>
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<tr>
<td>2-3 hours per week</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
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</tr>
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2) RESULTS AND DISCUSSION OF THE QUALITATIVE ANALYSIS

Each research interview lasted an average of 14 minutes (from 5 to 31 minutes) for patients, and an average of 31 minutes (from 6 to 40 minutes) for family members. When transcribed each inquiry produced 3-24 pages of material (double-spaced).

Data was analyzed following the Grounded Theory Method of analysis described in the method section. Following the grounded theory analyses, the domains found were compared and contrasted with each of the three utility-based measures, and with the DQOL and the WHOQOL. During the first audit, the average level of agreement obtained (each of three committee members with the investigator) was 72%. The average percentage of agreement for the two patient transcripts audited was 73% (ranging from 61% to 80%). For the family members transcripts which were audited the average percentage of agreement was 71% (ranging from 64% to 86%). The percentage level of agreement was obtained by comparing each committee member’s meaning units with the investigator’s meaning units, and then computing an average percentage of agreement. The level of agreement between the domains and the items on the measures was generally high. Certain matches with the measures were thought to be ‘limited’, as was the case when the items in the measure were too broad to actually represent the domains of the
interview. For instance, “pain and discomfort” in the EuroQol and the HUI, do not include mention of the variety of physical ailments, illnesses and frailties described by the subjects. When the match between the interview and the measures was considered to be ‘limited’ this was indicated in the following tables and discussion.

The domains found in the interviews were grouped into six broad categories: global impression of quality of life, physical well-being, social/family well-being, emotional well-being, functional well-being, and cognition. The decision of how each domain fit within a particular category was determined by consensus, as was the title of each domain. A summary of the results for the qualitative analysis is found on appendix 9. For a more detailed review, which includes subject’s verbatim, please refer to appendix 6.

2.1) Overview

The three utility-based quality of life measures examined in this study emphasize the functional aspects of life, or what Brock calls “primary functions” (Brock, 1993, p. 117). The primary functions are thought to be relevant to the pursuit of virtually any life plan. The specific functional domains included in these measures, such as self-care, mobility, recreational activities, etc, represent fundamental routine activities common to all lives. Nonetheless, this functional approach neglects the reflective subjective experience of living a life with an illness and the potential enjoyment the individual may experience when functioning. Moreover, the relative importance of each domain for particular individuals or groups of people may be different depending on the circumstances. This implies a need to create disease-specific measures since individuals
with different diseases may find different activities more or less relevant to their quality of life - depending on the symptoms, prognosis, or course of illness.

The general social and financial resources needed to sustain these primary functions are not included in any of the three utility-based measures. Both patients and family members indicated that these resources are an important aspect of quality of life (e.g. living arrangements, financial security, and access to medical care). Some of these domains which make reference to general resources are found in the World Health Organization Quality of Life Instrument (WHOQOL) under the general heading of environment.

Patients and family members described in the interviews broader interests in quality of life and, at times, a more pointed focus than looking at primary functions. This is seen in the number of domains elicited in the interviews compared to the small number of those that match the measures. This is only a rough estimate of comprehensiveness because the number of domains found in the interviews could be increased (as is the case when one conducts a more fine-grained analysis that closely distinguishes between themes) or decreased (as is the case when similar themes are collapsed into one domain). Nonetheless, out of fifty six domains (56) found in the interviews, less than half (27) were found in at least one of the three measures. Specifically, the EuroQol included only ten interview domains, the HUI eleven, and the QWB twenty five. These data provide a general impression of the narrowness of the quality of life perspective in these measures.

The patient group provided a total of 44 domains and the family member group provided 45 domains. There was a content match between both groups on 33 domains, indicating that the perspectives of both groups were to a large extent comparable. On the
other hand, patients provided 11 domains that family members did not provide, indicating that the patients’ perspective adds to the understanding of quality of life in dementia. These domains were Fatigue/ Lack of Energy, Vision, Feeling Useful/ Valuable to Others, Coping with Memory Loss/ Emotional Adjustment to the Diagnosis, Appreciation of Art, Hopes for Longevity, Fear of Embarrassment, Sense of Stability, Appreciation of Nature, Relief from Job-related Stress or Responsibilities, and Help with Word-Finding Difficulties. In addition, family members provided 12 domains that patients did not provide. These domains were Sleep Disturbances, Incontinence, Loss of Appetite, Lack of Interest or Motivation, Restlessness/ Agitation, Physical Appearance, Fear of Being Alone, Self-Care Activities, Subjective Sense of Confusion, Disorientation in Time, Disorientation in Person/ Loss of Identity, and Lack of Responsiveness to the Environment. This is an indication that the input of both groups is needed to obtain a more comprehensive understanding of quality of life and dementia. The complementary information was necessary; for example, patients showed a degree of denial in terms of the memory loss (domain Coping with Memory Loss).

The three utility-based measures are generic rather than disease specific. As noted in the literature review, The European Quality of Life Instrument (EuroQol) measures five domains (mobility, self-care, usual activities, pain/ discomfort, and anxiety/ depression). The Health Utilities Index (HUI) evaluates the health status of a person in terms of her/his ability to function on each of several domains (vision, hearing, speech, ambulating, dexterity, emotion, cognition, basic activities, and pain). The HUI adopts a less inclusive approach to health status than other measures. It focuses on a more narrow “within the skin” approach, including physical and emotional categories but excluding
social interaction (Feeny, Furlong et al. 1995). This approach characterizes the HUI’s specific conception of health-related quality of life as opposed to a broader conception of quality of life. Finally, the Quality of Well-Being Scale (QWB) evaluates functional status based on individual’s performance on five domains (acute and chronic symptoms, self-care, mobility, physical activity, and usual activity). These domains list a number of ways by which a disease or injury can affect the person’s behavior or performance (Bowling 1997).

The remaining two measures, the Dementia Quality of Life (DQOL) and the World Health Organization Quality of Life Instrument (WHOQOL) are included in the analyses because they offer broad guidelines as to which domains have been considered relevant in prior research. The DQOL offers a dementia-specific view and the WHOQOL is considered a comprehensive generic quality of life instrument. As the results section indicates, frequently the domains of the interviews that did not find a match in the utility-based measures, found a match on these two instruments. Thus, the comparison with these instruments offers indirect corroboration of the trustworthiness of the qualitative analysis. However, it should be noted that this analysis is limited because the original instruments were not available. The comparisons were made based on the published copies found in Brod et. al. (1999) and in the WHOQOL working group (1994).
2.2) Global Impression of Quality of Life

Overview

The global impression of quality of life category supports the inclusion of two aspects, the respondents' subjective evaluation of their overall physical condition and their overall life satisfaction. The literature distinguishes between happiness, life satisfaction, and morale. It has been argued that while life satisfaction and morale have cognitive underpinnings, happiness is rather affective. The cognitive aspects of life satisfaction and morale imply a form of evaluation, while happiness refers to positive or negative feelings. However, many researchers use these terms interchangeably (Bowling 1997). The global impression of quality of life category complements objective views of quality of life which in themselves are insufficient.

The HUI is the only one of the three utility-based measures that addresses both the life satisfaction and general health domains. The EuroQol partially addresses this category by asking for the respondents' own evaluation of their health state (general health), but it does not include a global index of life satisfaction. This approach is consistent with the prevailing theoretical trend in health care which holds that the broader conception of quality of life needs to be restricted to include the notion of health (health-related quality of life). The QWB does not inquire about this domain directly from the respondents.

The DQOL includes both life satisfaction and self-rated health under the general heading of overall perceptions. The WHOQOL incorporates overall quality of life and general health. The items of both instruments were generated through open-ended
interviews and focus groups with the interested parties: patients, relatives, professionals, etc.

**Review of Specific Domains**

<table>
<thead>
<tr>
<th></th>
<th>Patients (N=20) %</th>
<th>Family Members (N=20) %</th>
<th>EuroQol</th>
<th>HUI</th>
<th>QWB</th>
<th>DQOL</th>
<th>WHOQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Satisfaction</td>
<td>75</td>
<td>45</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<td>General Health</td>
<td>30</td>
<td>40</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

**Life satisfaction** conveys a broad understanding of how good or bad life is in general, without specific reference to health. It includes comments made by the participants on happiness, satisfaction, sadness, enjoyment, contentment, or pleasure. No descriptors of this domain distinguish patients and family members (e.g., patient: "*I can say that I am quite happy and satisfied with life the way it is*"; family member: "*He is very happy with his life the way it is*"). Although the participants mentioned both positive and negative aspects of life satisfaction, the positive ones were predominant. Patients were more likely to mention this domain than family members (Patients: 75%, N=20; Family members: 45%, N=20).

Amongst the three utility based measures, only the HUI offers a global index of life satisfaction in question 7: "Which one of the following best describes how you have been feeling during the past two weeks?". The answers go from "happy and interested in life" to "so unhappy that life was not worthwhile". As a point of reference, it should be noted that the life satisfaction domain can be found in both the DQOL (Overall perceptions: Life satisfaction) and the WHOQOL (Overall quality of life). The QWB does not include an index of life satisfaction.
General health includes explicit references to health status. In general, both patients and family members reported on this domain focusing on physical health separate from mental health. Almost all comments described the value of good health (e.g., patient: “One priority is to be very healthy”; family member: “My mother has been very fortunate with her general health”).

Both the EuroQol and the HUI include an index of general health as a measure of health-related quality of life. The EuroQol includes two items related to this domain: 1) “Compared with my general level of health over the past 12 months, my health state today is: Better; Much the same; Worse”. 2) “We would like you to indicate on this scale (thermometer) how good or bad your own health is today, in your opinion”. The HUI asks respondents to rate their health status as well in question 16: “Overall, how would you rate your health during the past 2 weeks? Excellent; Very good; Good; Fair; Poor.” As noted above, the QWB does not include a global index of perceived general health.

2.3) Physical Well-Being

Overview

The QWB addresses all domains of physical well being considered important by both patients and family members. In this respect, it is clearly superior to the other two utility-based instruments. The HUI includes three domains: 1) Physical illnesses, ailments, and frailty; 2) hearing problems; and 3) Vision. The EuroQol only includes one domain: Physical illnesses, ailments, and frailty.
### Review of Specific Domains

<table>
<thead>
<tr>
<th>Physical Illnesses/ Ailments/ Frailty</th>
<th>Fatigue/ Lack of Energy</th>
<th>Sleep disturbances</th>
<th>Hearing Problems</th>
<th>Falls/ Loss of Balance</th>
<th>Incontinence</th>
<th>Loss of Appetite</th>
<th>Vision</th>
<th>Loss of Consciousness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients (N=20) %</td>
<td>45</td>
<td>20</td>
<td>20</td>
<td>10</td>
<td>10</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Family Members (N=20) %</td>
<td>35</td>
<td></td>
<td></td>
<td>25</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>EuroQol</td>
<td>X*</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HUI</td>
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<td></td>
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<td></td>
</tr>
</tbody>
</table>

Note: * Limited

Both patients and family members reported concerns about physical illnesses, ailments, and frailty (e.g., family member: "She is getting very frail. Her legs are getting very wobbly"). In addition, patients reported that the fear of an injury that may disable them is an important event that may diminish their quality of life (e.g., patient: "Knowing that I had some crippling disease or something"). Patients reported on this domain more often than family members (Patients: 45%, N=20; Family members: 35%, N=20).

Both the EuroQol and the HUI include items that address this domain in a limited way, rather than covering physical illnesses, ailments and frailty, it asks for the level of pain/discomfort that the individual is experiencing. EuroQol: “Pain / Discomfort: I have no pain or discomfort; I have moderate pain or discomfort; I have extreme pain or discomfort”.

HUI: Questions 8 and 15: “Which one of the following best describes the
pain and discomfort you have experienced during the past 2 weeks?". The answers to question 8 concentrate on the degree to which pain or discomfort disrupts activities (pain and discomfort that prevented no, few, some or most activities). Question 15 focuses on the degree of relief obtained with medications, use of over the counter medication, or use of narcotics. In contrast, the QWB offers in Part I: Acute and chronic symptoms a comprehensive list of 57 items.

Only the patient group reported on the domain fatigue/ lack of energy (e.g., "I have no energy". "I'm tired very quickly"). Only family members reported on sleep disturbances- indicating disorders in the wake-sleep cycle, including hypersomnia or excessive sleepiness (e.g., “He is sleeping the whole day”).

The QWB includes both fatigue and sleep disturbances. However, the domain sleep disturbances does not include hypersomnia. The DQOL includes fatigue/ lack of energy, but does not include sleep disturbances. The WHOQOL includes both domains.

Both patients and family members mentioned hearing problems as relevant to quality of life. Both groups reported this domain in similar proportions (Patients: 20%, N=20; Family members: 25%, N=20). However, only family members reported on the need for or on difficulties associated with the use of hearing aids. One patient related his hearing problems with isolation.

Both the HUI and the QWB include both aspects of this domain: hearing problems, and the use of hearing aids. The HUI: Questions 3 and 4: “Ability, during the past 2 weeks, to hear what was said in a group conversation with at least three other people? / with one other person in a quiet room?”. The QWB: Part I: Acute and chronic symptoms: “Any hearing loss or deafness?/ Use of a hearing aid?".
The rest of the domains for this physical well-being section are all included accurately in QWB: Falls/ loss of balance (Patients: 10%, N=20; Family members: 10%, N=20), and loss of consciousness (Patients: 5%; Family members: 5%). On the other hand loss of appetite and incontinence were only reported by family members (loss of appetite: 10%; and incontinence: 10%).

2.4) Social / Family Well-Being

*Overview*

There is substantial support in the literature to include broader personal and social perspectives in the assessment of quality of life (Lawton 1994; Raphael, Brown et al. 1995). Researchers have repeatedly proposed the inclusion of several of the domains that were reported on by patients and family members in this study: family relationships, social interactions (Farquhar 1995; Rabins and Kasper 1997), social functioning (Ramsay, Winget et al. 1995), interpersonal relationships, finances, residence (Pearlman and Uhlmann 1991), loss of contact with friends, loss of employment (Burgener and Dickerson-Putman 1999), feeling useful, and access to appropriate medical care (Gwyther 1997).

Out of nine domains, four domains appear in at least one of the three utility-based measures. The QWB includes four domains: connection with family, social interactions, withdrawn/ loneliness/ boredom, and loss of competence. The three domains included in the EuroQol are included under the heading “Usual Activities”, which significantly limits the ability of this instrument to discriminate between disparate activities, such as family, work, housework, and leisure activities. The EuroQol is overly reductionistic since it is
conceivable that someone could face difficulties in one of these areas and not in others. The HUI does not include any of these domains. Their exclusion is part of the within-the-skin approach that does not address social or interpersonal abilities or deficits. This less inclusive approach is controversial. Proponents of the within-the-skin approach may argue that social variables have no place in a health-related quality of life. Opponents would argue that this runs the risk of overlooking the close link between illness and the individual’s ability to preserve their social identity. In the case of dementia, the link between illness progression and deterioration of social identity is well established. The medical/social distinction is thus unjustified. The findings in this study clearly support the inclusion of social variables. As the results section shows, both patients and family members overwhelmingly commented on the importance of this general category.

**Review of Specific Domains**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Patients (N=20) %</th>
<th>Family Members (N=20) %</th>
<th>EuroQol</th>
<th>HUI</th>
<th>QWB</th>
<th>DQOL</th>
<th>WHOQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connection to Family/ Family Support</td>
<td>85</td>
<td>75</td>
<td>X</td>
<td>X</td>
<td></td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Social Interactions</td>
<td>55</td>
<td>55</td>
<td>X*</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Withdrawn/ Loneliness/ Boredom</td>
<td>25</td>
<td>65</td>
<td>X*</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Loss of Competence</td>
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<td>X</td>
<td>X</td>
<td>X</td>
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</tr>
<tr>
<td>Access to Good Medical Care</td>
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<td>10</td>
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<td>X</td>
<td></td>
</tr>
<tr>
<td>Living Arrangements</td>
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<td>45</td>
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<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Financial Security</td>
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<tr>
<td>Feeling Useful/ Valuable to Others/ Helpful</td>
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<td>Supervision</td>
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</tbody>
</table>
A vast majority of patients and family members mentioned connection to family/family support (85% of patients and 75% of family members). Two main themes are included in this domain. 1) Connection to family: On the one hand, an important contribution to quality of life comes from having a close relationship with family members, wife, husband, children, and grandchildren (e.g., Patient: "We get along very beautifully and we do things together"; Family member: "He is a family man. The most important thing in his life is his children, his grandchildren, and they are wonderful to him"). On the other hand, family members reported that the prospect of having disagreements or arguments with their relatives is perceived to diminish the patient's quality of life (e.g., Family member: "there was conflict all the time", "so she knows there's been a problem with her son...she knows he does not see her"). 2) Family support refers to knowing that relatives are willing to provide emotional and pragmatic support (e.g., Patient: "I don't have to worry about anything. She takes care of it"; Family member: "We are very lucky that we got four children all grown up and they are very very supportive. It is very important to have family support").

Both the EuroQol and the QWB focus on the abilities to perform usual activities, including visiting family. This approach says very little about the experience of enjoying family interactions, which is essential according to the respondents. The EuroQol includes family in usual activities along with work, study, housework or leisure activities, by asking for the ability to perform them. Similarly, the QWB inquires about limitations in doing usual activities, such as visiting family. The DQOL is more consistent with the respondents' verbatim as it includes the domain intimacy, happiness with family (under the more general heading of social interactions). The WHOQOL includes the domain
personal relationships (under the broader social relationships), a domain that appears to be too vague.

Half the patients (55%) reported that social interactions outside the family were important. This includes meeting with friends, meeting people in a book group, seniors club, or at church. Some of them mentioned the enjoyment of spending time with long time friends (e.g., Patient: "I visit with friends. I always make a point of that every week") or making new friends (e.g., Patient: "I am getting together with people and we are becoming good friends"). A number of patients reported on the difficulties associated with losing contact with friends (e.g., Patient: "Now a lot of friends aren't around anymore...we are not as close as we used to be"). Family members also reported social interactions as an important component of quality of life (55%). In general, the relatives’ perception of this domain centers around the observation that the patients’ social sphere has become limited, with fewer opportunities to meet friends (e.g., Family member: "Her social circle became quite small"... "Her friends have shied away"... "I guess keeping the friendships would be important").

Both patients and family members reported withdrawn / loneliness / isolation, although family members reported it more than twice as often (Patients: 25%, N=20; Family members: 65%, N=20; e.g., Patient: "I don't like living alone. I get lonely and don't do anything. Then, I get a little bit cracked". Family member: "He's not active and so I don't think his quality of life is good"... "I can only tell you he is bored out of his wits"). The QWB addresses feeling lonely or isolated but it does not include boredom. The DQOL includes loneliness, isolation, and boredom under the heading of discretionary activities.
Living arrangements were also reported by both groups, although twice as often by family members (Patients: 20%, N=20; Family members: 45%, N=20). Family members reported that living in a retirement or nursing home would have a negative impact on quality of life (e.g., Family member: "What I am trying to do in keeping my mom home is giving her a little bit better quality of life because I have been in nursing homes...and I know there is no way she will be happy there". Patient: "I live in the basement. They don't interfere with me and I don't interfere with them"). Other family members mentioned the opposite: living in a supervised environment would contribute to quality of life because of safety considerations and as a way of getting involved in activities (e.g., Family member: "I think if he had more stimulation from outside and that is why we think he really does need to be in a nursing home with professional people").

This Living Arrangements domain is not in any of the three utility-based instruments, but is present in the WHOQOL under home environment. The rest of the domains (access to good medical care, financial security, feeling useful, and supervision) reported by the respondents are not included in any of the three utility-based measures. These domains are included in either the DQOL or the WHOQOL.
2.5) Emotional Well-Being

Overview

The inclusion of emotional or affective domains is important to quality of life: emotional function (Guyatt, Eagle et al. 1993), positive and negative affects (Lawton 1994), feelings and mood (Rabins and Kasper 1997), fears of embarrassment (Burgener and Dickerson-Putman 1999), feelings of frustration (Gwyther 1997), participation in religious activities, depression and anxiety (Pearlman and Uhlmann 1991). However, of the eighteen emotional well-being domains found in the interviews, only four are included in at least one of the three utility based measures. The EuroQol includes only depression, mentioned by 20% of patients and 5% of family members. The HUI includes only two domains: depression and frustration/irritability/anger, mentioned by 10% of patients and 50% family members. The QWB includes 4 domains: religion (patients: 30%, family members: 35%), depression, frustration/irritability/anger, and sense of control/autonomy (10% by both groups).
### Review of Specific Domains

<table>
<thead>
<tr>
<th>Domain</th>
<th>Patients (N=20) %</th>
<th>Family Members (N=20) %</th>
<th>EuroQol</th>
<th>HUI</th>
<th>QWB</th>
<th>DQOL</th>
<th>WHOQOL</th>
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<tbody>
<tr>
<td>Coping with Memory Loss/Emotional Adjustment to Dx</td>
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<td></td>
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<td>Personal Losses</td>
<td>45</td>
<td>25</td>
<td>N</td>
<td>N</td>
<td>N</td>
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<td>N</td>
</tr>
<tr>
<td>Lack of interest or motivation</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>35</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Religion</td>
<td>30</td>
<td>35</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
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</tr>
<tr>
<td>Depression</td>
<td>20</td>
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<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Appreciation of Art</td>
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<td></td>
<td></td>
<td></td>
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<td></td>
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<tr>
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<td>N</td>
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<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Hopes for a Cure or Arrest of the Progressive Cognitive Decline</td>
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<td>25</td>
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<td>N</td>
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<tr>
<td>Restlessness/Agitation</td>
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<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Frustration/Irritability/Anger</td>
<td>10</td>
<td>50</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Sense of Control/Autonomy</td>
<td>10</td>
<td>10</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>10</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Fear of Embarrassment</td>
<td>10</td>
<td></td>
<td></td>
<td></td>
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<tr>
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<td>10</td>
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<td></td>
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<tr>
<td>Concerns over Taking Medication/Side Effects/Overmedication</td>
<td>10</td>
<td>15</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>15</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear of Being Alone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>15</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sense of Stability</td>
<td>5</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Appreciation of Nature</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Relief from Job related Stress or Responsibilities</td>
<td>5</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
</tbody>
</table>

Note. N: New domain, not found in any of the measures
Fifty percent of the patients mentioned coping with memory loss or referred to the emotional adjustment to the dementia. Coping with memory loss includes comments minimizing the impact of the diagnosis and the extent to which the memory loss was troubling (e.g., Patient: "I don't find it much of a problem as previously". "I don't let it bother me"). Some patients stated that having a positive attitude regarding the memory loss helps them do better (e.g., "I believe that having a positive attitude helps you do better"). One patient reported being overwhelmed by the diagnosis. This domain is not included in any of the measures.

Both patients (45%), and family members (25%) reported difficulties associated with Personal Losses. This domain refers to the difficulties associated with the death of family and friends (e.g., Patient: "Since my husband passed away it has been a big change". "It's a heck of a time...I will never get over that, it hurts even to think about it"; Family member: "One of her best closest friends died about six years ago and she really misses her").

Only family members reported lack of interest or motivation (35%, N=20; e.g., "I have a difficult time getting him motivated to go out socially which we do rarely". "If you left it to him, he would never make an arrangement").

Both patients (30%) and family members (35%) mentioned religion or a sense of spirituality as important to quality of life (e.g., Patient: "I always said my prayers at night and going to church". "The people in the church. They pray consistently for me"; Family member: "She is very conscious about the religion". "my wife has to have a catastrophe to miss church").
Depression was mentioned more often by patients (Patients: 20%; Family Members: 5%). Items on depression are found in all measures.

Appreciation of art was mentioned by 20% of patients, indicating enjoyment in literature, dance, and music. This domain was not mentioned by family members, who had a tendency to focus exclusively on activities leading to social interaction. It is only included in the DQOL.

Frustration/ Irritability/ anger was mentioned by 50% of family members and only 10% of patients. Both the HUI and the QWB include this domain. Restlessness / agitation was mentioned only by family members (15%) and it is not included in any of the measures.

The remaining domains are not included in any of the three utility-based measures: Hopes for longevity, hopes for a cure or arrest of the progressive cognitive decline, fear of embarrassment, concerns over taking medication or side-effects, physical appearance, fear of being alone, sense of stability, appreciation of nature, and relief from job related responsibilities.

2.6) Functional Well-Being

Overview

Functional well being has been well represented in most quality of life measures. A number of researchers have suggested its inclusion: activities of daily living (Guyatt, Eagle et al. 1993; Lawton 1994), loss of independence, financial control and driving (Burgener and Dickerson-Putman 1999), enjoyment of activities (Rabins and Kasper

Overall, variables related to functional well being are well represented in the three utility-based measures. Five of the seven domains obtained in the interviews are included in at least one of the three measures. The EuroQol includes four domains: recreational activities/ hobbies/ leisure, self-care, instrumental activities of daily living, and mobility. The HUI includes two domains: self-care and mobility. The QWB includes five domains: recreational activities/ hobbies/ leisure, driving, self-care, instrumental activities of daily living, and mobility.

Review of Specific Domains

<table>
<thead>
<tr>
<th>Patients (N=20) %</th>
<th>Family Members (N=20) %</th>
<th>EuroQol</th>
<th>HUI</th>
<th>QWB</th>
<th>DQOL</th>
<th>WHOQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recreational Activities/ Hobbies/ Leisure/</td>
<td>60</td>
<td>70</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Driving</td>
<td>30</td>
<td>20</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Exercise</td>
<td>30</td>
<td>10</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Self-care Activities</td>
<td></td>
<td>30</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Instrumental Activities of Daily Living</td>
<td>15</td>
<td>70</td>
<td>X*</td>
<td>X*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Opportunity to Travel</td>
<td>20</td>
<td>15</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Mobility</td>
<td>15</td>
<td>15</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>

Note. *: Limited
N: New domain, not found in any of the measures
Recreational activities/ hobbies/ leisure was reported by the majority of patients (60%) and family members (70%). This domain includes outings, walking, painting, playing golf, reading, doing crossword puzzles, playing bingo, going to the movies, participating in day programs, going to shows, playing bridge, and watching TV. The HUI is the only measure that does not include this domain.

The literature distinguishes between self-care activities (eating, bathing, dressing) and instrumental activities of daily living (activities required for the maintenance of independence and optimum levels of functioning: doing laundry, housework, preparing meals) (Bowling 1997). These activities require planning and organization. Only family members (30%) reported self-care activities: the ability to dress, eat, bath, brush teeth, and put on jewelry. Both patients and family members (Patients: 15%; Family members: 70%) reported on instrumental activities of daily living, including housework, doing laundry, making the bed, cleaning, washing dishes, cooking, handling the mail, handling finances, and shopping.

Self-care activities are included in all measures, while instrumental activities are included in the EuroQol and the QWB. It is worth noting that the handling of finances is not included in any of the measures.

Closely associated to the previous domains are mobility and driving. Mobility is well covered by all measures. It refers to the ability of “move around” or walking. Driving is not specifically included in the EuroQol or the HUI. It is included in the QWB under the general domain of mobility - both the ability to drive a vehicle and the use of public transportation. Similarly, both patients and family members (Patients: 20%; Family members: 15%) mentioned opportunity to travel as a desirable activity.
Exercise was also mentioned by both groups (Patients: 30%; Family members: 10%) and it is not included in any of the measures. Some patients connected exercise with good health.

2.7) Cognition

Overview

The general category cognition warrants inclusion as a separate domain from emotional or psychological well being given the importance of cognitive abilities in dementia. Out of eleven domains, only three are included in at least one of the three measures. This finding was expected since none of the three utility-based measures is dementia-specific. The EuroQol does not include any of the cognitive domains. The HUI includes only two: memory problems and communication problems. The QWB includes three: memory problems, ability to read, and communication problems.
**Review of Specific Domains**

<table>
<thead>
<tr>
<th></th>
<th>Patients (N=20)</th>
<th>Family Members (N=20)</th>
<th>EuroQol</th>
<th>HUI</th>
<th>QWB</th>
<th>DQOL</th>
<th>WHOQOL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Memory Problems</td>
<td>65</td>
<td>70</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective Sense of confusion</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to Read</td>
<td>20</td>
<td>20</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disorientation in Space/ Getting Lost</td>
<td>20</td>
<td>30</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Ability to Benefit from Memory Aids</td>
<td>20</td>
<td>10</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Communication Problems/ Word-Finding Difficulties</td>
<td>10</td>
<td>30</td>
<td>X*</td>
<td>X*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disorientation in Time</td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Help with Word-Finding Difficulties</td>
<td>10</td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Psychomotor Difficulties (Apraxia)</td>
<td>10</td>
<td>5</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Disorientation in Person/ Loss of Identity</td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
</tr>
<tr>
<td>Lack of Responsiveness to Environment</td>
<td></td>
<td></td>
<td>N</td>
<td>N</td>
<td>N</td>
<td>N</td>
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</tr>
</tbody>
</table>

Memory problems were reported by the majority of respondents (Patients: 65%, N=20; Family members: 70%). Patients showed a tendency to minimize the impact of their memory disturbances (e.g., "I don't believe I have lost the memory that much. I have...but not to that extent"). Other patients denied having memory deficits (e.g., "I never had problems with my memory"). Included in this domain are a variety of indicators of cognitive deficits: Family members commented on difficulties in
recognizing people (e.g., "she is not able to recognize sometimes the people who work here. I think she knows they are familiar"); repetitive questions and behaviors (e.g., "He keeps asking me where we are going and why are we going there"); difficulties in remembering the names of close relatives (e.g., "Mom could not remember the names of some of her grandchildren let alone her great grandchildren"); and, difficulties following instructions (e.g., "If you give her instructions...she can't remember and she gets upset because she cannot remember"). The memory problems domain is included in the HUI, the QWB, and the WHOQOL. Surprisingly, it is not included in the DQOL.

Subjective sense of confusion was reported only by family members (30%) and it is included only in the DQOL (e.g. "He gets confused very quickly").

Communication problems were reported by both groups (Patients: 10%; Family members: 30%). It includes expressive and receptive language (e.g., Patient: "When somebody asks me a question or when it is not in my mind I have to fight for it". Family member: "It would be hard for him to get into a conversation."). There is a special emphasis on reporting word-finding difficulties (e.g., Patient: "I can't think of the word". Family member: "She knows what she wants to say. I am quite sure of that, but she can't think of the words"). This domain is found in the HUI, the QWB, and the DQOL.

Disorientation in person, space, and time are not included in any of the measures. Disorientation in person and in time was reported only by family members (5% and 10% respectively). Disorientation in space was reported by both groups (patients: 20%; family members: 30%). Also not included in the measures is the ability to benefit from memory aids, psychomotor difficulties, and lack of responsiveness to environment. These domains were reported by a relatively small number of subjects (psychomotor difficulties:
Patients: 10%, Family Members: 5%; lack of responsiveness to the environment: family members 5%). Both family members and patients discussed their reliance upon memory aids (e.g., Patient: “...and I would never take it (the medication) twice... I found a lot of easy ways to make things quick and easy and you never screw up. I think there is a lot of tricks you can do”; Family Member: “I have a series of notes around the house which schedule. I gave him a watch with the date on it so he looks at the watch. He sees the date and then he acts like he is in charge. So the system seems to work.”).

3) RESULTS AND DISCUSSION OF THE QUANTITATIVE ANALYSIS

3.1) RESULTS OF QUANTITATIVE ANALYSIS

All patients and family members completed the three utility-based measures. However, among the sample of 20 patients, 9 were unable or unwilling to fill out the feasibility questionnaires. In addition, of the 20 family members, 3 were unable or unwilling to complete the feasibility questionnaires. Therefore, the following three hypotheses (relevance, acceptability, and sufficiency) were tested for a sample of 11 patients and 17 family members. The completion time hypothesis was tested with the complete sample of 20 patients and 20 family members.
3.1.1) Test of Relevance Hypothesis
A two factor mixed analysis of variance was used to test this hypothesis. The between subjects factor was “group” (Patient / Family member); and, the within subjects was “measure” (EuroQol, HUI, QWB). There was no statistical evidence that either patients or family members considered any measure more relevant than any other.

Table 1: Summary of Analysis of Variance for the Relevance Hypothesis

<table>
<thead>
<tr>
<th>Source</th>
<th>Df</th>
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</tr>
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<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>between subjects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group (G)</td>
<td>1</td>
<td>3.39</td>
</tr>
<tr>
<td>Error</td>
<td>25</td>
<td>(11.60)</td>
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<tr>
<td>within subjects</td>
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<td></td>
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<tr>
<td>Measure (M)</td>
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<td>M x G</td>
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<td>2.90</td>
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<tr>
<td>Error</td>
<td>50</td>
<td>(1.74)</td>
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</tbody>
</table>

3.1.2) Test of Acceptability Hypothesis
A two factor mixed analysis of variance was used to test this hypothesis. The between subjects factor was “group” (Patient / Family member); and, the within subjects was “measure” (EuroQol, HUI, QWB). There was no statistical evidence that either patients or family members considered any measure more acceptable than any other.
Table 2: Summary of Analysis of Variance for the Acceptability Hypothesis

<table>
<thead>
<tr>
<th>Source</th>
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<td>between subjects</td>
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</tr>
<tr>
<td>Group (G)</td>
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<td>1.19</td>
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<td>Error</td>
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<td>(7.33)</td>
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<tr>
<td>within subjects</td>
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<td></td>
</tr>
<tr>
<td>Measure (M)</td>
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</tr>
<tr>
<td>M x G</td>
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<td>1.44</td>
</tr>
<tr>
<td>Error</td>
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<td>(.67)</td>
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</tbody>
</table>

3.1.3) Test of Sufficiency Hypothesis

A two factor mixed analysis of variance was used to test this hypothesis. The between subjects factor was "group" (Patient / Family member); and, the within subjects was "measure" (EuroQol, HUI, QWB). There was no statistical evidence that either patients or family members considered any measure more sufficient than any other.

Table 3: Summary of Analysis of Variance for the Sufficiency Hypothesis

<table>
<thead>
<tr>
<th>Source</th>
<th>Df</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td>between subjects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group (G)</td>
<td>1</td>
<td>6.60*</td>
</tr>
<tr>
<td>Error</td>
<td>25</td>
<td>(16.68)</td>
</tr>
<tr>
<td>within subjects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measure (M)</td>
<td>2</td>
<td>.67</td>
</tr>
<tr>
<td>M x G</td>
<td>2</td>
<td>2.87</td>
</tr>
<tr>
<td>Error</td>
<td>50</td>
<td>(2.12)</td>
</tr>
</tbody>
</table>

Note: * p<.05
3.1.4) Test of Completion Time Hypothesis

A two factor mixed analysis of variance was used to test this hypothesis. The between subjects factor was “group” (Patient / Family member); and, the within subjects was “measure” (EuroQol, HUI, QWB). There was statistical evidence that, on average, patients or family members took different amounts of time to complete different quality of life measures. There was statistical evidence that patients took longer than family members to complete the EuroQol and the QWB, but no statistical evidence that either group took longer to complete the HUI (see tables 4 and 5). Therefore, there is an interaction between the type of quality of life measure and the type of respondent. As expected, the longer the measure, the longer it took to complete (see tables 4 and 6). Furthermore, patients generally took longer to complete the measures than did family members (see tables 4 and 7).

Table 4: Summary of Analysis of Variance for the Completion Time Hypothesis

<table>
<thead>
<tr>
<th>Source</th>
<th>Df</th>
<th>F</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>between subjects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group (G)</td>
<td>1</td>
<td>20.80**</td>
</tr>
<tr>
<td>Error</td>
<td>36</td>
<td>(37307.51)</td>
</tr>
<tr>
<td>within subjects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Measure (M)</td>
<td>2</td>
<td>234.19**</td>
</tr>
<tr>
<td>M x G</td>
<td>2</td>
<td>14.16**</td>
</tr>
<tr>
<td>Error</td>
<td>72</td>
<td>(17586.77)</td>
</tr>
</tbody>
</table>

Note: Completion time measured in seconds.
** p<.01
Table 5: Summary of Mean Completion Times for the Test of the Completion Time

Hypothesis with Respect to the Interaction between Measure and Group

<table>
<thead>
<tr>
<th>Measure</th>
<th>Group</th>
<th>M</th>
<th>SE</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>EuroQol</td>
<td>Patients</td>
<td>183.11</td>
<td>14.32</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>140.21</td>
<td>14.32</td>
<td></td>
</tr>
<tr>
<td></td>
<td>members</td>
<td>42.90</td>
<td>20.25</td>
<td>2.12*</td>
</tr>
<tr>
<td></td>
<td>(Difference)</td>
<td>538.90</td>
<td>39.50</td>
<td></td>
</tr>
<tr>
<td>HUI</td>
<td>Patients</td>
<td>435.42</td>
<td>39.50</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>103.47</td>
<td>55.86</td>
<td>1.85</td>
</tr>
<tr>
<td></td>
<td>members</td>
<td>994.42</td>
<td>45.27</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(Difference)</td>
<td>645.74</td>
<td>45.27</td>
<td></td>
</tr>
<tr>
<td>QWB</td>
<td>Patients</td>
<td>348.68</td>
<td>64.02</td>
<td>5.45**</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>820.08</td>
<td>32.01</td>
<td></td>
</tr>
</tbody>
</table>

Note: Completion time measured in seconds
*p<.05; **p<.01

Table 6: Summary of Mean Completion Times for the Test of the Completion Time

Hypothesis with Respect to the Effect of Quality of Life Measure

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SE</th>
<th>t</th>
<th>1</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>EuroQol</td>
<td>161.66</td>
<td>10.13</td>
<td>1</td>
<td>----</td>
<td></td>
</tr>
<tr>
<td>HUI</td>
<td>487.16</td>
<td>27.93</td>
<td>2</td>
<td>12.23**</td>
<td>----</td>
</tr>
<tr>
<td>QWB</td>
<td>820.08</td>
<td>32.01</td>
<td>3</td>
<td>21.48**</td>
<td>9.91**</td>
</tr>
</tbody>
</table>

Note: Completion times measured in seconds
**p<.01
Table 7: Summary of Mean Completion Times for the Test of the Completion Time

<table>
<thead>
<tr>
<th>Measure</th>
<th>M</th>
<th>SE</th>
<th>t</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>572.14</td>
<td>25.58</td>
<td></td>
</tr>
<tr>
<td>Family members</td>
<td>407.12</td>
<td>25.58</td>
<td>4.56**</td>
</tr>
</tbody>
</table>

Note: Completion time measured in seconds

**p<.01

3.2) DISCUSSION OF QUANTITATIVE ANALYSIS

All patients and family members completed the three utility-based quality of life measures. However, a majority of patients required some help while completing at least one of the measures. In such cases the investigator read the measures out loud with the patients. Occasionally the investigator paraphrased some of the questions. It was apparent that some patients responded to the measures without giving much thought to the questions (i.e. selecting an answer without reading all the options) which raised some doubts about the validity of the information provided. Only a small number of family members required some help from the researcher because of vision problems.

The times required for completion were, on average, for the EuroQol (3 minutes for patients, 2.5 minutes for family members), the HUI (9 minutes for patients, and 7.2 minutes for family members), and the QWB (17 minutes for patients and 11 minutes for family members). As expected, the completion times were longer for the QWB than for the HUI, which in turn took longer to complete than the EuroQol. In terms of ease of administration the QWB may be too long an instrument for patients to complete, particularly when taking into account that patients needed assistance while completing...
this instrument. There is statistical evidence that patients, on average, took longer than family members to complete the EuroQoL and the QWB. On the other hand, patients and family member’s completion times for the HUI were not significantly different. It was observed that patients would not read all the answers of each item prior to selecting their response, which lowered the patient’s completion times on the HUI and compromised the validity and comparability of their opinions. Family members, on the other hand, usually read all the answer options of each question. Thus, the fact that both family members and patients completed the instruments in similar times is a reflection of the way they approached the task.

There was no statistical evidence that patients and family members were able to distinguish the three quality of life measures in terms of their relevance, acceptability and sufficiency. Almost half of the patients refused or were not able to complete the task of filling out the feasibility questionnaires to assess the three utility-based measures. It was apparent that patients had great difficulty completing this task. They were not able to distinguish the content of the three measures.

Patients had a tendency to group their responses towards the extreme positive end of the visual analogue scale, seemingly indicating that they felt all measures were equally adequate (see appendix 10, which shows the raw data for the responses to the visual analog scales). Thus, although to the trained observer the measures appear different, the patients were not able to distinguish amongst them. It is possible that the task of evaluating the complete measure was too complex or that the format of the questionnaire was confusing for patients to complete. It is possible that they might have performed better if questions were framed in a bipolar scale.
On the other hand, family members were able to better utilize the visual analogue scale in that they used a wider range of responses towards the middle of the visual analogue scale. Still, the family members were also unable to distinguish between the three measures.

In sum, the absence of significant results in the quantitative analysis may be due to methodological difficulties, but may also be interpreted to mean that neither patients nor family members are able to make differential judgments on particular measures. Indeed, quality of life is a multi-dimensional construct and determining whether a measure covers one's definition of quality of life may be too daunting a task for individuals without specific expertise. Overall, both family members and patients tended to agree that the instruments were appropriate, and did not engage in the more fine-tuned distinctions that are needed when conducting an evaluation of the relevance, acceptability, and sufficiency of the contents of these particular instruments.
IV. CONCLUSIONS

1) GENERAL CONCLUSIONS

1.1) Mild dementia patients are able and willing to provide useful descriptions of their quality of life.

This study supports the notion that it is possible and valuable to obtain the patient’s perspective on quality of life through a narrative process. This is evidenced by several findings: 1) Patients provided a much wider range of domains than the quality of life measures. The total number of domains found in the patient group was forty four. Of these forty four domains provided by patients, the EuroQol only captured nine dimensions (20%), the HUI ten domains (23%), and the QWB captured 21 domains (48%). This result suggests that the patient’s perspective is not properly captured by the measures. 2) The domains that patients provided were comparable (in numbers and content) to those provided by family members. Patients provided a total of forty four (44) domains and family members forty five (45). There was a content match between patients and family members on thirty three (33) domains. Family members provided an indirect confirmation of the findings in the patient’s group. We can conclude that the patient’s perspective is to a large extent comparable to the perspective of cognitively intact adults. 3) Finally, patients provided eleven (11) new domains that family members did not provide, thereby indicating that the patient’s perspective adds to the understanding of quality of life in dementia.
These conclusions are supported by the findings of earlier research which shows that the elderly can provide useful information about their quality of life (Pearlman and Uhlmann 1988; Cohn and Sugar 1991; Guyatt, Eagle et al. 1993; Patrick, Starks et al. 1994; Farquhar 1995; Raphael, Brown et al. 1995). Dementia patients can reveal those aspects of quality of life that are important to them (DeJong, Osterlund et al. 1989; David 1991; Foley 1992; Parse 1996; Acton, Mayhew et al. 1999; Brod, Stewart et al. 1999; Burgener and Dickerson-Putman 1999).

1.2) The quality of life perspective provided by patients and family members is broader in scope than that contained in the three utility-based quality of life measures.

Both patients and family members provided a number of domains not found in any of the three utility-based quality of life measures. Some of the domains were mentioned by a substantial percentage (>15%) of both patients and family members: Personal Losses; Disorientation in Space/ Getting Lost; Exercise; Hopes for a Cure; Access to good medical care; Financial Security; Living Arrangements; Opportunity to Travel; Supervision; Ability to Benefit from Memory Aids. Some of the domains that are not included in any of the three measures, but were reported by patients were: Coping with Memory Loss; Appreciation of Art; Hopes for longevity; Feeling Useful/ Valuable to Others. Some of the domains provided only by family members and were not reported in any of the measures were: Lack of Interest or Motivation; Confusion; Restlessness/Agitation; Physical Appearance; Fear of Being Alone.
Some of the domains referring to general social and financial resources (e.g., living arrangements, financial security, supervision, and opportunity to travel) are not included in any of the three utility-based measures. These domains may be useful when designing a dementia quality of life measure with a more general focus. However, these domains may not be as relevant when designing a measure for clinical trials.

1.3) **Null results in the quantitative analyses suggest that neither patients nor family members were able to distinguish between the three utility-based measures.**

The three utility-based quality of life measures were indistinguishable in terms of relevance, acceptability, and sufficiency. This finding casts doubts on the ability of both groups to determine which utility-based instrument is better suited to represent their perspective. Almost half of the patients (9) refused or were not able to complete the tasks of filling out the feasibility questionnaires. Patients had a tendency to group their responses towards the extreme ends of the visual analogue scale. It is possible that the use of visual analog scales was too difficult for patients, who otherwise might have performed better with bipolar scales. It was apparent that patients lacked the cognitive skills needed to handle the task. Surprisingly, family members were also not capable of finding significant differences amongst the measures although they were able to make finer distinctions on the visual analogue scales. We could speculate that these results suggest it is feasible to involve both patients and family members in the task of generating items for future dementia-specific measures, but it may not be feasible for them to participate in the item reduction or subsequent tasks involved in the creation of a dementia-specific measure. The latter may require more expertise than patients and
family members can provide. A possible alternative explanation for these null results is that the small sample size reduced the power of the test to identify differences. Additional research is required to determine an adequate level of participation of both groups in the evaluation of these measures.

2) SPECIFIC CONCLUSIONS

2.1) The European Quality of Life Instrument (EuroQoL):

The total time of completion of the EuroQol by patients and family members was 3 minutes and 2.5 minutes respectively.

The EuroQol covered one of the two domains included in the global impression of quality of life category. Although it addressed the general health domain, it did not address the life satisfaction domain which was mentioned by 75% of patients and 45% of family members.

On the physical well-being category, the EuroQol addressed only one domain out of nine provided by the respondents. Moreover, this domain (physical ailments, frailty and illnesses) was only captured by the EuroQol in a limited way because it only asks for levels of pain and discomfort. Thus, in the physical well-being domain the EuroQol fared very poorly.

In the social family well-being category, the EuroQol only captures three domains of nine reported by the respondents. In addition, the EuroQol includes all three under the general heading of usual activities, which severely limits the ability of this instrument to discriminate between disparate activities and experiences.
On the emotional well-being category, the EuroQol only includes depression. Respondents in this category provided an additional number of 17 domains related to emotional well-being which were not addressed by the measure. Thus, the emotional well-being domains are poorly represented by this measure.

On the functional well-being category, the EuroQol includes 4 domains out of 7. It includes recreational activities, self-care, instrumental activities of daily living, and mobility. Missing from the measure are driving, exercise, and opportunity to travel.

On the cognition category, the EuroQol does not address any of the eleven domains found in the interviews.

In sum, the EuroQol fares relatively well in the general impression of quality of life and functional well-being. It fares poorly in social/family well being. It fares very poorly on physical and emotional well being, and does not include any domain related to cognitive abilities. Therefore, it would be inappropriate to use this instrument in clinical trials for anti-dementia drugs.

2.2) The Health Utilities Index (HUI)

The total time of completion for the HUI was 9 minutes for patients and 7.2 minutes for family members.

The HUI is the only one of the three utility-based instruments that addresses both components of the global impression of quality of life category (life satisfaction and general health).

On the physical well-being category, the HUI only fully addresses two domains: hearing problems and vision. The third domain (physical ailments, frailty and illnesses) is
only addressed partially by asking for pain and discomfort. A component of physical well-being addressed by the measure but not mentioned by the respondents was the ability to use hands and fingers.

The social/family well-being category is not found in the measure. This is controversial given that this general category was most frequently mentioned by both groups of respondents.

On the emotional well-being category, the HUI addresses only two domains (depression and frustration/irritability/anger), out of the 18 domains found in the interviews.

The HUI covers only two domains of the functional well-being category (self-care and mobility). It does not include recreational activities, instrumental activities of daily living, driving, exercise, or opportunity to travel.

In the cognitive category, the HUI covers memory problems and communication problems which are important aspects of quality of life according to the respondents, but it leaves out nine other domains.

In sum, the HUI fares very well on the global impression of quality of life. It does poorly on physical, emotional, and functional well-being, and does not cover at all social/family well-being. The HUI’s lack of items to address these domains raises serious concerns about its suitability in clinical trials for dementia.
2.3) The Quality of Well-being Scale (QWB):

The total time of completion for the QWB was 17 minutes for patients and 11 minutes for family members.

The QWB does not inquire about global impression of quality of life directly.

On the physical well-being category, the QWB addresses all domains that are relevant for both patients and family members. It is clear that the QWB covers a wide array of symptoms including all that were mentioned as important to quality of life by both groups, and many others that were not. A shorter list of physical complaints would be more relevant to this population.

On the social/family well-being category, the QWB addresses some domains that are important for both groups: connection to family, social interactions, withdrawn/loneliness/boredom, and loss of competence. However, it does not include any items about the resources needed to sustain functional activities (e.g., living arrangements, access to medical care, financial security and supervision). These broader social variables may not be essential to a health related quality of life measure for use in clinical trials.

On the emotional well-being category, the QWB covers depression, participation in religious activities, frustration/irritability/anger, and sense of control/autonomy. It covers only 4 of the 18 categories found.

On the functional well-being category, the QWB covers the majority of domains: recreational activities, driving, self-care, instrumental activities of daily living, and mobility. It covers five out of the seven categories found. It does not cover exercise and opportunity to travel.
On the cognitive category, the QWB covers memory problems, ability to read, and communication problems. It does not cover confusion, disorientation, or psychomotor difficulties.

In sum, the QWB fares better than the two other measures because it covers more of the essential aspects of quality of life found in the interviews. It is an effective instrument for the assessment of physical and functional well being. It fared relatively well in the social/family, and cognitive well being. It fared poorly on emotional well-being. It does not include a global impression of quality of life (general health and life satisfaction). Thus, when compared to the other two measures the QWB appears to be a better instrument, which may be improved by including some dementia-specific dimensions in the cognitive, emotional and global impression of quality of life categories.

Quality of life is a multifaceted, multidimensional construct and its definition is often elusive. An adequate quality of life measure has to fulfill several criteria to establish its applicability in research and clinical practice. Standard requisites usually include content validity, feasibility, construct validity, reliability, and responsiveness. Within this broad terrain, this study only evaluates the content validity of the measures vis-a-vis the perspective of patients and family members who are affected by the disease. In this respect, all three utility-based measures had significant shortcomings, most of which derived from the fact that these are generic, rather than dementia-specific instruments. Overall, the QWB seems to take into account the perspectives of the disease-community better than the EuroQol and the HUI. Nonetheless, the use of these measures for anti-dementia clinical trials seems premature as they fail to address aspects of quality of life
which are of specific concern to this population. From an ethical perspective, their use would risk overriding the perspective of the interested parties. In the meantime – given the pressing need to evaluate new dementia treatments and the amount of time and resources needed to create a new measure – a modification of the Quality of Well-Being Scale (i.e. reducing the over-inclusive number of items in the acute and chronic symptoms domain) is recommended.
V. LIMITATIONS AND FUTURE RESEARCH

The results obtained in this study may not be generalizable to the general population. Since the study focuses on mild to moderate dementia patients, important aspects of quality of life for patients with moderate to severe dementia may be missing. This raises the question of how to incorporate the perspective of patients with moderate to severe dementia. It is unclear at which point in the progression of their illness do patients become unable to provide reliable impressions of quality of life in narrative form. For patients with severe dementia, a different method of obtaining their values is needed. This could be done either through behavioral observations or by taking the caregivers’ impressions. Another difficulty with the generalizability of these results stems from the fact that this study did not control for medical or psychiatric co-morbidity. It may be that individuals diagnosed with dementia together with other illnesses have a different view of quality of life. However, this may not be the case.

The sample size, although adequate for the qualitative analysis, may be small for the quantitative analysis. The lack of a balanced randomization scheme for the order of presentation of the measures is a deficiency. The sample size was further reduced with the high non-response rate for the feasibility questionnaires. This may have reduced the power of the test and could have resulted in missing significant differences. Further research will be needed to determine the most appropriate way of obtaining the input of patients and family members on the feasibility of the measures. It is likely that patients may perform better if they are asked to provide opinions on specific items, one at a time, as opposed to commenting on the whole measure. It is also recommended that future
research in this area make use of a bipolar scale instead of a visual analog scale. That
would reduce the scaling task, but may not reduce the cognitive burden of evaluating the
measures.

A small percentage of family members were unable to complete the feasibility
questionnaires. This highlights the need to screen caregivers for cognitive impairment.

A possible weakness of the qualitative analysis is that even though it gives an
account of those domains that are important to both patients and family members, it does
not provide an indication of the intensity of these preferences. In other words, the
qualitative analysis highlights which domains are important to both groups of
respondents, but it does not address the question of which domains are more important to
them. Perhaps those domains that were mentioned by a large number of subjects are more
important to this population.

The results of this study provide a reasonable argument for taking both patients’
and family members’ perspectives into account in the creation of a dementia-specific
quality of life measure. Future research needs to be conducted to include experts’
opinions as well. This could be done with a similar methodology to the one used in this
study or through focus groups. The aggregated results could then be generalized by
conducting a population survey including patients, caregivers, and providers.
REFERENCES


Appendix 1: The European Quality of Life Instrument (EuroQol)
By placing a tick (thus ☐) in one box in each group below, please indicate which statements best describe your own health state today.

**Mobility**
- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**
- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities (e.g. work, study, housework, family or leisure activities)**
- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

Compared with my general level of health over the past 12 months, my health state today is:
- Better
- Much the same
- Worse

Please tick one box.
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked by 100 and the worst state you can imagine is marked by 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your current health state is.
Appendix 2: The Health Utilities Index (HUI)
HEALTH UTILITIES INDEX MARK 2 AND MARK 3 (HUI2/3)
15-ITEM QUESTIONNAIRE FOR SELF-ADMINISTERED, SELF-ASSESSED
"TWO-WEEK" HEALTH STATUS ASSESSMENT

Instructions: This questionnaire contains a set of questions which ask about various aspects of your health. When answering these questions please think about your health and your ability to do things on a day-to-day basis, during the past 2 weeks. To define the 2 week period, please think about what the date was 2 weeks ago and recall the major events that you have experienced during this period. Please focus your answers on your overall abilities, disabilities and how you felt during the past 2 weeks.

You may feel that some of these questions do not apply to you, but it is important that we ask the same questions of everyone. Also, a few questions are similar; please excuse the apparent overlap and answer each question independently.

Please read each question and consider your answers carefully. For each question, please select one answer that best describes your level of ability or disability during the past 2 weeks. Please indicate the selected answer by circling the letter (a,b,c,...) beside the answer.

All information you provide is confidential. There are no right or wrong answers; what we want is your opinion about your abilities and feelings.

1. Which one of the following best describes your ability, during the past 2 weeks, to see well enough to read ordinary newsprint?
   a. Able to see well enough without glasses or contact lenses.
   b. Able to see well enough with glasses or contact lenses.
   c. Unable to see well enough even with glasses or contact lenses.
   d. Unable to see at all.

2. Which one of the following best describes your ability, during the past 2 weeks, to see well enough to recognize a friend on the other side of the street?
   a. Able to see well enough without glasses or contact lenses.
   b. Able to see well enough with glasses or contact lenses.
   c. Unable to see well enough even with glasses or contact lenses.
   d. Unable to see at all.

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3. Which one of the following best describes your ability, during the past 2 weeks, to hear what was said in a group conversation with at least three other people?

   a. Able to hear what was said without a hearing aid.
   b. Able to hear what was said with a hearing aid.
   c. Unable to hear what was said even with a hearing aid.
   d. Unable to hear what was said, but did not wear a hearing aid.
   e. Unable to hear at all.

4. Which one of the following best describes your ability, during the past 2 weeks, to hear what was said in a conversation with one other person in a quiet room?

   a. Able to hear what was said without a hearing aid.
   b. Able to hear what was said with a hearing aid.
   c. Unable to hear what was said even with a hearing aid.
   d. Unable to hear what was said, but did not wear a hearing aid.
   e. Unable to hear at all.

5. Which one of the following best describes your ability, during the past 2 weeks, to be understood when speaking your own language with people who do not know you?

   a. Able to be understood completely.
   b. Able to be understood partially.
   c. Unable to be understood.
   d. Unable to speak at all.
6. Which one of the following best describes your ability, during the past 2 weeks, to be understood when speaking with people who know you well?

a. Able to be understood completely.

b. Able to be understood partially.

c. Unable to be understood.

d. Unable to speak at all.

7. Which one of the following best describes how you have been feeling during the past 2 weeks?

a. Happy and interested in life.

b. Somewhat happy.

c. Somewhat unhappy.

d. Very unhappy.

e. So unhappy that life was not worthwhile.

8. Which one of the following best describes the pain and discomfort you have experienced during the past 2 weeks?

a. Free of pain and discomfort.

b. Mild to moderate pain or discomfort that prevented no activities.

c. Moderate pain or discomfort that prevented a few activities.

d. Moderate to severe pain or discomfort that prevented some activities.

e. Severe pain or discomfort that prevented most activities.

9. Which one of the following best describes your ability, during the past 2 weeks, to walk? 
Note: Walking equipment refers to mechanical supports such as braces, a cane, crutches or a walker.

a. Able to walk around the neighbourhood without difficulty, and without walking equipment.
b. Able to walk around the neighbourhood with difficulty; but did not require walking equipment or the help of another person.
c. Able to walk around the neighbourhood with walking equipment, but without the help of another person.
d. Able to walk only short distances with walking equipment, and required a wheelchair to get around the neighbourhood.
e. Unable to walk alone, even with walking equipment. Able to walk short distances with the help of another person, and required a wheelchair to get around the neighbourhood.
f. Unable to walk at all.

10. Which one of the following best describes your ability, during the past 2 weeks, to use your hands and fingers? 
Note: Special tools refers to hooks for buttoning clothes, gripping devices for opening jars or lifting small items, and other devices to compensate for limitations of hands or fingers.

a. Full use of two hands and ten fingers.
b. Limitations in the use of hands or fingers, but did not require special tools or the help of another person.
c. Limitations in the use of hands or fingers, independent with use of special tools (did not require the help of another person).
d. Limitations in the use of hands or fingers, required the help of another person for some tasks (not independent even with use of special tools).
e. Limitations in the use of hands or fingers, required the help of another person for most tasks (not independent even with use of special tools).
f. Limitations in the use of hands or fingers, required the help of another person for all tasks (not independent even with use of special tools).

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11. Which one of the following best describes your ability, during the past 2 weeks, to remember things?
   a. Able to remember most things.
   b. Somewhat forgetful.
   c. Very forgetful.
   d. Unable to remember anything at all.

12. Which one of the following best describes your ability, during the past 2 weeks, to think and solve day to day problems?
   a. Able to think clearly and solve day to day problems.
   b. Had a little difficulty when trying to think and solve day to day problems.
   c. Had some difficulty when trying to think and solve day to day problems.
   d. Had great difficulty when trying to think and solve day to day problems.
   e. Unable to think or solve day to day problems.

13. Which one of the following best describes your ability, during the past 2 weeks, to perform basic activities?
   a. Eat, bathe, dress and use the toilet normally.
   b. Eat, bathe, dress and use the toilet independently with difficulty.
   c. Required mechanical equipment to eat, bathe, dress or use the toilet independently.
   d. Required the help of another person to eat, bathe, dress or use the toilet.

14. Which one of the following best describes how you have been feeling during the past 2 weeks?
   a. Generally happy and free from worry.
   b. Occasional anxiety, irritable, angry, or depressed.
   c. Often anxiety, irritable, angry, or depressed.
   d. Almost always anxiety, irritable, angry, or depressed.
   e. Extremely anxiety, irritable, angry, or depressed; to the point of needing professional help.

15. Which one of the following best describes the pain or discomfort you have experienced during the past 2 weeks?
   a. Free of pain and discomfort.
   b. Occasional pain or discomfort. Discomfort relieved by non-prescription drugs or self-control activity without disruption of normal activities.
   c. Frequent pain or discomfort. Discomfort relieved by oral medicines with occasional disruption of normal activities.
   d. Frequent pain or discomfort; frequent disruption of normal activities. Discomfort required prescription narcotics for relief.
   e. Severe pain or discomfort. Pain not relieved by drugs and constantly disrupted normal activities.

16. Overall, how would you rate your health during the past 2 weeks?
   a. Excellent.
   b. Very good.
   c. Good.
   d. Fair.
   e. Poor.

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17. How did you complete the questionnaire? Please select the one answer that best describes your situation.

a. By myself, **without any help** from anyone else.

b. By myself, except **someone else circled** the answers on the questionnaire form for me.

c. **With the help** of someone else.

d. This questionnaire was completed by a family member, **without help** from the subject or patient.

e. This questionnaire was completed by a nurse or other health professional, **without help** from the subject or patient. Please specify type of health professional:

   ________________________________________________________________

f. This questionnaire was completed by another person, **without help** from the subject or patient. Please specify relationship to subject or patient:

   ________________________________________________________________
Appendix 3: The Quality of Well-Being Scale (QWB)
Quality or Well-being Scale
Self-administered Form 1.04 © Copyright 1996, All Rights Reserved
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prohibited without written permission

Roberto M. Kaplan, Ph.D.
Theodore G. Ganiats, M.D.
William J. Sieber, Ph.D.

This survey asks about health problems that you have experienced in the last three
days, not including today. Please make sure to answer all questions. Thank you for your
patience and time in carefully completing this survey.

Patient ID #: ________  Time: 1 or 2  Patient or Caregiver

Part I - Acute and Chronic Symptoms

1. Please indicate whether you currently experience any of the following health symptoms
or problems.

<table>
<thead>
<tr>
<th>Do you have</th>
<th>YES or NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. blindness, or severely impaired vision in both eyes?</td>
<td>Yes No</td>
</tr>
<tr>
<td>b. speech problems such as stuttering, or being able to speak clearly?</td>
<td>Yes No</td>
</tr>
<tr>
<td>c. missing or paralyzed hands, feet, arms, or legs?</td>
<td>Yes No</td>
</tr>
<tr>
<td>d. any deformity of the face, fingers, hand or arm, foot or leg, or back (e.g. severe scoliosis)?</td>
<td>Yes No</td>
</tr>
<tr>
<td>e. general tiredness or weakness?</td>
<td>Yes No</td>
</tr>
<tr>
<td>f. a problem with unwanted weight gain or weight loss?</td>
<td>Yes No</td>
</tr>
<tr>
<td>g. a problem with being under or over weight?</td>
<td>Yes No</td>
</tr>
<tr>
<td>h. problems chewing your food adequately?</td>
<td>Yes No</td>
</tr>
<tr>
<td>i. any hearing loss or deafness?</td>
<td>Yes No</td>
</tr>
<tr>
<td>j. any noticeable skin problems, such as bad acne or large burns or scars on face, body, arms, or legs?</td>
<td>Yes No</td>
</tr>
<tr>
<td>k. eczema or burning/itching rash?</td>
<td>Yes No</td>
</tr>
</tbody>
</table>

Which or the following health aides do you use/have?  YES or NO

| dentures | Yes No |
| oxygen tank | Yes No |
| prosthesis | Yes No |
| eye glasses or contact lenses? | Yes No |
| hearing aid? | Yes No |
| magnifying glass? | Yes No |
| neck, back or leg brace? | Yes No |
2. For the following list of problems, indicate which days (if any) over the past 3 days, not including today, you had the problem. If you have not had the symptoms in the past 3 days, do not leave the question blank, please check "no days". If you have experienced the symptom in the past three days, please check which of the days you had it; if you experienced it on more than one of the days, please check all that apply.

For example, if you had a headache yesterday and the day before that, the following should be checked:

<table>
<thead>
<tr>
<th>For example...</th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>a headache?</td>
<td></td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
</tbody>
</table>

Did you have... (Please Check All Days That Apply)

<table>
<thead>
<tr>
<th></th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. any problems with your vision not corrected with glasses or contact lenses (such as double vision, distorted vision, flashes, or floaters)?</td>
<td></td>
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<tr>
<td>B. any eye pain, irritation, discharge, or excessive sensitivity to light?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. a headache?</td>
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<tr>
<td>D. dizziness, earache, or ringing in your ears?</td>
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<tr>
<td>E. difficulty hearing or discharge or bleeding from an ear?</td>
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<tr>
<td>F. stuffy or runny nose of bleeding from the nose?</td>
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<tr>
<td>G. a sore throat, difficulty swallowing, or hoarse voice?</td>
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<tr>
<td>H. a toothache or jaw pain?</td>
<td></td>
<td></td>
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<tr>
<td>I. sore or bleeding lips, tongue, or gums?</td>
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<tr>
<td>J. coughing or wheezing?</td>
<td></td>
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<td></td>
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<tr>
<td>K. shortness of breath or difficulty breathing?</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Question</td>
<td>No days</td>
<td>Yesterday</td>
<td>2 days ago</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>---------</td>
<td>-----------</td>
<td>------------</td>
</tr>
<tr>
<td>L.</td>
<td>chest pain, pressure, palpitations, fast or skipped heart beat or other discomfort in the chest?</td>
<td></td>
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<tr>
<td>M.</td>
<td>an upset stomach, abdominal pain, nausea, heart burn or vomiting?</td>
<td></td>
<td></td>
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<tr>
<td>N.</td>
<td>difficulty with bowel movements, diarrhea, constipation, rectal bleeding, black tar-like stools, or any pain or discomfort in the rectal area</td>
<td></td>
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<tr>
<td>O.</td>
<td>pain, burning or blood in urine?</td>
<td></td>
<td></td>
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<tr>
<td>P.</td>
<td>loss of bladder control, frequent night-time urination or difficulty with urination?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Q.</td>
<td>genital pain, itching, burning, or abnormal discharge, or pelvic cramping, or abnormal bleeding? (does not include normal menstruation).</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>R.</td>
<td>a broken arm, wrist, foot, leg or any bone (other than in back)?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>S.</td>
<td>pain, stiffness, cramps, weakness, or numbness</td>
<td></td>
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<td></td>
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<tr>
<td></td>
<td>a) in the neck or back?</td>
<td></td>
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<tr>
<td></td>
<td>b) in the hips, sides, knees, or back?</td>
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<tr>
<td></td>
<td>c) in any of the joints or muscles of the hands, feet, or legs?</td>
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<td></td>
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</tr>
<tr>
<td>T.</td>
<td>swelling of ankles, hands, feet, or abdomen?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>U.</td>
<td>fever, chills, or sweats?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>V.</td>
<td>loss of consciousness, fainting, or seizures?</td>
<td></td>
<td></td>
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<tr>
<td>W.</td>
<td>difficulty with your balance, standing or walking?</td>
<td></td>
<td></td>
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</tbody>
</table>
3. The following symptoms are about feelings, thoughts, and behaviours. Please check which days (if any) over the past 3 days, not including today, you have had....

<table>
<thead>
<tr>
<th></th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td>trouble falling asleep or staying asleep</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B.</td>
<td>spells of feeling nervous or shaky?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C.</td>
<td>spells of feeling upset, downhearted or blue?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>D.</td>
<td>excessive worry or anxiety?</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>E.</td>
<td>feelings of little or no control over events in your life?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F.</td>
<td>feeling lonely or isolated?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G.</td>
<td>feelings of frustration, irritation or close to losing your temper?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>H.</td>
<td>a hangover</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I.</td>
<td>any decrease of sexual interest or performance?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>J.</td>
<td>difficulty understanding the written or spoken word, or significant memory loss</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>K.</td>
<td>thoughts or images you could not get out of your mind?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>L.</td>
<td>to take any mediation including over-the-counter remedies (aspirin/Tylenol, allergy medications, insulin, hormones, estrogen, thyroid, prednisone)?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>M.</td>
<td>to stay on a medically prescribed diet for health reasons?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N.</td>
<td>a loss of appetite or over-eating?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4. In the past 3 days did you have any symptoms, health complaints, or pains that have not been mentioned? (Please circle) 1. Yes 2. No

<table>
<thead>
<tr>
<th>If Yes, what were the symptoms and on which days did you have them?</th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>A.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C.</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

Part II - Self Care
Over the last 3 days.... (Please Check All Days That Apply)

<table>
<thead>
<tr>
<th></th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Did you spend any part of the day or night as a patient in a hospital, nursing home, or rehabilitation centre?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. Because of any impairment or health problem, did you need help with your personal care needs, such as eating, dressing, bathing, or getting around your home?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Part III - Mobility
Over the last 3 days.... (Please Check All Days That Apply)

<table>
<thead>
<tr>
<th></th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Which days did you drive a motor vehicle?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. Which days did you use public transportation such as a bus, subway, Medi- van, train or airplane?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. Which days did you either not drive a motor vehicle or not use public transportation because of your health or need of help from another person?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Part IV - Physical Activity**

Over the last 3 days.... (Please Check All Days That Apply)

<table>
<thead>
<tr>
<th>Question</th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. have trouble climbing stairs or inclines or walking off the curb?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>B. avoid walking, have trouble walking, or walk more slowly than other people your age?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. limp or use a cane, crutches or walker?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>D. avoid or have trouble bending over, stooping or kneeling?</td>
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<td></td>
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</tr>
<tr>
<td>E. have any trouble lifting or carrying everyday objects such as books, a briefcase or groceries?</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>F. have any other limitations in physical movements?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>G. spend all or most of the day in a bed, chair, or couch because of health reasons?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>H. spend all or most of the day in a wheelchair? If so, on which days did someone else control its movement?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Part V - Usual Activity

Over the last 3 days.... (Please Check All Days That Apply)

<table>
<thead>
<tr>
<th>A. Because of any physical or emotional health reasons, on which days did you avoid, need help with, or were limited in doing some of your usual activities, such as work, school, or housekeeping?</th>
<th>No days</th>
<th>Yesterday</th>
<th>2 days ago</th>
<th>3 days ago</th>
</tr>
</thead>
<tbody>
<tr>
<td>B. Because of physical or emotional health reasons, on which days did you avoid or feel limited in doing some of your usual activities, such as visiting family/friends, hobbies, shopping, recreational or religious activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>C. On which days did you have to change any of your plans or activities because of your health that you did not report on the previous two questions? Please describe:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 4: Domains included in the Dementia Quality of Life Instrument (DQOL)
Appendix 4:

The Dementia Quality of Life Instrument (DQOL)

1) Physical Functioning
   a) Physical functioning (e.g. walking, going up and down stairs, reaching, bending)

2) Daily Activities
   a) Self-care activities
   b) Instrumental activities (e.g. shopping, cooking, handling finances)

3) Discretionary Activities
   a) Hobbies, recreational activities, vacations
   b) Work/ Productivity
   c) Being active

4) Mobility
   a) Travel in neighborhood and outside of neighborhood
   b) Public transportation

5) Social Interaction
   a) Intimacy, happiness with family
   b) Social participation

6) Interaction Capacity
   a) Communication difficulties
   b) Ability to comprehend
   c) Confusion

7) Bodily Well-Being
   a) Fatigue
   b) Sleep

8) Sense of Well-Being
   a) Self-esteem
   b) Embarrassment, self-consciousness
   c) Sense of Control
   d) Depressed mood, sadness
   e) Feeling loved and wanted
   f) Anxiety/ worry
   g) Loneliness/ isolation
   h) Fears
   i) Anger/ irritability
   j) Frustration
   k) Boredom
   l) Feelings of belonging
m) Feeling useful, valuable to others, helpful
n) Calm, peaceful
o) Happiness, cheerfulness
p) Sense of humor

9) Sense of Aesthetics
   a) Enjoyment/ appreciation of beauty/ nature
   b) Creativity/ artistic expression and appreciation
   c) Awareness and appreciation of surroundings

10) Overall Perceptions
   a) Self-rated health
   b) Life satisfaction
Appendix 5: Domains included in the World Health Organization Quality of Life Instrument (WHOQOL)
Appendix 5

The World Health Organization Quality of Life Instrument (WHOQOL)

1) Overall Quality of Life and General Health

2) Physical Health
   a) Energy and fatigue
   b) Pain and discomfort
   c) Sleep and rest

3) Psychological
   a) Bodily image and appearance
   b) Negative feelings
   c) Positive feelings
   d) Self-esteem
   e) Thinking, learning, memory and concentration

4) Level of Independence
   a) Mobility
   b) Activities of daily living
   c) Dependence on medical substances and medical aids
   d) Work capacity

5) Social Relationships
   a) Personal relationships
   b) Social support
   c) Sexual activity

6) Environment
   a) Financial Resources
   b) Freedom, physical safety and security
   c) Health and social care: accessibility and quality
   d) Home environment
   e) Opportunities for acquiring new information and skills
   f) Participation in and opportunities for recreation/leisure
   g) Physical environment (pollution/noise/traffic/climate)
   h) Transport

7) Spirituality/Religion/Personal beliefs
Appendix 6: Verbatim Analysis for Patients and Family Members
Following are the results of the qualitative analysis of the forty interviews with patients and family members. Domains are organized into six broad categories: 1) Global impression of quality of life; 2) Physical well-being; 3) Social/Family well-being; 4) Emotional well-being; 5) Functional well-being; and 6) Cognition.

The results for the patients and the family members are presented in the same order as presented in the results and discussion section to bring forth the similarities and differences found between the two groups. For each domain we list: a) the frequency and percentage of subjects who mentioned that domain in the open-ended interview; b) how the domain corresponds with the items of each of the three utility based measures - EuroQol, HUI, and QWB - and the two additional measures - DQOL and WHOQOL (the latter two measures are only included for discussion purposes, since the complete measures were not available); and c) patients’ and family members’ verbatim.

A) GLOBAL IMPRESSION OF QUALITY OF LIFE
Life satisfaction (Patients: 15, 75%)
HUI: Question 7: Which one of the following best describes how you have been feeling during the past 2 weeks? Answers range from ‘Happy and interested in life’ to ‘So unhappy that life was not worthwhile’
DQOL: Overall perceptions / Life satisfaction
WHOQOL: Overall quality of life
P 1: “What is life like for you? Good...I always say it’s good. It’s good enough”
P 2: “What is life like for you? It is much better. I am having a good time now...”
P 3: “It is very interesting. It has been exciting up to now, but since I retired it is interesting” “I can say that I am really quite happy and satisfied with life the way it is”
P 4: “Pretty good, pretty good. Very good” “So what can I say, I am enjoying life”
P 5: “Well, it could be better, but it’s not bad” “Thanks God I am still here”
P 7: “I think is good” “I like it the way it is now”
P 8: “So I have been doing pretty well. I can’t complain...Happy can’t be the word. Content is a better word” “I led a pretty good life”
P 10: "Very satisfactory” “I am satisfied, Let me say that I feel very blessed...so you look back and you realize that you had a satisfying life. Very much so.”
P 11: “Broken. I can’t do anything”
P 14: “Well, we are here, we try to enjoy ourselves”
P 15: “It is very good”
P 16: “Well, it is not a pleasant one at the moment. But not a pleasant one, no. I wish it was better than it is...It’s not pleasant you know”
P 18: “Good. I am a happy person”
P 19: “My life has been very good for me”.
P 20: “I am doing pretty well, I am happy”.

Life Satisfaction (Family members: 9, 45%)
HUI: Question 7: Which one of the following best describes how you have been feeling during the past 2 weeks? Answers range from ‘Happy and interested in life’ to ‘So unhappy that life was not worthwhile’
DQOL: Overall perceptions / Life satisfaction
WHOQOL: Overall quality of life
FM 3: “He is very happy with his life the way it is”
FM 4: “Right now, I would say everything is fine” “She seems quite happy with her life...I think that she is quite happy”
FM 9: “So I would say he tells us how happy he is everyday” “He can enjoy the moment. There is no yesterday...He lives the moment. So he is pretty good” “He is happier now than I have ever seen him, certainly when he was younger”
FM 10: “Right now I don’t think she has much of a life”
FM 11: “What is life like for your wife? It is very pleasant. It is pleasant”
FM 14: “What is life like for your mother? In my view, it is very sad” “But right now she’s probably as happy as she can be” “and she also said to them: I hope you are as good as I am when you are 82.”
FM 18: “She’s very happy”
FM 19: “But otherwise, we have no complaints, no complaints”.
FM 20: “She is generally content with her life”.

2
General health (Patients: 6, 30%)
EuroQol: Two items: 1) Compared with my general level of health over the past 12 months, my health state today is: Better; Much the same; Worse; 2) We would like you to indicate on this scale (thermometer) how good or bad your own health is today, in your opinion
HUI: Question 16: Overall, how would you rate your health during the past 2 weeks? Excellent; Very good; Good; Fair; Poor.
DQOL: Overall perceptions / Self-rated health
WHOQOL: General Health
P 2: “One priority is to be very healthy” “I am being very careful about my health”
P 7: “As long I keep my health I am, I am happy.”
P10: “At the very moment I feel very blessed. I have been very athletic and even though there have been here and there little things but nothing I mean thank goodness” “Just good health. Good health”
P18: “Yes I worry, I think of staying healthy. I worry about health, that's important. No matter what, if you don't have your health you don't have anything.”
P 19: “My doctor gave me antibiotics, I go every 6 months, cancer.”
P 20: “I want to stay healthy, health is very important”.

General health (Family members: 8, 40%)
EuroQol: Two items: 1) Compared with my general level of health over the past 12 months, my health state today is: Better; Much the same; Worse; 2) We would like you to indicate on this scale (thermometer) how good or bad your own health is today, in your opinion
HUI: Question 16: Overall, how would you rate your health during the past 2 weeks? Excellent; Very good; Good; Fair; Poor.
DQOL: Overall perceptions / Self-rated health
WHOQOL: General health
FM 2: “My mother has been very fortunate with her general health, in that I can’t remember when she has been to the hospital.”
FM 4: “Certainly, there are no physical problems or anything at this stage”
FM 5: “Health wise, she is okay, Basically I mean arthritis, osteoporosis”
FM 8: “I think if you lose your memory you still have your health and everything else.”
FM 9: “He can be aware of his health. I guess that could be a concern but it is not with him all the time.”
FM 12: “What holds him back mostly is his physical disability because when this first struck him, it hit him physically”
FM 15: “You know, under the circumstances his physical health is pretty good. His blood pressure is excellent”
FM 18: “Health wise we’ve been very lucky too.” “But I think hope for health, that’s one of our main things... That thing is a main thing with seniors is health.”

B) PHYSICAL WELL-BEING

Physical illnesses, injuries, or frailty (Patients: 9, 45%)

EuroQol: (Limited) Pain / Discomfort
HUI: (Limited) Questions 8 and 15: Best describes the pain and discomfort you have experienced during the past 2 weeks?
QWB: Part I: Acute and Chronic symptoms
WHOQOL: Physical Health: Pain and discomfort

P 6: “The only problem I got is my knees and are almost the key in any thing you do. I tore the cartilage out of my knees, both knees.”

P 7: “Make my life worse? If I got injured or something like that. The only thing that I could think of that could make my life unbearable if you put it that way.”

P 8: “I never thought I would have had a stroke. That is another thing that set me back shortly after I had the stroke, end of August. I had a girlfriend who I used to talk all the time. She had a stroke near Christmas time and it was a dandy. She never pulled out of it. She was crippled all up. She went right out of it. She died three weeks later”

P 9: “Because it's Alzheimer's. It will deteriorate our body”

P13: “You'd be going here, going there it is too much for your back”. “They said they are going to do my back, K. (son) said no, I don’t know what they are going to operate on”

P 14: “And where I myself enjoy sports but I use to play lawn bowls. Now I've given up that of course I feel that my muscles have not got the strength any more to deliver the ball.”
P 15: “Knowing that I had some crippling disease or something. You know that I could not do for myself. I would not feel very good about it you know.”
P 16: “That's one of the things that makes it worse you know. My system deprives me from doing what I really love to do and there is quite a few things I love to do which I can’t today.”
P 17: “I've been living on transient ischemic attacks.” “and on one or two occasions, scrapped my skin in sort of a unfortunate way”

Physical ailments, frailty, or illnesses (Family members: 7, 35%)

EuroQol: (Limited) Pain / Discomfort

HUI: (Limited) Question 8 and 15: Best describes the pain and discomfort you have experienced during the past 2 weeks.

QWB: Part I: Acute and chronic symptoms

WHOQOL: Physical health / Pain and discomfort

FM 6: “He got an infection in his toe” “So we had to go to the dentist and to the doctor because of his foot”.

FM 7: “right now he’s got a bronchial infection” “cataract” “He has had major surgery on one leg because he has blocked veins and he should have it on the other leg, but the doctor did not say it was mandatory. But now all of a sudden, he has a swollen foot. So between not being able to breath because he has ephisema and he should be using an inhaler but he’s not, so I don’t know if there is a connection between the bronchial infection and the ephisema.”

FM 8: “And it has upset her stomach to an extent that she gets a nervous stomach. That has to be cured because it is not an ulcer.”

FM 9: “He has diabetes” “When I mentioned to him for example skin cancer which is mild, it is under control, I saw a shadow go over his face and may be concerned about himself”

FM 13: “She is getting very frail. Her legs are getting wobbly”

FM 17: “His own physical decline. If it declines any further I think he would probably be in assisted living situation. The situation here I think is fragile. So any decline would be fairly serious.” “Hopes, well I think that his life won’t become any more compromised than it is.
And pain management, he has stenosis so occasionally I hear the, you know he needs to take Tylenol 3's to manage the pain.”

FM 20: “She has diabetes, arthritis, and high blood pressure, she needs to take all these medications and watches what she eats. I worry that she is getting frail”.

**Fatigue, Lack of Energy (Patients: 4, 20%)**

QWB: Part I: Acute and chronic symptoms / Do you have a general tiredness or weakness?.

DQOL: Bodily well-being / Fatigue

WHOQOL: Physical health / Energy and fatigue

P2: “I get tired sometimes because I am getting a bit older.”

P9: “In the morning I say I am going to this and it is not possible. The next moment you don’t have the energy to do the things you want to do”

P13: “I have no energy.”

P17: “what do you think would make your life better? Energy, more energy.” “I like that but I'm tired very quickly. I'm tired you know.”

**Sleep disturbances (Family members: 4, 20%)**

QWB: Part I: Acute and chronic symptoms / Trouble falling asleep or staying asleep? (Limited: It does not include hypersomnia)

WHOQOL: Physical health / Sleep and Rest

FM 3: “Other times, he is always tired. He sleeps a lot during the day.”

FM 6: “He is sleeping the whole day” “Sometimes, he goes to bed and then wakes up in the middle of the night and then...he wants me up too.”

FM 7: “he sleeps all the time... He is asleep all the time. He sleeps in the daytime. He has a nap in the afternoon. He wants to go to bed early. He is up for the night because his body closes off.”

FM 13: “So our days are changing because she's sleeping in a lot more and staying up later at night.”
Hearing problems (Patients: 4, 20%)
HUI: Questions 3 and 4: Ability, during the past 2 weeks, to hear what was said in a group conversation with at least three other people? / with one other person in a quiet room?
QWB: Part I: Acute and chronic symptoms: Any hearing loss or deafness? / Use of a hearing aid?

P 8: “Being hard of hearing is another thing”
P 11: “I have problems hearing”
P 14: “and if I can't hear and then some days you hear better than others. But if you can't hear what's going on the other side of the table well you might as well stick out of the way.”
P 19 “ I hope that I will hear a little better.”

Hearing problems (Family members: 5, 25%)
HUI: Questions 3 and 4: Ability, during the past 2 weeks, to hear what was said in a group conversation with at least three other people? / with one other person in a quiet room?
QWB: Part I: Acute and chronic symptoms: Any hearing loss or deafness? / Use of hearing aid?

FM 7: “He can’t hear. He won’t wear a hearing aid.”
FM 11: “She is also a bit deaf and I don’t know. She denies that.”
FM 15: “He is very hard of hearing. We cannot give him the second; He has been wearing a hearing aid for years. We cannot give him the second hearing aid. Because we are now afraid it is going to confuse him. It would be a great help. He listens to the T.V. He needs it very, very loud. I am afraid of the neighbours so he turns it soft so he cannot hear.”
FM 18: “She had a hearing problem. Dr. ------ felt she needed a hearing aid that she got yesterday. So we are trying it out there today.”
FM 20: “ I have been trying to get her to wear the hearing aid but she doesn’t she refuses to wear it, maybe it is uncomfortable for her.”
Falls / Loss of Balance (Patients: 2, 10%)
QWB: Part I: Acute and chronic symptoms: Difficulty with your balance, standing or walking?
P 8: “I still get that I might fall...I have to be careful. I lose my balance”
P16: “Well I guess falling down is one. I wouldn't like it. Like in the bathroom there one day I went in the bathroom. I washed my head and my hair and all like that and even before I finished what I am doing, down to the floor.”

Falls / Loss of Balance (Family members: 2, 10%)
QWB: Part I: Acute and chronic symptoms: Difficulty with your balance, standing or walking?
FM 1: “She also had some falls” “She has fallen a few times before. She fell and broke her shoulder. We did not see if she tripped...she just crumbled to the ground.” “Falling is another important issue.”
FM 12: “It manifested itself in an imbalance and that has always been a leading cause of all his problems as his imbalance has gotten worse”

Incontinence (Family members: 2, 10%)
QWB: Part I: Acute and chronic symptoms: Loss of bladder control, frequent night time urination or difficulty with urination?
FM 6: “He wets his underwear, pijamas, and you know”.
FM 12: “He has incontinence which bothers me” “His bladder control has gotten worse”

Loss of appetite (Family members: 2, 10%)
QWB: Part I: Acute and chronic symptoms: A loss of appetite or over-eating?.
FM 6: “The last few days, he eats maybe half. Then he pushes his plate.”
FM 13: “She has not eaten meat in years. She doesn't eat anything hardly now. I'm having a real problem trying to get food into her”
Vision (Patients: 1, 5%)
HUI: Questions 1 and 2: Which one of the following best describes your ability to see well enough to read ordinary newsprint? / to recognize a friend on the other side of the street?
QWB: Part I: Acute and chronic symptoms: blindness, or severe impaired vision? / Do you use eye glasses or contact lenses? / Any problems with your vision not corrected with glasses or contact lenses?
P 19: “That I want to get the operation from my cataracts, the right eye a little and the left eye is worse.”

Loss of consciousness (Patients: 1, 5%)
QWB: Part I: Acute and chronic symptoms: Loss of consciousness, fainting or seizures?
P17: “You never know when I might pass out. In fact yesterday I dropped down”

Loss of consciousness (Family members: 1, 5%)
QWB: Part I: Acute and chronic symptoms: Loss of consciousness, fainting or seizures?
FM 1: “She fell forward but she has no recollection of losing consciousness. Maybe she blacked out. Happened twice in a few months. I am not sure if she had any dizzy spells or things like that. That is the connection seemingly between that and the deterioration of her mental functioning.” “He said she just kind of passed out.” “She doesn’t remember feeling that she blacked out.”

C) SOCIAL / FAMILY WELL-BEING
Connection to Family / Family Support (Patients: 17, 85%)
EuroQol: Usual activities / Family
QWB: Part V: Usual Activities/ Did you avoid or feel limited in doing some of your usual activities, such as visiting family /friends, hobbies, shopping, recreational or religious activities?
DQOL: Social interaction / Intimacy, happiness with family.
WHOQOL: Social relationships / Personal relationships
P 1: “If I was with her (daughter). You know that would make a big difference.” “She is easy to get along”. “Every day I am with my daughter and that is the best thing that could happen to me.” “I miss being with my daughter. I missed her very much because she is a wonderful daughter.” “I don’t have to worry about anything. She takes care of it. All right.”
P 2: “being well connected to your family and good healthy happy time with your family. I really enjoy being the connection.”
P 3: “My priorities. My grandchildren playing in the tennis court” “my grandchildren are the greatest. I always enjoy my children, but with my grandchildren I have a ball.” “My wife drives me around”
P 4: “My husband is very good.” “What makes your life better? Well, for one thing having a husband that is very understanding make a big difference. That is very important. Yes. Definitely.”
P 5: “My children say we’ve got to get you to the show”. “My grandchildren come to see me, and that is very very nice”
P 6: “I would like to be married again and happily.” “I would like to settle preferably with a wife with whom I can live.” “What makes life worse? Fight with my family. This sort of thing. We don’t do that. I guess I am a little bit stronger than my sons who are obviously younger. They make it easier to be agreeable.” “I have these three sons that are very close to me and they help me through many situations I get into and I don’t get into any bad situations. I have their support and I am often surprised that I do. (laughing) It is very rewarding.” “if I make a mistake, they will correct the mistake.”
P 7: “I enjoy staying with my son and daughter. We get along.” “I think the main thing is I get along with my daughter-in-law and son.”
P 8: “with my grandchildren, son and company coming I have been doing pretty well” “My son said mom you go, you need that. You get ready and go. You’re right and it’s true”
P 10: “We get along very beautifully and we do things together…My kids take after me too”
P 12: “I have my two brothers but one brother does not pay much attention. So the other one I take care of him. And we can go anywhere together.”
P 13: “I get along with K. (son) that is good too.” “He is very good to me K. (son) and W. (second son) is very good to me too, but in different ways”. “They (grandchildren) come over”. “I want to go see my sister because she is 90...I like her.”
P 14: “But well we'd always have the Shabbat. If we make it. If the children make it but it is a family here, part and parcel, a family...What makes my life better? Well I think that being yourself makes a big difference to my manner of living. For example you have got to have a lot of people around the table” “I'd like to be with family. That is number one. When I say family it is the wife and children” “And I have love and respect for my grandchildren which is also a very big factor” “I've got to rely on my wife to take me where I want got to go.”
P 16: “Right now to see my wife was, she has been so wonderful to me and I wish life compensates her for the things that she's been doing for me. You know this is something I'd love to see happen in our lives... I mean the wife, sure you marry her for so many years, it will be about fifty years. You know I'd love to see that she gets the rewards....Compensated for what she is doing.” “The one that was here the other night with us and invited us for dinner and we went and we had a nice little family eating together and all that.” “You surely don't feel like your are, if it was not for her, because of my wife, a good feeling she creates. So much on my mind. She does so much for me but then at her expense. It's too much on her I think.”
P 17: “In general I enjoy life especially with my wife. We met when we were sixteen and so we chose off getting married until I got through. She's a good woman. We will have been married sixty eight years this year I think. Fifty eight years this year. She has not beaten me up and I have not beaten her up her up. Oh we get along very well together... I can almost read her mind, what she is thinking you know.” “She makes life pretty good for me and we have been happy together.”
P 18: “Well I think I have a very nice family. And we like staying in touch with them and our grandchildren.” “Well if I didn't stay in touch with my family I'd be unhappy... It's important to us. Our family is important to us...I've got one son and his wife who live near here and they have two girls. We like to see them. You know they come over here quite a bit.”
P 19: "Very important that I should have what I need, this is what I need he is a very good son, I only have one and a good one”. "When he walks into the house I am happy, when he is out of the house I am unhappy”.
P 20: “Family is very important, my children, grandchildren, that is important to me”.

Connection to family / Family support (Family members: 15, 75%)
EuroQol: Usual activities / Family
QWB: Usual activities / Did you avoid or feel limited in doing some of your usual activities, such as visiting family/friends, hobbies, shopping, recreational or religious activities?
DQOL: Social interaction / Intimacy, happiness with family
WHOQOL: Social relationships / Personal relationships
FM 1: “I think she always wants to be with her family. I think that’s important. You know to be with the people she likes.” “She does respond to close relationships. She enjoys company.” “I guess that would be having more time to spend with her family.”
FM 2: “I think this retirement residence is very good for her. Before she was living at home with my brother and his son. They would come home at night. They would have supper with her and then ignore her for the rest of the day. They’d go downstairs, watch television. Then obviously they wanted to watch something differently than she did so they would watch it on their side downstairs.” “What we had was an 80 year old, a 50 year old and a 20 year old living in the same house and there was conflict all the time” “Seeing her two daughters who both live out of town with their families and so forth would be very helpful.”
FM 3: “Of course, if I say we are going to the grandchildren he is in the car before I get it open because the grandchildren are his life now.” “He lived for his children and he lives for his grandchildren.”
FM 5: “just seeing her grandchildren. I guess. It is very important to her... The kids come around maybe once every couple of weeks. She sees them once a week when she goes to my sister’s. I would say she sees them once a week”
FM 8: “My oldest brother lives with me too. And he would not spend a nickel to come back so that aggravates her a little too. We are away from that because that is why I
actually started going shopping. She puts something in the cart and then he takes it out. You don't need that.” “We are very lucky that we got four children all grown up and they are very very supportive. You can't ask for better children.... but basically they are very supportive. It is very important to have family support....They do a lot of things together. You know they go out together and they always considered her a very close friend.”

FM 9: “He is happy to be with us.” “because he knows me and my wife would take care of him.”

FM 10: “She wants me she is happy if I take her out to the mall to have coffee. Drive her around. Play the Patsy Klein tapes in my van. That is what she wants to do all day....She wants to be with you 24 hours a day.” “if I wasn't here looking after her, she would be in a home”

FM 11: “Every night when we go to bed, we give a kiss and a hug. We kiss and hug”

FM 13: “there is always people coming and going. She needs that, it's too quiet at her house, it is boring.” “So she knows there's been a problem with her son and that makes me, she knows it internally but she also knows that she just can't understand what's happened but she knows he does not see her.” “I think the fact that she gets paid a lot of attention. The fact that I get there. She's got her purse on her arm, she is ready to go. So I think that, that I mean I take her to the Zoo. I take her to Riverdale farm. Go down to the lake. Two days ago we went down by the exhibition and we were watching the boats go in and out”

FM 14: “think she is just happy to be here because the family is here. It could be any day of the week. The fact we like having her, I am sure she appreciates that.”

FM 15: “He is a family man. The most important thing in his life is his children, his grandchildren and they are wonderful to him. They've come and they take him out at night and my son in law comes when he can and takes him with him. He wants to be involved with the family.” “So mostly I take him with me. I'm going shopping I take him with me. I phone from the store. It is black, I am at Fairview Mall. I phone him from the store in Fairview Mall and say we have ran short of milk. He does not say to me why he is going to get it. He goes across and he goes to buy the milk. It is one day of me getting him out. But I do take him mostly with me when I can just to get him out.”
FM 16: “first of all he'd like to have his children all the time with him. Children, sister, brother, everybody must be with him all the time and nephew. And understand I mean have them with him everyday...He's a person that always wants to be with family. He's a person who needs children and wife and you know....We were always you know helping one another and doing things just about together.”

FM 17: “he is very caring towards my mother. That is very important to him too.” “His concerns, well my mother of course is a top priority for him. That she looks good. That the basic needs are met. And that they can live here together.”

FM 18: “We've been happy with our family” “We've been very happy actually, fifty eight years. Fifty eight years. Fifty eight years, the big thing is we are still talking to each other....Well the most important things are her family and her health I would imagine.” “Well we've kind of accepted it. You mean you live together, you kind of accept it you know. You try and compensate for it and that is what marriage is, you compensate for each other. And she tries to help me and vice versa. She can't remember something I take over and try.”

FM 19: “He wants me to stop working or to take him with me. He likes the coffee shops at the mall, as long as there are no stairs. I take him out when I can, now that I am not working I take him out places”.

Social interactions (Patients: 11, 55%)

EuroQol: (Limited: does not include friends) Usual activities / Family

QWB: Part V: Usual activity / Did you avoid or feel limited in doing some of your usual activities, such as visiting family/friends, hobbies, shopping, recreational or religious activities?

DQOL: Social interaction / Social participation

WHOQOL: Social relationships / Social support

P 2: “I a member of the group book” “I think that these gather togethers with people are really good.” “We are sort of enjoying chatting together” “we have a discussion, we get to meet other people” “I am getting together with people and we are becoming good friends. We are going to each other’s houses to practice.” “I am getting too busy. I got an email this morning before 9:00 a.m. because I had to leave at 9:30 a.m. and I had to be
home soon for the meeting to meet everyone downtown and I have been in touch with a lot of people because of these 10 to 12 tickets for tonight and I will be whipping home and then I will take the little boy to his piano class and then we’ll be getting together to that place.” “Now a lot of my friends aren’t around any more. Now that they are retired many have traveled so much, so we are not as close as we used to be.”
P 4: “I visit with friends. I always make a point of that every week...I spend time with friends”
P 5: “Some people aren’t very nice to older people and some people are too nice, you know what I mean” “I still get cards from some of those people, some that are still living” “Because for an older person to get friends is very hard. One likes to talk and I don’t talk too much about this or that. They criticize too much. So I don’t. When I meet a person and they talk to me, I say it is very nice. Thank you very much. I will see you again I hope. That’s all. But you don’t have many friends now then? No, I don’t have any. Somebody just called me one lady that I had known from when we were kids together and we went to school together. She is still living. Their husband’s gone like my husband’s gone. We sometimes talk to each other. But you would like to have more friends then? Well sometimes but for older people to get friends they criticize too much.”
P 8: “I had a few invitations from my friends and family about weddings that are coming up and all that so that’s all right” “If you were talking with any of my friends they would say that Mary has a good sense of humor and she is never at a loss of words. This is from my friends who love me. I take it. It is true” “She befriended me and I befriended her. We got together” “I have lose touch with a lot of people because everyone has their own things to do, you know”
P 9: “I have a lot of friends...But sometimes when you are ok the friends are there, but if you are not okay today or tomorrow, you finish your life alone”
P 10: “We have dear friends who are not longer here, but the friends that we have very good relations with and we enjoy it. We enjoy people and I am a people person”
P 12: “And I go to visit family and friends.” “Meeting, socializing...Going to parties and so.” “Entertaining friends at home...entertaining people at home. They drop by, you have a nice discussion...Socialize.”
If I move to London I would have to make new friends. And that is a concern? Yes because in London they are not like here...I was introduced to a couple, and then they did not say hello or nothing. So they are colder? They are colder, but some of them are nice.”

We belong to a seniors club at the church. I go to church and I have a friend that I go out a lot... My friends. And going to church. Meeting people there. I've gone there all my life. Known them for about fifty years.”

I enjoy the company of people, being together with people.” “if I'm speaking my mind when I go to the day program then I love to talk really.” “I have some friends who can go fishing. I could go out fishing, which I way back I used to do but not any more. But if they go out swimming, I can't swim.”

I correspond with a lot of friends in Florida. We sold our place there two years ago.”

Social interactions (Family members: 11, 55%)

EuroQol: (Limited: does not include friends) Usual activities / Family

QWB: Usual activity / Did you avoid or feel limited in doing some of your usual activities, such as visiting family/friends, hobbies, shopping, recreational or religious activities?

DQOL: Social Interaction / Social Participation

WHOQOL: Social Relationships / Social Support

FM 1: “Her social circle became quite small”

FM 3: “He has never been a very sociable person. When he was with his own friends, it was fine. We have friends that we created through me and their my girlfriend and their husband know. He will always say I don’t have anything to talk about. Because none are in the same business as he and he did not have a common thread to connect to them.”

FM 4: “Mainly her social sphere” “And social active, I think. Yes, that’s right. Not withdrawing not simply because she has this problem. She certainly doesn’t wish to withdraw. She always likes being with people.”

FM 5: “Her friends have shied away because they are getting to that age too. They see what they might come to. So they want to avoid it. And Alzheimer’s you know can be very trying because it’s the repetitiveness that can get on your nerves and I don’t think they don’t have much patience. She has friends, but they don’t come around often. They
see what’s coming and they want to avoid it. That’s unfortunate. Because she realizes that they don’t come around and she gets very angry. But that is the way it is.”

FM 8: “And I say she has her circle of friends gets a little tighter as you get older. She has one friend where she will be going this afternoon. She goes every week and sometimes more than that. She knows and she is just wonderful with my wife.”

FM 10: “She did not really have a busy social life. She didn’t have a lot of friends. She didn’t go a lot of places. So now, it is even worse”

FM 12: “He is a very social person. He tends to be happiest when he is with people and particularly with people that are at least at his level or even better. I think that if he is at Providence and there are people much worse off than him, he finds it difficult to relate”

“I have to hold him back and remind him that he is now retired and he is not able to be involved in everything that he was at one time” “I think that the people that he used to associate with are too busy in their own life to give him the support that I think he needs, and I think that he finds that difficult”

FM 14: “Sure because she does not have someone there all the time. The friends aren’t there as often and she used to be very active socially.” “I think when people are around even with that talk and activity going she is just happy to be listening to us.” “It is harder and harder for her friends to come around when she asks the same questions over and over again. They come, they do not come as often as we would have hoped…I guess keeping the friendships would be important.”

FM 17: “Occasionally meets with friends for lunch but that might be twice a year. He does correspond with people, writes letters and stuff. And speaks to them on the telephone.”

FM 19 : “He meets with a rabbi and one of the other ladies, he likes those kinds of discussions, because he is a learned man. He likes that, with rabbi K, Monday night discussions he goes to classes, talks to people”.

FM 20: “I wish she would see friends more often, she used to go out a lot to her friend’s but now she does it less. I know a friend of hers always calls her and tries to take her out, sometimes she will go, if I encourage her”.

17
Withdrawn / Loneliness / Boredom (Patients: 5, 25%)
QWB: (Limited) Part I: Acute and chronic symptoms: Have you felt lonely or isolated?
DQOL: Two items: Discretionary activities / Loneliness or Isolation. Discretionary Activities / Boredom.
P 2: “Things have sort of bumped up again which keeps me going because it is certainly different from being housebound and not with people. That is a real downer in my opinion.” “I think that really helps because if you are alone in your house all the time you really get burned down.” “It is better than being housebound and bored”
P 6: “I was telling the doctor this a little while ago, that the only thing I feel really bothered and don’t do nothing and when you live alone it is not hard not to do nothing.” “I don’t know, just you are alone and you have to make it now.” “I guess that I am alone otherwise. I don’t have many friends. I am not a friend maker, although I talk enough that you would think otherwise and fairly easily.” “I don’t like living alone. I get lonely and don’t do anything. Then I get a little bit cracked.”
P 11: “I cannot do anything... What could make your life better? Well, finding something that I could do. Knowing that I could.”
P 13: “Well I haven’t been going out that is another thing that is a bad thing. I did stay in bed and get up and clean and then go back to bed, cause I used to go to bingo every night, and now I am not going. So you would stay in bed a lot? Yes that is a big change”.
P 20: “I don’t like to be alone I like to be with people, I always liked people”.

Withdrawn / Loneliness / Boredom (Family members: 13, 65%)
QWB: (Limited: Does not include boredom) Part I: Acute and chronic symptoms: Have you had feeling lonely or isolated?
DQOL: Two items: Sense of well-being / Loneliness – isolation. Sense of Well-being / Boredom
FM 1: “she feels very lonely”
FM 2: “So she really had very little interaction with anybody except on a weekly basis with my branch of the family because she comes to our place for dinner every Sunday”
FM 3: “but I think that because he’s in the house so much. That he’s not active and so I don’t think his quality of life is good.” “And I felt bad for him because he was sitting
there. He did not want to leave the room or do anything. I don’t think his quality of life was good.”

FM 4: “The only limitation would be somewhat I think she was very vivacious before and she still can be but she will not in a group feel as confident because she may not be able to get her words she wants. So that holds her back in a certain amount.” “The only risk you see there she would withdraw because of the social difficulties. Yes. We go to a book group and now she does not speak up as much as she used to. She will have conversations with the group and then there will be conversations with the individuals. She will be certainly talking to people individual, but she doesn’t speak up as much than certainly as she used to.”

FM 6: “The whole day he is sitting around the kitchen table and you know he is making lines and lines and lines.”

FM 9: “His life was probably more active certainly before my mother died.”

FM 11: “She used to be very active...We spend more time here and that is sort of gone”

FM 14: “On the weekend she is very bored. She complains about nothing to do.” “Yes other than being very bored. I think the biggest problem is my father died almost a year ago and from that point on her memory has changed significantly and she is alone.” “Boredom and being alone.”

FM 15: “He is very, very disillusioned because he has never sat all day or got up in the morning with nothing to do....Today it is sheer boredom. He does not know what to do with his day. He’s always asking me what I am doing....Today he is a man of eighty six and very, very bored with life. I took him to Baycrest. We showed him around. To go twice a week just to stimulate him. We have an expression in South Africa, he is going to seed. Like when a flower stops blooming it makes seeds. That is all it is good for and this is what is happening here.” “I can only tell you he is bored out of his wits.” “I can just say that there is sheer boredom here” “I only know that he is here all day. At least I take him out....He’d be very happy now to sit. He has got a little den with a T.V. there. He’d be very happy. You give him three meals a day he’ll sit there. And then at eight o’clock at night he’ll go to bed. He’ll be very, very happy.”

FM 16: “Well I think he is bored, very bored”
FM 17: “He pretty well spends most of the time here inside the apartment though. And feels he can’t exercise because of his heart condition and low energy level. But I perceive in a way, I think he’s a more social person but kind of the situation I think he doesn’t get as much social interaction as maybe he needs.”

FM 19: “It’s nice he gets away (to Baycrest), not to be alone by himself”.

FM 20: “Maybe she’ll be bored at times, I try to encourage her to do things, not to withdraw”.

Loss of competence / loss of knowledge base (Patients: 6, 30%)

EuroQol: Usual activities / Work

QWB: Part V: Usual activity / Which days did you avoid, need help with, or were limited in doing some of your usual activities, such as work, school, or housekeeping?

DQOL: Discretionary activities / Work / Productivity

WHOQOL: Level of independence / Work capacity

P 1: “I used to work and had a very good position, but now I would not accept it because I could not remember, you know, what I should do. There are a lot of people who don’t retire. People live until they are 75 and they don’t retire. I worked most of my life… Yes. Through high school, I went to work and I was a good worker… I miss that.”

P 3: “All of electronic that I used to be quite knowledgable. I would recall that people used to ask me and now I find that I don’t recall all. In other words, there is a computer in my den and I honestly cannot remember how this thing goes together. It is all apart because I took it apart to repair it. Now, I can’t remember how to put it together”. “I was very good at it. Yes, I was supposed to be quite good at it and that bothers me more than anything.”

P 5: “I would like to work again, but they won’t keep me. I’m too old.”

P 10: “I don’t know if it would be as easy for me to be able to administer my job as effectively as I did then”

P 19: “I was a Hazan (synagogue cantor) for fifty years, all I can tell you is I had a very good voice, the only thing that hurts me, is because I can’t sing as well as I used to”. “I used to sing beautiful, three shuls, they all liked my style and my interpretation.” “It hurts
me I remember most of the songs that I used to sing when I was a kid, but I can't sing them the way I used to”.

P 20: “I could do 20 things at once, solve all the problems but now I get confused, I can’t organize a big dinner or something like that, that bothers me”.

**Loss of competence (Family members: 1, 5%)**

EuroQol: Usual Activities / Work

QWB: Part V. Usual Activity / Which days did you avoid, need help with, or were limited in doing some of your usual activities, such as work, school, or housekeeping?

DQOL: Discretionary Activities / Work - Productivity

WHOQOL: Level of Independence / Work Capacity

FM 13: “Her priorities, to get things straightened out. To work, she wants to work so bad. She had a very strong work ethic. She's always wanted, if you want something you have to work for it and if you work you get money and then you get what you want. She does not understand that she is older. That she has plenty of money and it is about time that she is able to relax and enjoy her money and her freedom and her time.”

**Access to good medical care (Patients: 4, 20%)**

WHOQOL: Environment / Health and social care: accessibility and quality

P 2: “I have a really good doctor, Dr.-----, and I think I am really lucky that I got such a doctor. And I think I am really lucky that he is helping me in whatever he can do and so I am feeling quite positive about that.”

P 5: “But some of these women at Baycrest should be taught a little. They should have someone in to sort of guide them…They should have someone in, someone that would volunteer to do a thing like that"

P 11: “the doctor never tells me anything…He is quite regularly a very very busy man and there is always a line of people wanting to see him and I don’t feel I have the right to really go in and ask him to clarify it…He’s got more to do than talk to me. Is that right? I think there are times when you would like to ask the doctor something maybe at a particular time and we are just not there. We have no access to him.”
P 16: “I explained that to the doctors that came from, sent from Dr.-----. She's busy and you have to excuse her. Of course, she has other doctors that assist her.” “And as I said I am supposed to meet this Dr. ---- in a short while again and I'll express all these feelings to her or to her associate doctors but I have to express them. I have to really tell it to her. Tell them if you can do something fine. If you can’t let her just tell me just the same. I'll have to accept whatever is being said in my case because she is, I trust that woman, she and her whole team. So much, I have so much confidence in her.”

Access to good medical care (Family members: 2, 10%)
WHOQOL: Environment/ Health and social care: Accessibility and quality
FM 7: “He is waiting for an operation. And that takes forever because eye specialist are just impossible to see.”
FM 18: “So now one at a time I think very and the way our system is, they are expected ten minutes or something they just have to talk to you or to a patient. Finish. Next. It's like cattle through the line.”

Living arrangements (Patients: 4, 20%)
WHOQOL: Environment/ Home environment
P 7: “I live in the basement. They don’t interfere with me and I don’t interfere with me. That is a good relationship. It helps a hell of a lot.”
P 8: “I have been living with my son. He told me mom give up your apartment. Come live with me. There were times right after I felt this was not my home….I felt lost”
P12: “I would like to see that I have my own home. My own place.”
P13: “I didn’t want to sell my house, I wanted to stay there, and then they said they wanted to get a nurse to come there to see me, but that did not work out. K (son) sold it, the money is all in the bank, but now of course there is nothing I can do about it.” “He sold everything, the furniture, the fridge, I didn’t think he would sell everything, the washer the drier”. “The other thing is you don’t know who you are getting in with (in a retirement home)”
Living arrangements (Family members: 9, 45%)  
WHOQOL: Environment / Home environment
FM 2: “I think this retirement residence is very good for her.” “What do you think would diminish her quality of life? First, if she had to share her room with somebody else. That would bother her.” “A full room by herself. She gets quite upset when sometimes she hears people talking about the possibility that they are all going to have to share a room. And I say no, no. You got a private room. That’s the way it is going to stay.”
FM 6: “I believe he would be happier if he was like at Sunnybrook.”
FM 7: “I think if he had more stimulation from outside and that is why we think he really does need to be in a nursing home with professional people.” “And he might have something in common with them and remember the war and talk about it. This is the stimulation he needs.”
FM 9: “He lives on the first floor and in the basement. He has his own section and my wife and I live on the second and third floor, so we are right there. We are just seconds away.”
FM 10: “I think what I am trying to do in keeping my mom home is giving her a little bit better quality of life because I have been in nursing homes I have to eventually put her into a nursing home and I know there is no way she will be happy there. She just hates being in a nursing home, so this way with the help of family members I am trying to keep her home. Trying to keep her happy that way. And these day programs have been. She doesn’t really like going.” “What could make her life worse? Being in a nursing home. For sure.”
FM 14: “What could make her life worse? I guess if we moved her from her apartment. That is one thing she does remember. I am not ready for her to, old people there and I am not ready... She doesn’t feel she needs it.” “Well it is very hard when you visit all the retirement homes. We think maybe that’s the way to go but we are not sure. It’s a huge judgement call and we are not ready to make that upheaval in her life without being absolutely sure.”
FM 16: “He said he wanted to go and live in an apartment, where he thinks that I don't have to worry about gardening and that. But I said it is not going to help me in a way because he is not going to leave the apartment and I have to be sitting there in the apartment all day.”
FM 17: "I guess being hopeful that they can stay here in this place. With assisted living assistance caregivers that come in regularly. " "He would like to be in the country where the air is better. He hates the air here. He finds it difficult to breath. But because of services that are here he finds he is pretty well..."

FM 20: "She is with assisted living right now, I hope she will not need a nursing home in the future that would be terrible."

Financial security (Patients: 3, 15%)

WHOQOL: Environment / Financial resources

P 2: "I guess because I would like to have more money because we have been a bit frugal but it hasn’t been bad."

P 6: "I am all right financially" "I worry about money but my boys get more money than they can spend and maybe tomorrow I won’t. So it is financial security. I should say. It is very important. I think anyone who see this will think you miserable little old bastard. Is there any other things beside financial matters? I have to have financial security. No doubt about it."

P18: "Having enough money to do what we want to do. If I want to go and buy a new dress I can go and buy it."

Financial security (Family members: 6, 30%)

WHOQOL: Environment / Financial resources

FM 2: "We are quite fortunate in that she has her own home which she paid for and when we move her out. We invested that money to pay for here."

FM 9: "So for him it is almost ideal and it is much cheaper for him to live with us"

FM 13: "She thinks she can't afford her house. Her biggest concerns are money. She can't afford her house, she is not working, can't afford her house"

FM 15: ""We spend very little. We go out and buy what we have to."

FM 17: "That his funds of course will hold out. Will look after their care needs until they are no longer here."
FM 18: “That made her life better? Well we've been well established through life. We have been fairly secure financially, I've worked fairly hard, brought up four children. Educated them all.”

Feeling useful, valuable to others, helpful (Patients: 3, 15%)
DQOL: Sense of well-being / Feeling useful, valuable to others, helpful
P 2: “they made me the president the second year in a roll, so I have jobs to do with that” “we decided to set up for a new book group and we started that last year for the first time.” “I want to write the email to the guy about my suggestions for what kind of book we should be doing and I have a plan.” “I have to get there early, so I can give the tickets to everybody…” “So I started practicing with him (piano with grandchild) and we did one week and we spend quite a bit of time and it had to be fun but we had to start from the beginning and now he is playing very well.” “my friends and book group were really concerned about me when was in the down thing because I have been talked for quite a while and they were very worried about me. And even when we would have a dinner, I would not speak at all and they were scared about me.”
P 6: (interceding on behalf of son getting divorce) “so I sympathize. I tried to talk to her on the phone but I could not get her on the phone.
P 20: “ I play with the children and teach them things, they like me”.

Supervision (Patients: 1, 5%)
WHOQOL: Environment / Freedom, physical safety and security
P 16: “You get up in the morning, especially in the morning. You get up and you don't feel secure you know. Something is happening....You don't feel safe.”

Supervision (Family members: 6, 30%)
WHOQOL: Environment / Freedom, physical safety and security
FM 5: “constant attention is very very important.” “We do have another caregiver when I’m not home.” “She needs supervision. She knows how to do it, but she needs to be told”
FM 8: “Even my grandchildren, I tell them to keep an eye on your grandmother. No problem grandpa. They do. If we are at a do or something like that, you have to make
sure she doesn’t do something or looked after type thing. Keep an eye on her because she gets frustrated. You know if someone says go in and do something or the time she gets in there she will forget. The kids will help her out and make sure she is looked after. Very important.”

FM 10: “And that is why she needs constant supervision.” “Joity said to her that she couldn’t go and she put her on the phone to me and I said mom, you can’t go out by yourself. You have to have someone with you”

FM 14: “She lives all alone but we do have a caregiver there Monday through Friday.”

FM 19: “I can’t be baby-sitting all the time”.

FM 20: “I worry she needs more supervision than she has now, I try to check on her regularly and we have a nurse”.

D) EMOTIONAL WELL-BEING

Coping with memory loss / Emotional adjustment to the Dx (Patients: 10, 50%)

P 2: “I am trying to keep myself very positive and in fact I believe that having a positive attitude helps you do better.” “if you have a choice I think I would rather have this problem than her problem (sister’s cancer)”

P 4: “Are there things that bother you about having memory problems, about not being able to recall some things? Yes, sometimes, but it doesn’t do you any good if you are going to fret about it, so I forget about it.”

P 6: “I don’t let it bother me. I don’t let it last. I stop thinking about things I know I am thinking wrong about”

P 8: “I am not worried about that too much. It is inconvenient, mind you”

P 9: “This moment my life is very disturbed because I never thought I was going to get this sickness” “They say it is Alzheimer’s. For me, it is terrible”

P 10: “I don’t find it much of a problem as previously. It has been enhanced considerably. I don’t know if I am contributing to those pills you know or concentrating more on remembering certain things maybe that it is, but I don’t worry, I don’t even think about it too much…That kind of comes with age. You don’t remember as much”

P 15: “I just take life as it comes. You live day by day. You do not know what is going to come tomorrow. Why worry about yesterday because it is gone.”
P 16: "something has to be done and whoever can, if they can, if they can do it. Maybe they can't, then you cannot do. I have to accept those things you know. Whatever can be done, fine."

P 18: "it doesn't really bother me, getting older. And you know my favourite saying is my mother said Kate is growing old ain't no joke."

P 20: "I don't let it get to me."

Personal losses (Patients: 9, 45%)
P 1: "my husband has passed away so there is nothing else that would make it any better. There is nothing else."

P 5: "Maybe if my parents were living it could be better. Now that they are gone I miss them. "Some of my friends passed away and the others are not so well you know not to do that or this." "Some of them come to see me and some of them are gone. I ask about them, but they don't tell me that they are gone. Oh, they are away in Europe or some place and you know next time I don't ask about them because I understood what has happened."

P 6: "I have personal pressures. My mother died. My wife died." "All the people I know are dead"

P 8: "I lost a granddaughter at 19 years old. She was killed instantly in a crash on the highway Caledonia.... It is a heck of a time you know and then I will never get over that, it hurts even to think about it. My oldest son... passed away just over a year ago" "They have lost friends and family that they cared for. I guess I don't want to go through anymore of that. I have a few friends left"

P 10: "losing a precious family, death. At this stage we are all going to have to go. It is something you have to be able to live with. It is not easy" "That is the important thing and we have dear friends who are no longer here but the friends that we have very good relationships with and we enjoy it. We enjoy people and I am a people person"

P 13: "Since my husband passed away it has been a big change (becomes tearful). I miss George, he was very good, I didn’t think he was going to go”. "K. (son) took me to the grave yesterday and fixed it all up. Put the stone up.” "People say, oh he left you well, but that is not the point, leaving you well, it’s having him that is it."
P 17: “We are getting on and most of my friends are dead. When you get into your eighties it's something else you know.”

P 19: “One thing I know I can’t have is my wife, I loved her for 65 years, I only knew one woman, that was my wife. I used to be able to talk my heart out I would tell her all. first of all my children don’t speak Jewish, I miss her.”

P 20: “My husband died 10 years ago, I still miss him”.

Personal Losses (Family members: 5, 25%)

FM 3: “As he said all his close friends and dear friends have passed on. They were younger than he some of them. And I would come home sometime and he’ll say I wanted to phone someone, but I didn’t have anyone to call. Her sister died about four or five years ago and he was close with her. She is gone. His parents are gone of course.”

FM 11: “All of her friends are dead now...A lot of her friends are dead. I am talking about her close friends”

FM 13: “One of her very best closest friends died about six years ago and she really misses her....That's because she's always saying, I want to see my friends. I want to see my friends. So if her friends are around I would dig them up if I could.”

FM 18: “Friends, they've all died. I'm just kidding. They are dropping like flies. No, it's true. You know we used to have a, we came from Orillia to here. You know we had a two table bridge club. Then they got down to two and now it's none. And I think of all our bridge group that would be seven, then six of them, then us. They've all died but two, and they are very, very sick.”

FM 19: “My mother passed away two years ago, last July, so sometimes he cries about it, but you know, he has some memories, some of our family passed away too, so you know that sort of gets them”.

Lack of interest or motivation (Family members: 7, 35%)

FM 1: “She doesn’t really make any effort though to say that she wants to do things with my family rather than the people here.” “I think the problem is allowing her to initiate some of her projects.”
FM 2: “She really did not do anything at home except go outside and sit on the veranda and watch the people go by. She did less and less walking" “She did not go anywhere except stay home”

FM 3: “I have a difficult time getting him motivated to go out socially which we do rarely.” “he has lost interest in reading.” “And I do take him but if I say is there some place you’d like to go. Do you want to do something? No. The answer is no. The rare occasion that he says yes. I say let’s go.” “but I wish I knew what I can do to get him interested in something. I can’t get him motivated. That’s the way I’m looking for. Can’t motivate him.” “I would like him to go to something even here at Baycrest for seniors, but I know he would be miserable. I know he would be very unhappy. And I don’t need to make him more unhappy than he is.”

FM 6: “I don’t think he is interested.”

FM 7: “He doesn’t do anything. He has very little stimulation. But it is hard to get him to participate in things. Like it was major like pulling teeth to get him to go down to this coffee shop now.” “It is like trying to drag him some place where he doesn’t want to go.” “There is a change in personality. They change in personality. He has always been difficult. Those are definitely character traits and they have not gone away. They have not been enhanced by Alzheimer’s…. The changes in his personality are the laziness. The not doing anything. The sleeping. He was the opposite before. He had a lot of hobbies and interests. He did a lot of reading. Now, all he does is stare and sleep. Stares and sleeps. That is all he does.”

FM 13: “She is very discouraged. She is very depressed. I think right now she just, we have a hard time getting her out of bed in the morning and my aunt who lives with her, will say come on now Joanne is coming. Will she really come, nobody comes.”

FM 15: “If you left it to him he would never make an arrangement.”

Religion (Patients: 6, 30%)

WHOQOL: Spirituality/ Religion/ Personal beliefs

P 8: “I talk to the Lord….I always said my prayers at night and going to church and there were times when I did not go but I tried to follow religion”
P 9: “Maybe the Lord is good and he takes me before” “The Lord is going to restore me accordingly….The people in the church, they pray consistently for me”
P 12: “Because I am highly spiritual.”
P 14: “Well I've been brought up in a Jewish home but it is that not orthodox, put it that way. I adhere to the main Jewish Festivals”
P 15: “I go to the church, I used to go to always, all my life”
P 19: “Definitely, going to shul is important, because it says in the Sidur or the Talmud, everywhere you go mention his name, and he will bless you”.

Religion (Family members: 7, 35%)

QWB: Part I: Acute and chronic symptoms: Avoid or feel limited in doing some of your usual activities, such as visiting family/friends, hobbies, shopping, recreational or religious activities.

WHOQOL: Spirituality/ religion/ personal beliefs.

FM 5: “Yes, she is quite religious. She is very conscious about the religion. She knows the holidays not a problem. She is quite aware of that. Is it important for her? Very important. Very important.”

FM 8: “I would say my wife is a very devoted catholic woman. Always has been. Always has been and it is very very important to her. Very important. She wants to make sure she goes to church and now you see with her memory she doesn’t remember what date it is to go to church. It is very important. Like my wife has to have a catastrophe for her to miss church. To go every week. That is the way she was brought up and that is always the way she has been. It is good for her to go to church. It is very very good. That is one of her main pillars I guess that she leans on is the church and she is very strong about it.”

FM 9: “Even my father now has started watching the odd watch on Sunday with inspirational speakers. He didn’t use to do that. There used to be a show in the fifties, Bishop Sean which was very famous in the early days of television in the US and Canada, but he has a 40 years hiatus… We will watch it on Sundays”

FM 11: “Well, we belong to a synagogue or temple…so we have that background”
FM 13: “I agree 100%. My mom goes to mass. We go to mass every week. Every week, we don’t miss mass. She knows every prayer and she knows every hymn...It is part of her upbringing”

FM 15: “Yes, he reads in the synagogue...He was brought in a Jewish home...And he has always gone. We had never gone for a small Jewish holiday. That the New Year and the first few days have always been important in our home. On Friday night my husband speaks a prayer with the wine. Shabbat dinner you know, and that’s to me to see that it’s done and it’s fun”

FM 19: “He takes it easy, he still goes to the Shul every day, except for Shabbos, because during the day its a long service, he can’t sit, particularly he can’t stand long, but the evening service which is 20-25 minutes he goes.” “Shul is a big priority”. “If it wasn’t for the synagogue he’d be home waiting for the phone, waiting for me to call”. “If he doesn’t go he daven here”.

Depression (Patients: 4, 20%)

EuroQol: Anxiety - Depression
HUI: Question 14: How have you been feeling during the past 2 weeks: Fretful, angry, irritable, anxious or depressed.
QWB: Part I: Acute and chronic symptoms: Spells of being upset, downhearted or blue?
DQOL: Sense of well-being / Depressed mood, sadness
WHOQOL: Psychological / Negative feelings

P 2: “I could be very depressed and I was”
P 8: “I am in a depressed state, not a lot mind you”
P 9: “I feel tried. I feel depressed” “I don’t want to finish my life without, like for example, I can’t say to you I can’t take this. It is really bad for me. Go to finish like an old blouse, old vent and no address”
P 17: “I felt depressed at times. I’ve got a certain doom but I do not think it is any more than normal people who get depressed. When I was younger, I was depressed just as often but you know what I mean...When I was talking about depression I mean just being sad, not like being suicidal or anything like that.”
**Depression (Family members: 1, 5%)**

EuroQol: Anxiety / Depression

HUI: Question 14: How have you been feeling during the past 2 weeks: Fretful, angry, irritable, anxious or depressed.

QWB: Part I: Acute and chronic symptoms: Spells of being upset, downhearted or blue?

DQOL: Sense of Well-being / Depressed mood, sadness

WHOQOL: Psychological / Negative Feelings

FM 13: “She gets really very depressed. She is on medication. She is on two medications and she gets really discouraged and it is really hard.” “She is very, very depressed since there is nothing to do. There is no work to do, what is the point? She is very discouraged. I would think she does not have a lot of hope right now.”

**Appreciation of art (Patients: 4, 20%)**

DQOL: Sense of aesthetics / Creativity / artistic expression and appreciation

P 2: “I think it would be good to do one really excellent book. Like there was a page in the newspaper of the best books of the last 100 years. So you know that you can look in that list and you pick one of the books that might be of interest. And it might be one of the older ones. And it might be a wonderful book to do. And sometime you read that when you were in university or you read it 40 years ago. You know. It would be lovely to do that book again. So I thought do one excellent important book like that.”

P 5: “I want to see a good dancer. Oh oh, I say I love that. Because I used to dance at a show, you see.”

P 6: “There is a certain amount of music in my family if you know what I mean. Darick is with me. He is a wonderful musician and plays beautifully. He is going to Edmonton to play. I enjoy that music, but I don’t go to it very often.”

P 16: “You mentioned before the interview that you enjoy opera and music. Oh I love that. Yes I love that and I see quite a bit of that and I enjoy that. Singing is something I have always loved. I go down there too. When at the day program they ask me we why don't you sing a song... Anyway I'm not a tenor. I'm not a great singer but I love singing. That's one thing I love to do. That's the only thing I can, sing.”
Hopes for longevity (Patients: 3, 15%)
P 2: “that my mother is 91 makes me feel a bit good.”
P 3: “My whole family has reached the 90’s and I am 81. I hope that I will be there for my grandchildren.”
P 9: “Until I see my grandchildren, some of them, grow up”

Hope for a cure or arrest of the progressive cognitive decline (Patients: 3, 15%)
P 2: “I want to be very healthy. I want to have my brains better and my big hope is being healthy and I am going to stop this stupid problem that I’ve got and preferably stop it is what I want and preferably make it better again.”
P 9: “It is not going to get worse. That is what I think” “Making my life better if I see the sickness not in progress”
P 16: “Well if I had someone that could tell me okay we are going to try our best. Whatever, I mean…we are going to try our best. Not that my life is going to improve all of a sudden because they are not gods. You know, but at least I have a hope.” “My hope that my health will improve more than it is exactly now I'm telling you. I'll wait it out till it is.”

Hope for a cure or an arrest of the progressive cognitive decline (Family members: 5, 25%)
FM 4: “I guess her main hope would be that it doesn’t get worse. She hopes that it gets better.”
FM 7: “he has been getting progressively worse the last year. The last two years he has been diagnosed with Alzheimer’s and / or dementia. He has gotten much worse. In the last few months, it has been an incredible downslide.”
FM 8: “Well, I would think that they would find the cure for this that they are doing now or it doesn’t get any worse. We can live with what we got now with the situation. Sure isn’t the greatest but at least we know it can be worse. You can get by.”
FM 12: “I think the only thing that could make his life better would be to see this go away and you and I both know it is not going to go away. In some ways maybe, his inability to think it through protects him” “He would hope that this is going away, but we know that it is not going to go away”
FM 20: “She is worse, and we know she will get worse as time gets by, there is no real cure.”

Restlessness / Agitation (Family members: 3, 15%)

FM 7: “he is anxious for it to be over, but at home he is restless too. And I think in part the restlessness and irritation has to do with all these physical things that I mentioned.”

“My father gets very agitated when my son visits with my mom and then it’s time to go home and there is still a toy on the carpet or something like that or you know something out of place. Just little things. They really get quite upset when something is a little out of order.”

FM 13: “Like she gets agitated and agitated and sometimes it is better than others”

FM 16: “he will want it right away. Do you understand when he wants something he must get it right away. If we want to go somewhere I can tell him we are going on a day trip a lot of the time but I keep it away from him coming closer to the time or he will never rest. He'll be up and down, up and down you know. So then before we get to go he's too tired, too over anxious”

Frustration/ Irritability/ Anger (Patients: 2, 10%)

HUI: Question 14: How have you been feeling: Fretful, angry, irritable, anxious or depressed.

QWB: Part I: Acute and chronic symptoms: Feelings of frustration, irritation, or close to losing your temper?

DQOL: Sense of well-being/ Anger/ Irritability/ Frustration

WHOQOL: Psychological/ Negative feelings

P 8: “sometimes I get mad because when I don’t want to think of something it is like I am battling with someone inside me…It is like I am fighting. No, I am not going to get depressed and turn on the tv”

P 11: “I get very frustrated…. That makes me very angry…and I am very impatient and that doesn’t help. I am impatient with my wife and that doesn’t help either.”
Frustration / Irritability / Anger (Family members: 10, 50%)

HUI: Question 14: How have you been feeling during the past 2 weeks: Fretful, angry, irritable, anxious or depressed.

QWB: Part I: Acute and chronic symptoms: Feelings of frustration, irritation, or close to losing your temper?

DQOL: Sense of well-being / Anger / Irritability / Frustration

WHOQOL: Psychological / Negative feelings

FM 1: “There is some frustration there.”

FM 3: “It just frustrates him because he has forgotten and you know it was his bread and butter and it’s something I think that he thought he would never forget. He would be able to do it forever. It’s quite frustrating. He is very frustrated just for 5 minutes.” “He has these little explosions at home like over nothing.” “He is angry for 5 minutes and then he has just forgotten.” “His anger span is minimal. I mean he can blow off the top of his head at me sometimes if I say good morning. You know something insufficient like that. And in 5 minutes it is like he never said anything.”

FM 4: “She has a bit of frustration when she cannot obviously recall the word that she wants to use. That seems to be the main problem.”

FM 5: “Sometimes, she gets frustrated. She gets frustrated because she can’t remember. So yes.” “Anger. She gets angry that she can’t do it. I used to be able to, but now I can’t you know. It could be very very frustrating.”

FM 7: “We don’t know how they feel and as far as how he feels like his anger and agitation because now he is on two drugs. One for Alzheimer’s and I don’t know what the current drug is. I knew he was on Aricept and now he is on Respiton to calm him down” “So we have been able to calm him down since he was menacing. He was threatening to kill people, punch them and beat them up. And he hasn’t done anything physical violence, but the concern was that he might reach that point and it’s because of the physical you know irritations and things that are wrong with him and so that was a concern.”

FM 8: “I would say it could get frustrating for her.” “Then she gets upset because she can’t remember what she did with it or where it was, that type of thing”
FM 10: “She thinks that she should be able to just come and go as she pleases like she has always done and she can understand why these people are always around her trying to do things for her. It is upsetting for her.” “She gets a bit cranky sometimes… And she got cranky with me. And she gets mad whenever someone tells her what to do. Whether that is part of that frustration is being told what to do but she has always been so stubborn.”

FM 12: “Frustrating. He used to be very high functioning. Very bright person. He finds it very hard to accept, because I think because his former status in life”

FM 13: “the hardest part is seeing the decline and seeing the frustration and the anger at times.”

FM 20: “She gets frustrated when we tell her she needs to accept the help of a nurse, or when we talk about her illness, she gets upset”.

Sense of Control / Autonomy (Patients: 2, 10%)
QWB: Part I: Acute and chronic symptoms: Feeling of little or no control over events in your life?
DQOL: Sense of well-being / Sense of control
P 4: “that is what makes it wonderful because you are not waiting to do what is going to happen and see what is going to happen.”

P 12: “I have got to listen to all the people telling me you can't go here, you can't go there. You have to get a pass and this is not my lifestyle.” “And I have a lot of things to straighten out in my personal life and if I do not get these straightened out, who can get these straightened out for me?”

Sense of control / Autonomy (Family members: 2, 10%)
QWB: Acute or chronic symptoms: Feeling of little or no control over events in your life?
DQOL: Sense of Well-being / Sense of Control
FM 13: “And she has a public trustee which she just can't understand. She says you know if you have things you are suppose to look after them yourself. Other people won't maybe look after them as good as you can. Well she can't look after things now but she is aware of
that other people sometimes screw people around.… So she is frustrated about things that she can't control.”

FM 17: “Well I think he has control and that is important to him.” “He has control, this is what he wants.”

Fear of embarrassment (Patients: 2, 10%)

DQOL: Sense of Well-being / Embarrassment, self-consciousness

WHOQOL: Psychological / Negative feelings

P 2: “I am not stupid is that I just can’t get the names out.”

P 6: “I am always afraid I am going to embarrass myself.” “I pretend that I have not made a mistake”

Concerns over taking medication (Patients: 2, 10%)

P 2: “I guess a concern I have because of these new pills I am taking”

P 3: “I feel that I am in quite control with the medication I take” “I haven’t had any strokes or any side effects from the pills I take”

Fear of side-effects of medication or overmedication (Family members: 3, 15%)

FM 6: “I don’t know if it is those pills that the doctor gave him and if this is the effects. I don’t know.”

FM 7: “So I don’t know if it’s the drugs or a combination of things.” “Well it seemed that the patients didn’t appear to be so drugged. They weren’t all sleeping. There were different levels and they are different levels of care. Some people maybe need more medication. Everyone seemed to be participating. Every nursing home we went into had a schedule of activities, but it seemed that most of the nursing homes they were sleeping and they don’t have to worry about locking or resisting patients because the patients looked like they were so drugged…. But at Sunnybrook I noticed that people were active. They were doing things”.

FM 9: “Now, this morning he said no more pills for him. No more pills. Because Dr. Freedman gave him pills too. I still have two boxes full. And he said I am not taking no more pills.”
Physical appearance (Family members: 3, 15%)
WHOQOL: Psychological / Bodily image and appearance
FM4: “She looks after herself. That is not her main focus, but obviously to be well
groomed and that”
FM 8: “Always very particular on how she dresses” “The appearance. I would say
definitely. She has always been very conscious and always dressed well and looked well.
I think it is because it is your self esteem.” “I think that appearance is, I think once you
start losing that then you go down”
FM 14: “Absolutely. I do not think she is aware that it's got a stain on it very much…it is
very important for her to have to go away and to look good…we sat at Dr. ---- office
waiting. And she looked at the people who I am sure are her age and she said that lady looks
old. Look at all her wrinkles. She does not foresee herself like that.”

Fear of being alone (Family members: 3, 15%)
DQOL: Sense of Well-being / Fears
FM 1: “She has a fear of being alone. That seems to be a concern” “Sometimes she will
call to say she feels frightened and she doesn’t want to stay alone.”
FM 10: “And whenever I leave, she says are you leaving. Aren’t you coming back? She
is really concerned that she is gone to be left alone. I think maybe she must sense that
something is not right with her because she needs that security of knowing that she has
someone there.”
FM 19: “Every time I go out he is a worry-wort, when am I coming back (he wants to
know), right now because my mother passed away a couple of years ago, he doesn’t like
to be alone, we have a couple of women coming in, …. All the other time he doesn’t like
to be alone”. “If I had my cell phone he would be calling all the time,… why don’t you
come home, why don’t you come home, all the time”. “I tell him you have to go alone (to
his activities) without me all the time.”
Sense of stability, sense of stable future (Patients: 1, 5%)
P 4: "To keep managing as we are doing right now just until it's time for us to flop over."

Appreciation of nature (Patients: 1, 5%)
DQOL: Sense of aesthetics / Enjoyment- Appreciation of beauty - nature.
P 2: "I love that environment. It is very beautiful" "I don't believe there is such a thing as a God. And I go to the natural environment, I look up at the sun and the sky, I think it's very beautiful.

Relief from job related stress or responsibilities (Patients: 1, 5%)
P 6: "I suppose it is very easy now. I worked under stress all sorts of pressures. Most of those have gone away or I went away. I am not sure. (laughing) I did a life of discipline in the army for 30 years longer than that. Since then, I am my own lord and master." "I certainly worked under strain. That is no longer the case"

E) FUNCTIONAL WELL-BEING
Recreational Activities/ Hobbies/ Leisure (Patients: 12, 60%)
EuroQol: Usual activities / Leisure
QWB: Part V: Usual Activity/ Did you avoid or feel limited in doing some of your usual activities, such as visiting family/friends, hobbies, shopping, recreational or religious activities?
DQOL: Discretionary activities / Hobbies, recreational activities, vacations
WHOQOL: Environment / Participation in and opportunities for recreation - leisure
P 2: "I think there was a good reason for taking a day off and I think when you are doing seven days a week all the time, you need to have a bit of a rest. So it doesn't bother me that I am tired and I feel get a good rest and here I go again." "That was a good outing for me" "Like we are working and we are trying to learn, but we have fun doing it." "To be able to be in that environment with people and practicing something where you can learn and you have a book so you can keep checking and you can go home and review it and everything."
P 3: “when I retired I suddenly found that I can paint or draw and I have been involved with that. I continue on with that... I draw pictures. I paint figures. I paint portraits. I found that I enjoy doing it as opposed to having it” “the most interesting thing I do is paint” “We have a dog who drives me crazy. Every night I take him for a walk. We walk for 15 to 20 minutes.”

P 4: “And we both play a lot of golf so we are busy and occupied.” “We play golf quite a bit, sometimes too much. That’s all right”

P 7: “I like doing crossword puzzles. I like reading. I like time to myself to do what I like.”

P 6: “I am waiting two weeks to a month to playing golf with another son. So I don’t expect to win but they will know that I am playing.”

P 8: “first of all in the mornings we talk about the news, discuss the newspaper and we discuss what’s in the paper. Well, to me the whole thing is depressing but anyways...and then we play games like bingo, all those different kinds of games and we have little talks about this.” “I joined the club in January last year. It is wonderful. It is wonderful. They have so many things they do. I can’t praise it high enough. I still go and will keep on going as long as I can unless something comes up”

P 10: “Well, for example I have a whole sheet of activities that are going to take place and we will be involved. We will be going. If there is something going on, we will be there. We don’t sit back. Let me put this way, I am not a withdrawn individual. I am outgoing”

P 12: “When I am out, I go out, I dress up. I feel very nice and I dress up and I go out.” “Okay, well when I’m at home I dress up and I go out. I have a nice meal and I come back in...I go to the movies and so.” “Yes, the outdoor activities.”

P 14: “First I am so glad that you people go mad on sport. That’s the biggest factor of recreation from what I can see. Whereas in South Africa it was just a bi pass, that is all.” “I actually do not stay home every day. I stay home some days more than other days but the point is this. That I feel very comfortable in my own home...Well my zest for life has changed from when I was a young man. Today I’m an elderly person and I can't partake in the other things you notice for zest is there.”
P 16: “I can go to the day program but recently these last few weeks I haven't been able to go out... I love to go to these places... But when I can't it hurts. It hurts. It is not a nice thing you know.”

P 17: “Well it is pretty quiet. We go out for walks every day”

P 19: “I go to Baycrest they are very intelligent, some people speak very good hebrew, we go to meetings.”

Recreational Activities/ Hobbies / Leisure (Family members: 14, 70%)

EuroQol: Usual activities / Leisure

QWB: Part V: Usual activity / Did you avoid or feel limited in doing some of your usual activities, such as visiting family/friends, hobbies, shopping, recreational or religious activities?

DQOL: Discretionary activities / Hobbies, recreational activities, vacations

WHOQOL: Environment / Participation in and opportunities for recreation / leisure

FM 1: “She has not participated that much, I don’t think, in some of the activities.”

FM 2: “I know it has because she goes on almost all the bus trips. She looks forward to them. Last week, she was on the Dini Patti show. And really enjoyed that. She has been to the Harland Globe Trotters basketball team and she goes out shopping with the group. In here she has widen her horizons. I think and all of us think that it’s the best thing for her and it has been very good for her.” “Her immediate priority is for the weather to get better so that she can get out and walk.”

FM 3: “We go out for dinner or have a bite to eat.”

FM 4: “And obviously when she was working she did not have as much time, so now she is picking up activities to fill in. In that sense, she is broadening out.” “She is quite active. She is involved in many activities.” “I would see it as being keeping active and contacts with people. She joined. She goes on a walk every Tuesday morning with a group university women from there. They have various activities.” “So remaining active is one of the most important.” “She is taking lessons in bridge, etc... She is broadening out and now has more time” “She has her bridge also which she also goes to lessons and also plays bridge as a learning experience once a week.”
FM 5: "She goes to the club twice a week now. "She goes out a lot...She goes out to nice restaurants and she goes out a lot" "She goes out for walks with her"

FM 6: "He is going to the Day Centre...and he liked it" "They do woodworking and all kinds of things like you now they watch tapes, they talk together and do things. So he's happy to go there."

FM 8: "It has cut down into her golfing and the rest of it." "One of the things that is the same is the golf. My wife has never been a good golfer, but she enjoys it. She took it up very late in life, but she enjoys it. And we belong to the golf club. She only plays with one woman and this woman has got Parkinson's type of thing. I say you have to talk to these other ladies about arranging a game for another day because this girl and the same with her. She used to play before this happened she played with quite a few ladies. Basically all she would play is three or four times a week regular."

FM 9: "His love is cribbage. If he could play cribbage for seven hours a day, he would be happier." "He says he would like to play golf and he would like to try curling. So maybe I could take him to miniature golf and curling... But I mean he likes to get out of the house to do things...He never complains about the activities, so I know they are important to him." "So my perception of him is that he is very happy and part of that is coming to Woodgreen four times a week and he also goes to Senior Link activities at least twice a week and sometimes three times."

FM 10: "Not being able to go for walks. That is all she seems to like to do"

FM 11: "Because of me, we don’t play golf. We used to play golf. She is a much better golfer than others...She enjoys television. She enjoys going out with family, children and grandchildren."

FM 13: "when we are out she has a wonderful time. Yesterday we went up to Edwards Gardens and we walked along...So she is very happy watching all the activity even though it was very quiet there... Every day we go some place. In the winter time we do a lot of mall walking. I take her to a mall and we will walk around for maybe fifteen or twenty minutes."

"But she enjoys going out. She enjoys being with people and I've tried to take her to a day program up at the health station." "You know we go down by the airport a lot. It is great, lots of birds, lots of people, lots of airplanes and lots of boats. You get everything for the price of one sitting there for free. In the winter time we'd feed the birds but don't tell
Ministry of Environment. We take loads of bread down and we stand where the sign says do not feed the birds.”

FM 14: “I guess being busier, however, she does tire a lot so I am not sure how much busier.”

FM 17: “I mean he likes to read. I would say that is his main activity….So he likes to watch movies on T.V. Saturday night.”

FM 19: “He likes to watch baseball or hockey and once in a blue moon a football game. Mostly baseball and hockey but he doesn’t understand football. I got him extra channels from Rogers with extra channels with sports. I wanted to try it, it is cheap, so I asked him, do you want me to keep it ? or do you want me to give it back? No, no he said keep it (laughs).” “He goes to Baycres day-care, we are trying to get him more days there to go in, to get away from it all. We started only with two days because he didn’t want more, but now we are going to talk to him about increasing”.

Driving (Patients: 6, 30%)

QWB: Part III: Mobility: Which days did you A. drive a motor vehicle? / use public transportation?

DQOL: Mobility / Travel in the neighborhood and outside of neighborhood - Public transportation

WHOQOL: Level of independence / Mobility

P 2: “I can drive the car well”

P 3: “It bothers me that I can’t drive anymore. I feel I can drive quite nicely”

P 14: “I then drove a motor car. I used to drive with my wife.”

P 15: “It's down on Hiawatha Road. Just to far for me to go now. And I take buses…. Have to take a cab.” “I get a ride there usually. Or I either take a cab down and I get a ride home.”

P 16: “Driving, I am not permitted my doctor stopped me and he says in my condition. Knowing the facts today as the doctor says, you should be happy. So I am saying you should be happy that your not driving today because the traffic out there is not what it used to be. But it makes you sad”

P 17: “I would like to get out more but I sold my car to my son. I figured with these attacks I thought I wouldn't really be safe for me to drive. So I haven't been driving for the last two
years, I miss that. We used to drive to Florida and back.” “I’ve really don’t miss not driving a car because everything is so handy here. Don’t have to go longer than two or three hundred yards for anything though. You have got drug stores, post office. The grocery store is across the street there…No we don’t have any trouble but bringing up other people to do it for us. Brought home four bags of groceries yesterday.”

Driving (Family members: 4, 20%)

QWB: Part III: Mobility: Which days did you A. drive a motor vehicle; B. use public transportation?

DQOL: Mobility / Travel in the neighborhood and outside the neighborhood - Public transportation

WHOQOL: Level of independence / Mobility

FM 8: “She did does all of things on her own like she can still go out and drive in the daytime. She was never good on directions any ways.”

FM 11: “She can’t drive anymore…She is no longer able to drive”

FM 16: “And driving, he wants to drive a car. That bothers him a lot.”

FM 19: “He stopped driving when he was 82-81”. “Those are the things you give up with time”.

Exercise (Patients: 6, 30%)

P 2: “I try to go to the YMCA. Like today I did not have time to go. I was there maybe two days ago because I go to the acqua fitness stuff. I did exercise at home this morning and exercised yesterday with the tv where you do a lot of stuff like this. I think that is another factor. I think it is very very important that you have to keep yourself. Exercise and strong and helpful and if I get really tired and burned down I feel that I havenot got enough exercise. And when I do that exercise, I have much more energy and so I do a hell of a lot more.”

P 6: “At my age, I should not be thinking athletic sports but I do.” “Swim a lot. I have this pool in the building I live in.” “So I enjoy that. I feel good physically. I walk a great deal. I walk until I am bored.”

P 8: “Then we do exercise”
P 14: “I can't participate in sport any more because of my age and ability and that is it.”
P 16: “I would say no, why walk, but it is necessary. It is important for your health and you should do it you know.”
P 19: “I go to Baycrest, we do a little exercise.”

Exercise (Family members: 2, 10%)
FM 7: “He doesn’t exercise anymore. He doesn’t get any exercise.” “You know when you don’t exercise you are more tired.”
FM 11: “They are wonderful water exercises for women downstairs in the pool. She does that on a weekly basis. Yes, three times a week.”

Self-care activities (Family members: 6, 30%)
EuroQol: Self-care
HUI: Question 13: Ability to perform basic activities
QWB: Part II: Self-care / Did you need help with your personal care needs, such as eating, dressing, bathing, or getting around your home?
DQOL: Daily activities / Self-care activities
WHOQOL: Level of independence / Activities of daily living
FM 5: “She gets up. She brushes her teeth. She does pretty well by herself. She gets dressed by herself. That’s all.”
FM 8: “She can dress herself. She can feed herself. She bathe herself”
FM 9: “As long as we are there to feed and to get his clothes ready everyday and make sure he shaved and the homecare worker or whatever it is called under the new set-up she is very helpful as well and that is social as much as it is practical.”
FM 10: “we did not realize my mom had a problem until the bills were piling up. Because she always paid her bills on time... I would say now that she cannot cook...bathe... She pretty well cannot do anything for herself. I do everything for them.”
FM 14: “Bathing now she needs a reminder sometimes. Sometimes she gets up and bathes on her own. Sometimes it just seems the caregiver will have to remind her. Dressing, putting on the jewellery, no problem. Noticing that her clothes are stained, yes she does not
notice that but I mean that could be her eye sight as well. When she was well, she would never put on something that had a stain on the front.”

FM 19: “We had two women, but recently we have had to increase to two hours in the morning and one at night. For a while he didn’t have nights. To make him supper, breakfast, lunch before he goes away, give him a bath.”

**Instrumental activities of daily living (Patients: 3, 15%)**

*EuroQol*: (Limited: Does not include finances). Usual activities / Housework

*QWB*: (Limited. Does not include finances). Part V: Usual activities / Did you avoid, need help with or were limited in doing some of your usual activities, such as work, school, or housekeeping?

*DQOL*: Daily activities / Instrumental activities

P 2: “really important to me is keeping the house because I don’t want to hire someone to come in. I always want to have the house looking pretty well, perfect because it saves a hell of a time. I learnt some ways to do that to keep it clean all the time, so that you don’t have to spend so much time doing housework.”

P 15: “And then I’d be fine if I look after myself, that is important. Like I do everything. You know if I need to do something during the week I do it. Like I make my bed. I am putting the laundry away now...And then I clean the sink and all what you have to do.”

“Well for instance I could not wash the floor now and I use to do that. Things like that. I can get my own mail. Keep my place tidy. I do my own cooking and I have a dinner every night. I eat well.”

P 17: “I like cooking and I used to do a lot of it. My hand is quite shaky now and it interferes but I still do cook.”

**Instrumental activities of daily living (Family members: 14, 70%)**

*EuroQol*: (Limited: Does not include finances). Usual activity / Housework

*QWB*: (Limited: Does not include finances). Part V: Usual activity / Did you avoid, need help with, or were limited in doing some of your usual activities, such as work, school, or housekeeping?

*DQOL*: Daily activities / Instrumental activities
FM 1: "she used to be quite independent so I think that the fact she is no longer carried that on. I think that she doesn’t feel happy about that. She misses you know that form of independence." "The loss of independence is the main problem. When she had her memory, she was going out every day doing things on her own. She was reliable. She could pick and choose what she wanted to do." "She is no longer able to do her own things" "Go to the bank or go downtown or find some activity that she can generate so that she can have something to plan around her day." "It is very hard to help her plan." "She realized that it was not safe for her to go out on her own"

FM 4: "She does not have any major limitations. No major limitations."

FM 5: "She depends on me a lot" "She does a lot of the house stuff quite nicely. So she’s not bad" "Well, when we go shopping, she picks out the bananas. She knows about the shopping and groceries. At home, she makes her own bed in the morning." "She does not do the housework anymore or the washing or washing dishes. No, but she can cook. She can cook as long as she has supervision. She can do it very well. Okay. She still remembers the ingredients that go in. She knows that."

FM 8: "because she has not made arrangements. In golf, you don’t usually go up and see if you can get a game. It happens the odd time. Sometimes you can do it. Most time, they already got their four sons. That is the most major thing." "and she can still hit the golf ball and things like that." "We do a lot of it together like the cooking... We do basically a lot of that stuff together. And I again am the leading hand in these things because she doesn’t with her memory. We work together on the getting the dinner and cleaning up and things like that and shopping type of thing."

FM 9: "He expected to go into a home when my mother died and he knows he is dependent." "So he was a little more himself then because he was concerned that I was taking control. He could see that. We had a neighbor who was borrowing money everyday and was never paying us back so I took everything so he did not have money etc. There was resistance at the beginning to that but that has diminished. Either he has deteriorated or he accepts the fact that it is easier this way. So but other than that it has been a couple of years. Where is my wallet? Where is my bank book? I am the father. You are the son tone. I don’t get any of that really now." "He does not plan activities outside of the circle."
FM 11: “We had to get a young lady who does the housekeeping here. You work it out”
FM 12: “It has taken his freedom away from him. To come and go on his own, it has make him dependent and I think that bothers him the most of all.”
FM 13: “she does her dishes up and stuff like that” “Could care less about the house like we always had help coming in but she did not have to really clean. So she's more into money and figures and even now with her memory gone she's really good at adding, subtracting and everything. It's amazing you know how some things don't work and she can't tell you what this is but she could add up a column of figures.”
FM 14: “She can't do any banking. All of her mail is directed here now. She can't cope with any for that.” “she'll make herself a cup of coffee but she'll let the caregiver make. She'll take over for me on the weekend, isn't interested. Could not care less about being in the kitchen or shopping for food.”
FM 15: “On the other hand he's got the numbered account at the bank. He goes to pull money. He knows how to fill in the form. He brings money.”
FM 17: “He likes to keep in touch and be in control with finances. Whether he wants to go around or not that is important too.”
FM 18: “She does not do very much cooking any more.... she was a good cook...she's a good cook but she doesn't seem to find the time or the interest any more. We eat out quite a bit. I don't know... And cleaning and stuff and she never was a real whiz at that. We always had help generally. That's what makes life a little easier for her to go her own way.”
FM 19: “ Doing banking, taking him to the doctor, because that is very hard for him”. “he understands, asks me to write the check and he signs, at this age its like that, it doesn't matter if it is a man or a woman”.
FM 20: “She still cleans the house and goes to some activities when they pick her up, she has some independence, not like in a nursing home”.

Opportunity to travel (Patients: 4, 20%)
DQOL: Discretionary activities: Hobbies, recreational activities, vacations
P 2: “I would love to do more traveling if we had a lot of money. I want to go to any place around the world to see this and that and everything and I want to get going soon
because the older you get I think the less you feel like doing it, so that is one of the things I would like to do."
P 9: "My idea was to travel to go to Jerusalem, Cuba. Jerusalem and Cuba are part of my life. I can’t travel alone"
P 11: "What could make your life better? Travel. I have been doing it all my life...with the military I traveled all over the world"
P 18: "And we like to travel. I don’t mean overseas or anything but we like to go places and do things...We don’t really ever travel outside of Canada. We just got back from a little trip to the Hill. No, it was Christie Mill, Christie Mill. We like to do things like that and stay over night and eat out."

Opportunity to travel (Family members: 3, 15%)
DQOL: Discretionary activities: Hobbies, recreational activities, vacations
FM 4: "She would like to do a little more traveling. She mentioned that."
FM 9: "If we got on a plane when for a trip to somewhere, he would be glad to go. He can enjoy the moment."
FM 16: "My husband will talk about he wanted to travel."

Mobility (Patients: 3, 15%)
EuroQol: Mobility
HUI: Question 9: Ability to walk
QWB: Part IV: Physical activity / B. Avoid walking, have trouble walking, or walk more slowly than other people your age? C. Use of cane, crutches or walker? G. Spend most of the day in a bed, chair, or couch because of health reasons?
DQOL: Physical functioning
WHOQOL: Level of independence / Mobility
P 14: "Well fortunately I am pretty well. I’m mobile for my age. And that’s a big factor. A very big factor that I have not got to be shlept around in my wheelchair. Because you see quite a lot of that here in this city.
P 16: "Imagine what it is like not being able to get around as you like."
P 20: "Being able to go places on my own not on a wheelchair, like there are people in the day treatment"

Mobility (Family members: 3, 15%)  
EuroQol: Mobility  
HUI: Question 9: Ability to walk  
QWB: Part IV: Physical activity / B. Avoid walking, have trouble walking, or walk more slowly than other people your age? / C. Use of cane, crutches or walker? / G. Spend most of the day in a bed, chair, or couch because of health reasons?  
DQOL: Physical functioning  
WHOQOL: Level of independence / Mobility  
FM 1: "She cannot get around very well"  
FM 9: "physical immobility"  
FM 13: "I'd think I have been really lucky because she has been so mobile so far."

F) COGNITION  
Memory problems (Patients: 13, 65%)  
HUI: Question 11: Ability to remember things  
QWB: Part I: Acute and chronic symptoms: Significant memory loss?  
WHOQOL: Psychological / Thinking, learning, memory and concentration  
P 1: "There are many things I have forgotten. Yes, there are many things. Believe me. You know. You tell me and I forget who. That bothers me. Sure. Anything that I am supposed to know and I can't remember is really very bad for me."  
P 3: "The fact that I have this whatever it is that I had and woke up five days later. I don't know how it happened. That makes me forget all. I think it's old age"  
P 5: "Well, I still remember things from years ago. Sometimes it's good and sometimes it isn't" "You know, I still remember things that I want to remember... Sometimes, I remember it. Sometimes, it's not good to remember. Is that not right? That's right."  
P 9: "That is something you don't know before, I am going to forget this. It is gone and gone and gone"
P 10: “But for example, I am giving quite the contrast and I mean the extreme contrast when I was talking about professional theater. We used to do a full three hour performance every week, and I mean every week in the theater. Take a three hour play and memorize it and learn it every week. At that time, I must say I don’t even know how I did it. I don’t think I could do that today, but I could certainly pick up something and memorize it, but not to the extent I did in certain activities…”

P 11: “I can’t remember anything…She asks me questions and I don’t get the answers or I don’t remember them”

P 12: “I never had problems with my memory…I remember all these things.”

P 14: “I have a memory problem. I’ve forgotten what I got to do.”

P 15: “Not really, just sometimes I can’t think of things but not all the time. You know I can remember most things. Like for dates and appointments I have to write them down but so does everybody else. Because my cousin I was at the other night and he writes it on a calendar.”

P 16: “I don’t believe that I have lost the memory that much. I have…but not to that extent.”

P 18: “I don’t think I’ve got much of a memory problem. My memory’s pretty good.”

P 19: “Well I remember things from a long time ago better than recent. Like my bar-mitzva, that is a long time ago.”

P 20: “I do something and then I forget, where I put things or what I wanted to say”.

Memory problems (Family members: 14, 70%)

HUI: Question 11: Ability to remember things

QWB: Part I: Acute and chronic symptoms: Significant memory loss?

WHOQOL: Psychological / Thinking, learning, memory and concentration

FM 1: “I think that it is hard to say what would make it better because of her memory loss” “She is very forgetful to what she can sort of do. So I think it is hard to say what she doesn’t really want to do and what she wants to do.” “She can’t recall what you told her” “But maybe she is not able to recognize sometimes the people who work here. I think she knows they are familiar. She does realizes she knows them because they have been here. Certain ones she does. I think she seems to know them. I am not sure she knows them by name but more by sight that they look familiar.” “I think she is aware of
"Usually, she can accept the fact that she could do something repeatedly without any recollection."

FM 2: "It scares her that she cannot remember the names. For instance, my sister in Guelph was talking to mom last night on the phone and mom could not remember the names of some of the grandchildren let alone her great grandchildren and that really scared her. It frustrates her."

FM 3: "I mean there are times when he calls me by his sister’s name, but then he calls every grandchildren by a different name anyways."

FM 4: "She is obviously worried that the problem with recalling. That it gets worse. That would be one of the main concerns then. I would say so. Yes."

FM 5: "Her mental state, obviously" (memory) "She is aware of that"

FM 7: "He doesn’t remember" “He keeps asking me where we are going and why we are going there.”

FM 8: "The biggest thing is her memory especially short memory is completely gone. You can tell her something and turn your head just one revolution if you want and she will forget what you said. If you give her instructions or whatever anything like that, she can’t remember and she gets upset because she can’t remember.” “She will continue to ask the same questions because she doesn’t remember that you already thought her the answer. I think that is the basic down side that she encounters.” “She recognizes the face, but she could not put a name to that person even though she has known them for a long time” “The same thing if you ask her to go get something and if you are downstairs, I will say go get your purse, she will go upstairs and she will forget why she went upstairs for and will come back downstairs upset that she can’t remember what she went upstairs for”

FM 9: "He knows his memory is not there. He is aware of that."

FM 10: "Right now I don’t think she has much of a life. Because if you don’t have your memory, you know…. You could say something to her one minute and then she forgets the next. She forgets people’s names.”

FM 11: "She doesn’t remember. I recognized it and don’t make issues of it. I know that she has that disability. She can’t remember. She forgets names.” “I gave her this paper. A day or two when the pills did not come in on time, I said Dorothy I need that paper with
the phone number. She denied that she had the paper. I gave it to her. But again, I don’t make a big deal about it.”

FM 12: “He just can’t understand why he doesn’t remember things. He does remember things that I wonder how he remembers them and things I think he should know…”

FM 13: “She can’t understand why she can’t remember a lot of things. She can’t understand” “She cannot remember what happens” “I pick her up every day. She doesn’t ever remember me hardly coming and getting her. So that’s how far gone her memory is.”

FM 14: “She isn’t particularly perturbed about it. She doesn’t see herself for the most part losing her memory. When she forgets something she blames it on her age and says but I am eighty two years old.”

FM 17: “Yes he valued his memory and his mind it’s been very important to him. He was a lawyer and you may know that he had his own law firm and his whole business centred around his mental acuity. So to find that diminishing in any regard is very disturbing to him.”

Subjective Sense of Confusion (Family members: 6, 30%)

DQOL: Interaction capacity / Confusion

FM 1: “She started getting confused” “One thing is she feels that her mind is not clear. So that could upset her.”

FM 2: “She is confused”

FM 9: “He gets confused very quickly” “certainly if his awareness got any worse and I have been told to be prepared that when it happens it could happen quickly”

FM 10: “She even thinks I live upstairs. She has got it in her mind that I live upstairs and I don’t live upstairs…She is very confused. Cause my other daughter lives upstairs.”

FM 13: “Confusing, a dream, upside down, inside out” “But she may have asked me a hundred times where do you really think the people are going? Mom they don’t tell us where they’re going. You know and she gets confused about almost everything but I think that is very normal with the elderly.”

FM 20: “At times she seems confused, like she won’t know what to say or do, and she covers up and makes believe she is ok.”.
Ability to Read (Patients: 4, 20%)

QWB: Part I: Acute and chronic symptoms: Difficulty understanding the written or spoken word, or significant memory loss?

P 2: "I think that one of the things I am not doing so well now is reading fast"

P 6: "I used to read a lot but I have not gotten into reading again."

P 8: "I read a book. I turn on the radio. I turn on the T.V."

P 17: "And I subscribe to the Star and the Globe and Mail and I get the Sunday edition of the New York Times. So there is always something to read. I've been reading quite a few books too."

Ability to read (Family members: 4, 20%)

QWB: Part I: Acute and chronic symptoms: Difficulty understanding the written or spoken word, or significant memory loss?

FM 3: "Before he started having little problem with his eyes, he was a voracious reader and he would pick up a book and start to read it and he didn't put it down until he finished it. And now he is no longer able. He does read but not the same way. I see when I reading the paper in the evening because he has already read the paper during the day and picks up a book and he will read two or three pages and then puts the book down."

FM 4: "I would think her reading has slowed down from what it used to be."

FM 17: "And reads the paper regularly and likes to discuss issues. That is important to him and he likes to have something to do with computers. He has a fairly primitive model here he works on, writes letters."

FM 20: "She likes to read, I always bring her magazines, she doesn't read books anymore."

Disorientation in space / Getting lost (Patients: 4, 20%)

P 6: "when I first came up to this area I got lost a couple of times and sometimes in these large apartment blocks I can get lost and even in my own. It doesn't happen often and it doesn't take long to find my way but I feel Jesus Christ what is the matter."
P 7: “If I go out some place and I get there and I don’t know what the hell I am going there for. And you know I have those days.” “I never ever thought about it before. I thought it happened to everyone at my age. You know.” “I get out some place and cannot remember how the hell I got there and how I am going to get back which happens now and then. Not very often, but it does happens.”

P 14: “Yes, he said what floor do I stay on. I said twelve and I said no, no, no it’s fourteen. And I would be pressing number twelve. Number fourteen for four years.”

P 20: “I am afraid of getting lost, I am not as good as I used to be with directions, my daughter takes me places”.

Disorientation in space, Getting lost, Wandering (Family members: 6, 30%)

FM 6: “He disappeared from here”
FM 7: “he has wandered away”
FM 10: “For sure, because she has wandered away. We have lost her twice now. She walked to Lakeshore and Islington and Queen and Rockville. She just keep on walking. She doesn’t have memory of it.” “Because when she wandered away on me and got lost, I said mom if you keep doing this I am going to have to put you into a nursing home because you are endangering your life and Norma’s life.”
FM 13: “She is in her own home. She has been there fifty two years and quite often she doesn’t know where she is. She just doesn’t. Then she will get up she has got to go home. I said mom you are home. This is your home mother. Oh, no, no, no this is my other home, I have another one. So that’s a very big problem at dinner time.”
FM 15: “This week a man on this floor stopped me and said to me you know I came up in the elevator with your husband a few weeks ago… and he said your husband said to me I’ve never come this way before. He said, you say it is an elevator. You either go up or you go down. When they walked out the elevator he could see that my husband could not quite make out what he should do. So he said to him, you go to the left, that is your apartment.”
FM 20: “She will not go to new places on her own, if she is around the apartment, or in an area she knows well she doesn’t have much of a problem, but I still worry she will get lost”.

55
Ability to benefit from memory aids (Patients: 4, 20%)

P 2: “one priority is that I am taking all my pills exactly right and I have not made a mistake yet, so I am really pleased about that. And I have a system about doing that and I don’t need to go into that. But it makes it quick and easy and you know that you haven’t missed it.” “So I have it all set up for seven days of the week, you know. I can tell actually when I take it and I can see for sure that I took it. And I would never take it twice. And those little systems and I think doctors are people. I found a lot of easy ways to make things quick and easy and you never screw up. I think there is a lot of tricks you can do.”

P 4: “Write down names and I have a really good book that if I need to look up the names of people or if I go to phone people, I have all the information about them of their family and their friends. So I don’t have to try to remember that stuff. So it doesn’t frustrate me any more.”

P 8: “I used to always have a letter ready in case I forgot the address. But the phone was out of the blue”

P 20: “I always look it up the phone numbers just in case I forget”.

Ability to benefit from memory aids (Family members: 2, 10%)

FM 8: “She will either have to write it down in notes what she will have to do. Or if I happen to be going out or something so that she will know what she will be doing and then she will in time take the note and put it somewhere and she will forget where she put it.” “We have a watch that tells you the year and she forgets the watch will do that. There is also an alarm watch to tell her when to take the medication”

FM 9: “I have a series of notes around the house which schedule. I gave him a watch with the date on it so he looks at the watch. He sees the date and then he acts like he is in charge. So that system seems to work.”
Communication problems / Word-finding difficulties (Patients: 2, 10%)

HUI: Question 5 and 6: Ability to be understood when speaking with people who do not know you / who know you well

QWB: (Limited: Does not include expressive language). Part I: Acute and chronic symptoms: Difficulty understanding the written or spoken word, or significant memory loss?

DQOL: Interaction capacity / Communication difficulties

P 2: “this is my name thing”

P 11: “When somebody asks me a question or when it is not in my mind, I have to fight for it….I wanted to say something but I can’t think of the word. I have to wait for it to come. That is frustrating”

Communication problems, Word-finding difficulties (Family members: 6, 30%)

HUI: (Limited: Does not include receptive language). Question 5 and 6: Ability to be understood when speaking with people who do not know you? / who know you well?

QWB: (Limited: Does not include expressive language). Part I: Acute and chronic symptoms: Difficulty understanding the written or spoken word, or significant memory loss?

DQOL: Interaction capacity / Communication difficulties

DQOL: Interaction Capacity / Ability to Comprehend

FM 2: “She knows what she wants to say. I am quite sure of that but she can’t think of the words.”

FM 3: “but I can understand that it would be hard for him to get into a conversation with our family that he doesn’t know.”

FM 4: “She has a bit of frustration when she cannot obviously recall the word that she wants to use. That seems to be the main problem.” “That is the only draw back she cannot recall the words and sometime she will not know the meaning of what word that has not been used for. Not a common word she would have known the meaning of before and the spelling. She might not know the spelling words as she did before and she gets frustrated when that happens.” “She spends more time checking a word in the dictionary partly because she wants to keep up but words that she would have probably would have
known before or known enough about would not matter. She might not know the exact
definition of a word but you know the sense of what they are meaning. That gets worse
and worse. Obviously, that is going to diminish.”
FM 7: “He never talks about anything. He never talks about anything.”
FM 10: “When she is trying to explain something to you and she cannot find the proper
words, she just shakes her head and giggles about it. She tries to hint it.” “She never says
nothing….She cannot make conversation. If you say something to her, she will agree or
whatever”
FM 15: “He goes to a movies. He does not understand the whole movie. I often ask him, if
you cannot grasp the plot. He understands what is going on but the plot is difficult for him to
grasp.”

Disorientation in time (Family members: 2, 10%)
FM 8: “Like you can ask her anytime you want or what day and if she gets it, it is a lucky
guess.”
FM 9: “Although he does not have specific idea of what date it is and what time it is”

Help with word-finding difficulties, “interpretative communication”(Patients: 2, 10%)
P 2: “Sometimes when I am trying to rush that is when you don’t forget names for sure. I
can just yell what is --- and he just says the name for me. He is very good about that. I
know exactly where it is, but it doesn’t come up you know and he knows that’s my
problem and so he helps me out that way, which is very lucky for me. If I didn’t have
that.”
P 20: “The people in day treatment they help me they are very good, they know when I
name things, I can’t remember they help me say it, tell me not to rush”.

Psychomotor difficulties (apraxia) (Patients: 2, 10%)
P 8: “I could hardly write. It takes all I can do. Sometimes I write OK”
P 19: “I write, I used to write I had a beautiful hand-writing now I can’t I have to take
my time and sometimes I get a little mixed up.”
Psychomotor difficulties (apraxia) (Family members: 1, 5%)
FM 6: “If you see him in the morning eating an egg, it is unbelievable. It takes him maybe half an hour or more. He sits.”

Disorientation in person / Loss of identity (Family members: 1, 5%)
FM 6: “He has no idea whatsoever. No. No idea. It’s just like he is in another world.”
“And it’s getting worse everyday, everyday. And your impression is that he is no longer your husband then because the person you knew is no longer there. No he is not there at all. No. No.”

Lack of responsiveness to environment (Family members: 1, 5%)
FM 6: “He was sitting on the kitchen table and paying no attention. He was just making his lines. And he does that everyday every day. She asked him questions and he didn’t know how to answer.”
Appendix 7: Feasibility Questionnaires to assess Relevance, Acceptability and Sufficiency of the three utility-based measures
INSTRUCTIONS:
Please make a mark on the scale for each one of these statements that indicates the strength of your agreement or disagreement with the statement.

1) This questionnaire allows me to report important information about my quality of life

   Strongly Disagree  ________________________________ Strongly Agree

2) This questionnaire is easy to understand

   Strongly Disagree  ________________________________ Strongly Agree

3) This questionnaire addresses all areas of quality of life that are important to me

   Strongly Disagree  ________________________________ Strongly Agree

4) This questionnaire gets at what life is like for me

   Strongly Disagree  ________________________________ Strongly Agree

5) The length of this questionnaire is acceptable

   Strongly Disagree  ________________________________ Strongly Agree
6) The items included in this questionnaire are enough to describe my quality of life

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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7) The items contained in this questionnaire are consistent with my understanding of quality of life

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<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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8) This questionnaire includes items that are confusing

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<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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9) There are other areas of quality of life which I want my doctor to know about before making decisions about my care

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<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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10) This questionnaire is worded in everyday language

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<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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11) I feel comfortable that medical decisions concerning me are being based on my answers to this questionnaire

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<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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(FAMILY MEMBERS VERSION)

INSTRUCTIONS:
Please make a mark on the scale for each one of these statements that indicates the strength of your agreement or disagreement with the statement.

1) This questionnaire allows me to report important information about my relative's quality of life

   Strongly Disagree  ___________________________  Strongly Agree

2) This questionnaire is easy to understand

   Strongly Disagree  ___________________________  Strongly Agree

3) This questionnaire addresses all areas of quality of life that are important to my relative

   Strongly Disagree  ___________________________  Strongly Agree

4) This questionnaire gets at what life is like for my relative

   Strongly Disagree  ___________________________  Strongly Agree

5) The length of this questionnaire is acceptable

   Strongly Disagree  ___________________________  Strongly Agree
6) The items included in this questionnaire are enough to describe my relative’s quality of life

Strongly Disagree ___________________________ Strongly Agree

7) The items contained in this questionnaire are consistent with my relative’s understanding of quality of life

Strongly Disagree ___________________________ Strongly Agree

8) This questionnaire includes items that are confusing

Strongly Disagree ___________________________ Strongly Agree

9) There are other areas of quality of life which I want my relative’s doctor to know about before making decisions about her/his care

Strongly Disagree ___________________________ Strongly Agree

10) This questionnaire is worded in everyday language

Strongly Disagree ___________________________ Strongly Agree

11) I feel comfortable that medical decisions concerning my relative are being based on his/her answers to this questionnaire

Strongly Disagree ___________________________ Strongly Agree
Appendix 8: Certificate of Research Approval and Consent Forms
CERTIFICATE OF RESEARCH APPROVAL

The joint Baycrest Centre/University of Toronto Research Ethics and Scientific Review Committee has examined the following research proposal and considers the experimental procedures, as outlined by the applicant(s), to be acceptable on scientific and ethical grounds for research involving human subjects. The project is approved, provided that the necessary resources are available.

Investigator(s): Silberfeld, Naglie & Krahn

Title of Project: Adequacy of three quality of life scales: Patient & family input

Date of Approval: January 18, 1999

Composition of Research Ethics Committee (by discipline):

- Audiology
- Client Representation
- Diagnostic Imaging
- Epidemiology
- Ethics
- Geriatric Medicine
- Neurology
- Nursing
- Pastoral Care
- Physiotherapy
- Psychology
- Quality Methods
- Research Administration
- Social Work
- University, Legal & Board Representative

Sylvia Teaves, MHSc, CHE
Deputy Chair
Research Ethics and Scientific Review Committee

NOTE: It is the responsibility of the Principal Investigator to notify granting agencies about receipt of ethics approval, if required.

The new Apotex Centre, Jewish Home for the Aged, and The Centre for Cognitive Disorders...Opening Fall 1999
INFORMATION/CONSENT FORM
(PATIENT VERSION)

Title of the study: Adequacy of three quality of life scales: patient and family input.

Researchers: Dr. Michel Silberfeld
Dr. Gary Naglie
Dr. Murray Krahn

Research Assistant: Mr. Sergio Rueda Phone: (905) 709-0293

Why are we doing this study?
Many new treatments for dementia are becoming available. One way of understanding the benefits of these treatments is to measure their effect on the quality of life of patients and relatives. Questionnaires are often used to gather information about quality of life. In this study, we want to find out which ones can be used to evaluate dementia because none were originally designed for this purpose. Thus, this study will evaluate the usefulness of these questionnaires.

What will happen during this study?
We will ask you to answer some questions in order to find out what aspects of quality of life are important for you. A tape recorder will be used during this interview. This first visit will last approximately 30 minutes. Then, in a second visit, we will ask you to fill out three questionnaires, and ask for your reactions to them. This second meeting will take approximately 30 minutes.
Are there any good things and possible negative things about the study?

Aside from knowing that you have taken part in a study which can further our understanding of dementia, you will receive no direct benefit. A possible negative is that the task may be too demanding, and this may upset you. If any signs of distress are observed you will be asked to withdraw from the study.

Confidentiality

Only the investigators will see your responses. The information and the tapes will be coded so it cannot be identified with your name, and locked in the researcher’s office. The tapes will be destroyed when the study is completed. If you wish, you can obtain a copy of the final results when they are published.

Can I decide if I want to be in this study?

You are free to decide if you wish to take part or not. If you choose to take part, you may withdraw from the study at any time. If you choose not to take part, or if you withdraw from the study, the care that you receive from your physicians, and the hospital, will not change in the least.
CONSENT

The research procedures described above have been explained to me, and all my questions have been answered to my satisfaction. I have been informed that I would be able to withdraw from the study at any time. Withdrawing will not affect the quality of my medical care at the hospital. As well, the potential discomforts have been explained to me, and I also understand the benefits (if any) of participating in the research study.

I know that I may ask now, or in the future, any questions I have about the study. I have been assured that records relating to my care and my answers to the questions asked of me, including the content of the tapes, will be kept confidential, and that no information will be released or printed that would disclose my personal identity without my permission.

I hereby consent to participate

__________________________________________
Signature of patient

__________________________________________
Printed name of patient

__________________________________________
Name of person who obtained consent

__________________________________________
Signature
Date:_______________
INFORMATION/CONSENT FORM
(FAMILY MEMBER VERSION)

Title of the study: Adequacy of three quality of life scales: patient and family input.

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Many new treatments for dementia are becoming available. One way of understanding the benefits of these treatments is to measure their effect on the quality of life of patients and relatives. Questionnaires are often used to gather information about quality of life. In this study, we want to find out which ones can be used to evaluate dementia because none were originally designed for this purpose. Thus, this study will evaluate the usefulness of these questionnaires.

What will happen during this study?
We will ask you to answer some questions in order to find out what aspects of quality of life are important for your relative who has been diagnosed with dementia. A tape recorder will be used during this interview. This first visit will last approximately 30 minutes. Then, in a second visit, we will ask you to fill out three questionnaires for your relative, and ask for your reactions to them. This second meeting will take approximately 30 minutes.
Are there any good things and possible negative things about the study?

Aside from knowing that you have taken part in a study which can further our understanding of dementia, you will receive no direct benefit. A possible negative is that the task may be too demanding, and this may upset you. If any signs of distress are observed you will be invited to withdraw from the study.

Confidentiality

Only the investigators will see your responses. The information and the tapes will be coded so it cannot be identified with your name, and locked in the researcher's office. The tapes will be destroyed when the study is completed. If you wish, you can obtain a copy of the final results when they are published.

Can I decide if I want to be in this study?

You are free to decide if you wish to take part or not. If you choose to take part, you may withdraw from the study at any time.
CONSENT

The research procedures described above have been explained to me, and all my questions have been answered to my satisfaction. I have been informed that I would be able to withdraw from the study at any time. As well, the potential discomforts have been explained to me, and I also understand the benefits (if any) of participating in the research study.

I know that I may ask now, or in the future, any questions I have about the study. I have been assured that my answers to the questions asked of me, including the content of the tapes, will be kept confidential, and that no information will be released or printed that would disclose my personal identity without my permission.

I hereby consent to participate

________________________________________
Signature of family member

________________________________________
Printed name of family member

________________________________________
Name of person who obtained consent

________________________________________
Signature

Date:___________________
Appendix 9: Summary of Results for the Qualitative Analysis
Appendix 9: Summary of results for qualitative analysis

**TABLE A: DOMAINS FOUND IN THE INTERVIEWS (PATIENTS)**

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<th>DQOL</th>
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Note. N: new domain, not found in any of the measures.
*: Limited.
TABLE B: DOMAINS OBTAINED IN THE INTERVIEWS (FAMILY MEMBERS)

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Note. N: new domain, not found in any of the measures.
*: Limited.
TABLE C: COMPARISON BETWEEN DOMAINS FOUND IN PATIENTS AND IN FAMILY MEMBERS

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**Functional Well-Being**

| **Recreational Activities/Hobbies/Leisure** | 60 | 70 | | | | X | X | X | |  
| **Driving** | 30 | 20 | | | | X | X | X | |  
| **Exercise** | 30 | 10 | | | | N | N | N | N | |  
| **Self-care Activities** | 30 | | | | | X | X | X | |  
| **Instrumental Activities of Daily Living** | 15 | 70 | | | | X | X | X | |  
| **Opportunity to Travel** | 20 | 15 | | | | X | X | X | |  
| **Mobility** | 15 | 15 | | | | X | X | X | |  

**Cognition**

<p>| <strong>Memory Problems</strong> | 65 | 70 | | | | X | | X | |<br />
| <strong>Subjective Sense of confusion</strong> | 30 | | | | | X | | X | |<br />
| <strong>Ability to Read</strong> | 20 | 20 | | | | X | | X | |<br />
| <strong>Disorientation in Space/Getting Lost</strong> | 20 | 30 | | | | N | N | N | N | |</p>
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Note. N: new domain, not found in any of the measures.
*: Limited.
Appendix 10: Raw Data of the Responses to the Visual Analog Scales
Appendix 10: Raw data for responses of patients and family members to the visual analog scales (feasibility questionnaire)

Relevance dimension: Questions 1, 4, and 7.
Acceptability dimension: Questions 2, 5, 8, 10, and 11.
Sufficiency dimension: Questions 3, 6, and 9.

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