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**Quality of Life in dementia: A comparison of the  
perceptions of people with dementia and care staff in  
residential homes**

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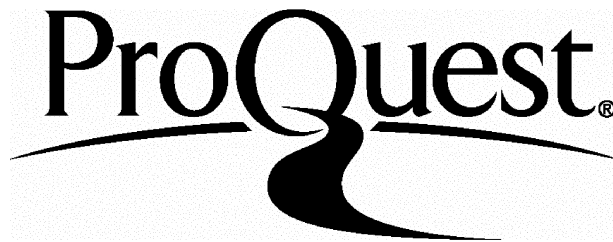
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### **Abstract**

Quality of Life (QoL) in people with dementia is considered increasingly important, for example to test the effectiveness of interventions. Since QoL is essentially a subjective experience, it is important to know how far proxy ratings compare to self ratings of QoL. This thesis examines the level of similarity between ratings of QoL made by people with dementia and their care staff in residential care homes, person and staff factors which might impact on the discrepancy between ratings, and the relationship between homes in staff factors and resident QoL. 76 dyads of people with dementia and care staff in nine residential homes were recruited. People with dementia were interviewed about their QoL, using the 'Quality of Life – Alzheimer's Disease' (QoL-AD, Logsdon, Gibbons, McCurry & Teri L, 1999) and assessed for severity of cognitive impairment. Staff completed the QoL-AD with respect to a person with dementia, and measures assessing their job satisfaction, level of hope and person-centredness.

The results showed that people with dementia and their care staff consistently rated QoL differently, demonstrated through a lack of correlation and a marginally higher mean person-rated QoL score. Some items on the QoL-AD ('physical health', 'family' and 'friends') were rated similarly between the two groups and others significantly differently ('ability to do chores', 'marriage / closest relationship', 'memory' and 'life as a whole'). Neither staff hope, person-centredness or job satisfaction, nor severity of cognitive impairment in people with dementia, were associated with the discrepancy between scores. However, when data was aggregated within residential settings, a



correlation between hope in staff and resident QoL emerged. Person-centredness and job satisfaction in staff were not related residents' QoL. This thesis addresses some important issues, such as the complex relationship between staff and residents in care homes and the results have clinical implications, with more effort required into ways of instilling hope into staff who are so often undervalued.

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## **Chapter 1: Introduction**

### **Overview**

In recent years, evaluating Quality of life (QoL) in people with dementia has become increasingly valued, for example in assessing the effectiveness of an intervention or making treatment decisions. A number of dementia-specific QoL measures exist, all of which are rated by the person with dementia and/or a proxy. This proxy is typically a family carer or member of staff. However, since QoL is quintessentially a subjective experience, it is important to know how far proxy ratings compare to self ratings of QoL. Moreover, Logsdon, Gibbons, McCurry & Teri (2002) note that “future research should address factors that affect both patient and caregiver ratings (of QoL)” (p.518).

In dementia care and research, there is also a growing emphasis on person-centred care and in directly asking people with dementia about important issues in their care and management. Many people with dementia live in residential care homes. The concept of a ‘Malignant Social Psychology’ (Kitwood, 1997) suggests a complex relationship between staff and people with dementia and there is evidence that factors such as stress, job satisfaction and person-centredness may affect staff attitude towards people with dementia (Moniz-Cook, Millington & Silver, 2000). The aim of this thesis is to examine the level of similarity between ratings of QoL made by people with dementia and a rating of it made by their care staff. Secondly, it evaluates the influence of particular factors on this discrepancy: job satisfaction, hope and person-centredness in staff, and level of cognitive impairment in the person with dementia.

This chapter begins by considering the nature of dementia, outlining some theoretical models. It then moves on to discuss QoL, including QoL as a construct, its measurement, subjective versus objective QoL and QoL in residential care. From this, factors which might affect the perception of QoL in both people with dementia and care staff are explored. Finally, a conceptual model, considering the perception of QoL from both perspectives, is proposed. A rationale for making such comparisons is offered in the context of previous research. The chapter ends with the research questions and hypotheses.

### **The nature of dementia**

The DSM IV criteria (APA, 1994) define dementia as:

- The development of multiple *cognitive deficits* manifested by both
  - (1) *memory impairment* (impaired ability to learn new information or to recall previously learned information)
  - (2) one (or more) of the following cognitive disturbances:
    - *aphasia* (language disturbance, i.e. inability to name people or objects)
    - *apraxia* (impaired ability to carry out motor activities despite intact motor function, which may lead to deficits in cooking, dressing or drawing)
    - *agnosia* (failure to recognise or identify objects despite intact sensory function)
    - disturbance in *executive functioning* (planning, organising, sequencing, abstracting)

Further, these deficits cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning. Other symptoms might include delusions, hallucinations, depression, wandering, repetitive activity and physical or verbal aggression.

Different dementias are typically defined by pathological and neurological damage, and cognitive and behavioural change. For example, Alzheimer's Disease (AD), the most common type of dementia, is characterized by gradual onset and continuing cognitive decline, with raised numbers of neuritic plaques and neurofibrillary tangles in the brain pathology. Vascular Dementia consists of a number of small infarctions in the brain, due to a series of tiny strokes and is more likely to have a sudden onset and a stepwise deterioration.

However, neuropathology is only a limited explanation for the clinical presentation of dementia, since there is only a weak correlation between symptoms of dementia and neurological damage post mortem (Homer, Honavar, Lantos, Hastie, Kellett & Millard, 1988). Kitwood and Bredin (1992) argued that the dementing process should be viewed as a dialectical interplay between two tendencies: (i) neurological impairment (which sets upper limits to how a person can perform) and (ii) the personal psychology an individual has accrued, together with the social psychology with which (s)he is surrounded. This was later developed into a simple equation (Kitwood, 1993):

$$D = P + B + H + NI + SP$$

where D = dementia, P = personality, B = biography, H = physical health, NI = neurological impairment and SP = social psychology. For example, a person's personality and life experiences (biography) might shape their reaction to their condition. A negative social environment might devalue the person, resulting in excess disability. Spector (2001) added that 'mental stimulation' 'multisensory stimulation', 'life events' and 'mood' might contribute to this equation. This is because there is evidence that mental and multisensory stimulation can improve cognition and quality

of life in dementia (Spector, Thorgrimsen, Woods, Royan, Davies, Butterworth et al., 2003). Further, life events may trigger decline in dementia (Orrell & Bebbington, 1998) and there is a substantial literature on the effects of depression on dementia (Woods, 1999).

### **Person-Centred Care**

Discussing how many cultures tend to depersonalise people with a serious illness, Kitwood (1997) stated that our frame of reference should be the PERSON-with-dementia, not the person-with-DEMENTIA. This he described as the concept of 'personhood': "A standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust." (Kitwood, 1997, p.8). His extensive writings on personhood emphasised that the way in which people with dementia are viewed and treated by others, particularly by those on whom they are dependent, as an integral feature of their quality of life. In recent years, Person-Centred Care, involving providing care in which the person's individuality and needs are central, has become a focus in service provision in the UK. For example Person-Centred Care for older people is Standard Two of the National Services Framework for Older People (Department of Health, 2001). Its definition in the context of people with dementia (Brooker, 2004) includes:

1. Valuing people with dementia and those who care for them by treating them as they would want to be treated at all stages of the dementia.
2. Treating people as individuals, for example through consideration of their histories, personality and coping mechanisms.
3. Looking at the world from the perspective of the person with dementia, as the subjective experience of the individual is considered reality. This might be

achieved, for example, by encouraging people with dementia to write poetry (Killick and Allen, 2001).

4. Providing a positive social environment in which the person with dementia can experience relative well-being.

Thus it appears that recognising 'personhood' is integral to person-centred care. Following these principles, Kitwood (1997) described 'Positive Person Work' as twelve types of positive interaction occurring between people with dementia and those around them. These were (1) 'Recognition': verbal or non-verbal, (2) 'Negotiation': consulting people about their preferences and needs, rather than making assumptions, (3) 'Collaboration': care not being something that is 'done' to a person, but involves their own initiative and abilities, (4) 'Validation': acknowledging the emotional level of people's behaviour, (5) 'Play': activities which have no goals but are simply an exercise in spontaneity and self-expression, (6) 'Timilation': expression developed to describe sensory stimulation with reassurance and pleasure, (7) 'Celebration': a form of interaction in which boundaries between caregivers and the person diminishes, (8) 'Relaxation', (9) 'Holding': providing a safe psychological space where areas of vulnerability can be exposed, (10) 'Facilitation': enabling a person to be able to do what s/he otherwise wouldn't, (11) 'Creation': allowing the person with dementia to offer something socially and (12) 'Giving': when the person with dementia is able to express concern or gratitude. These factors are particularly relevant when considering the quality of relationships between people with dementia and those caring for them.

Therefore, 'Positive Person Work' should improve quality of life by working against

the 'Malignant Social Psychology' which can surround the person with dementia. Kitwood (1997) described the Malignant Social Psychology as seventeen negative elements of communication that can affect people with dementia, particularly through staff in residential care settings. These were (1) 'treachery' (using deception to distract or manipulate a person), (2) 'disempowerment' (not allowing the person to use their abilities), (3) 'infantilisation' (treating the person like a child), (4) 'intimidation' (inducing fear in a person), (5) 'labelling' (using the category 'dementia' as a basis for interaction), (6) 'stigmatisation' (treating the person as a deceased object or outcast), (7) 'outpacing' (acting or behaving at a rate too fast for the person to follow), (8) 'invalidation' (failing to acknowledge a person's feelings), (9) 'banishment' (excluding a person physically or psychologically), (10) 'objectification' (treating the person as a lump of dead matter), (11) 'ignoring' (acting as if as person is not there), (12) 'imposition' (forcing a person to do something), (13) 'withholding' (refusing to give attention), (14) 'accusation' (blaming a person), (15) 'disruption' (disturbing or disrupting them without consideration), (16) 'mockery' (making a joke of the person's losses) and (17) 'disparagement' (telling someone they are worthless). In his theory of the Malignant Social Psychology, Kitwood make particular reference to the difficulties in communication between care staff and people with dementia in institutionalised settings.

### **Quality of life (QoL) in dementia: background**

The World Health Organisation QoL group (1995) included in their definition of QoL 'the individual's perception of his/her position in life in the context of the culture and value system in which s/he lives and in relationship to his/her goals, expectations and standards'. Yet with the impairment and disability associated with dementia, some



might question how much QoL people with dementia experience and how able they are to evaluate it. People have attempted to address the above question, for example by asking 22 people with dementia in a specialist day hospital what was of value to them. Barnett (2002) identified certain issues frequently emerging: (i) Awareness of themselves and their situation (e.g. of their own confusion), (ii) The importance of other people (e.g. friendships), (iii) Loss (e.g. of home, of role in life) and (iv) Perspectives on dependence (e.g. feelings regarding the care relationship).

The limitations of using survival rates and symptom levels as the only outcome variables in dementia have become increasingly evident, with the idea that QoL may be more desirable and meaningful to people with dementia and their families. There has also been research indicating that people with dementia can both have QoL and rate QoL, even in the later stages of the illness (Brod, Stewart, Sands and Walton, 1999; Thorgrimsen, Selwood, Spector, Royan, de Madariaga Lopez, Woods and Orrell, 2003). A joint consensus statement issued by the American Association for Geriatric Psychiatry, the Alzheimer's Association and the American Geriatrics Society indicated that improving QoL was one of the primary goals for treatment of Alzheimer's patients (Ready, Ott, Grace & Fernandez, 2002). Brod et al (1999) highlighted the importance of QoL as an outcome in (a) evaluating service programs, (b) testing the efficacy of drug treatments, (c) the ethical debate regarding health care resource utilisation, (d) end of life decision making and (e) developing clinical guidelines.

### **QoL in dementia as a construct**

Authors are beginning to consider what might contribute to QoL in dementia, some ideas which are as follows. Kitwood and Bredin (1992) described people with dementia as being in a relative state of 'well-being' or 'ill-being', independent of cognitive skills. For example, they noted that some people scoring zero on cognitive tests appear to be faring well as persons, yet others with moderate cognitive impairment appear to fare less well, for example because they are depressed. Kitwood and Bredin (1992) listed the following twelve 'indicators of well-being': (1) the assertion of desire or will; (2) the ability to experience and express a range of positive and negative emotions; (3) initiation of social contact; (4) affectionate warmth; (5) social sensitivity; (6) self-respect; (7) acceptance of other people with dementia; (8) humour; (9) creativity and self-expression; (10) showing evident pleasure; (11) helpfulness; and (12) relaxation. They further hypothesised that these indicators are an expression of four global sentient states that are expressed by these indicators: (1) sense of personal worth; (2) sense of agency (ability to control personal life in a meaningful way); (3) social confidence; and (4) hope. The authors informally confirmed the validity of the indicators through consultation with seven experts in dementia.

Definitions of QoL and "well-being" suggest that there is an important overlap between the two concepts, with aspects of QoL relating to how that person feels about themselves also being indicators of well-being. It might be, however, that QoL involves a broader definition of the person's life, with some aspects not directly impacting on their well-being. For example, QoL measures tend to ask people to rate

their memory, yet as Kitwood and Bredin stated this might not impact on their psychological well-being. Perhaps, assessing the relative importance of aspects of QoL for that individual is a route to understanding their impact on the person's well-being.

Lawton (1983) proposed, through past research and his own hypotheses, that well-being in older people may be represented by four domains: behavioural competence, perceived QoL, psychological well-being and objective environment. He suggested that psychological well-being was the most important with regard to outcome. Logsdon et al (2002) considered these four domains to be highly relevant in QoL for people with cognitive impairment, and designed a dementia-specific measure of QoL, the Quality of Life: Alzheimer's Disease (QoL-AD) to reflect these four domains. Thorgrimsen (2003) concluded that QoL in dementia represents individual responses to the physical, mental and social factors affecting well-being, which influence the extent to which personal satisfaction with life circumstances can be achieved.

Brod et al (1999) provided a dementia-specific definition of QoL, which included five domains: (1) aesthetics (enjoying / appreciating beauty, nature and surroundings), (2) positive affect (experiencing humour, feeling happy, cheerful, content, hopeful), (3) negative affect (experiencing worry, frustration, depression, anxiety, sadness, loneliness etc), (4) self-esteem (feeling accomplished, confident, able to make own decisions) and (5) feelings of belonging (feeling loveable and liked, useful). In their model, QoL is determined by a) context (dementia signs and symptoms, co-morbid illness, physical and social environment and individual characteristics such as age, gender and socio-economic status) and b) functioning and behaviour (extent of

limitations and difficulties, and behaviours that people 'do', such as wandering or shouting). The model states that the individual's subjective experience of his behaviour and functioning is what determines how he will perceive his QoL.

None of these models explicitly define cognitive ability as a contributor to QoL, which is interesting in light of the value placed on intellectual abilities in many societies and cultures. There is mixed evidence regarding the impact of cognitive impairment on QoL. Gonzalez-Salvador, Lyketsos, Baker, Hovanec, Roques, Brandt et al (2000), using a sample of 120 people with dementia, found a significant positive correlation between cognitive impairment and QoL, as rated by caregivers. This suggests that cognition is regarded as an important factor in QoL by caregivers, yet this study provides no evidence that people with dementia value it in the same way. In contrast, Logsdon et al (2002) found no correlation between cognitive impairment and QoL (rated by people with dementia and their caregivers), suggesting that cognitive ability did not impact on ratings of QoL in either group.

### **QoL: Measurement**

Lawton (1997) stated that measurement of QoL should involve a) multidimensionality (the assessment of many domains of QoL) and b) subjective-objective criterion (each domain being evaluated by both the person and by external observers or methods). There remain a number of debates surrounding both the definition and measurement of QoL, including:

1. Measuring something so subjective and individualised through using standardised scales (Selai, Trimble, Rossor & Harvey, 2001). By using pre-conceived categories and quantitative measurement, some of the richness of individual data

might be lost.

2. Placing equal weight on different areas of QoL, with an assumption that each subsection is of relevance and of equal importance to the individual. Lawton stated that adding together sub-scale items to derive an overall score might mask the different patterns of those who experience quality on some items and not in others.
3. The idea that people might not volunteer all information important to them, or that information may change over time or according to context and mood.
4. The idea of how able people with dementia are to evaluate their QoL. Appraisal of QoL requires a complex procedure of introspection and evaluation, hence one might predict that at a certain stage of dementia, self-assessment of QoL may no longer be possible. Further, in assessing QoL, language almost inevitably has to be used, something that might be impaired as a result of dementia (Thorgrimsen, 2003).

The first two concerns above led Thorgrimsen et al (2003) to conduct a validation study on the QoL-AD (Logsdon et al, 1999). Through running focus groups for people with dementia, they found that all thirteen items on the scale were identified as important and relevant for people with dementia. Additionally, no further areas of QoL were identified that had not been included in the scale. This demonstrated that measures of QoL can have content and face validity. Addressing the fourth point (above), both Logsdon et al (1999) and Thorgrimsen et al (2003) reported using the QoL-AD on people with Mini Mental State Examination scores (Folstein, Folstein and McHugh, 1975) as low as three, indicating that some people with severe dementia are able to rate their QoL. How closely their reports relate to objective outcomes

might be questioned, although it could be argued that the subjective assessment of QoL is of greater importance than objective/proxy evaluations.

Within the last five years, a number of QoL measures have been developed for people with dementia, including the Quality of Life – Alzheimer’s Disease (QoL-AD, Logsdon et al, 1999), Dementia Quality of Life (DQoL, Brod et al, 1999), the Quality of Life Assessment Schedule (QOLAS, Selai et al, 2001) and the Alzheimer’s Disease Related Quality of Life (ADRQL, Rabins, Kasper, Kleinman, Black & Patrick, 1999). Alternatively, QoL might be evaluated by external observers. Logsdon et al (2002) stated that evaluations of ‘observed affect’ and ‘pleasant events’ have been proposed to measure observable attributes of QoL, but are limited by the uncertainty about whether what is being observed is considered important to the individual’s QoL. Assessment measures of QoL tend to rely on either proxy ratings (e.g. the ADRQL) or both person and proxy ratings (e.g. the QoL-AD and the QOLAS), which suggests that there remains doubt as to the reliability of ratings made solely by people with dementia.

### **Subjective versus objective QoL**

Some researchers advocate the use of both subjective and objective measures of QoL (e.g. Logsdon et al, 1999). Lawton (1997) identified the essential facets of ‘objective’ QoL as being activities of daily living, disturbed or agitated behaviour, clinical depression, discretionary time use, social interaction, basic affect states and environmental quality. He concluded that attributed ratings of these QoL domains by ‘others’ are easiest to obtain but are more subject to observer bias and other causes of unreliability than direct behaviour observation. However, direct observation itself

cannot be considered objective, with the observer using his own values as a point of reference, hence potentially resulting in bias. Further, there will not necessarily be a relationship between factors judged by some to be of high quality (e.g. having good physical safety and the presence of amenities in the environment) and the QoL of individuals. Again, this relates back to Lawton's (1997) argument that different factors might have varying levels of importance for individuals.

It could hence be argued that there is no such thing as 'objective'. Ratings made by others ('proxies') might be influenced by people's expectations and values, relationship with the person and their own agendas. Lawton (1997) concluded that objective reports: "are objective in the sense that they may be placed toward the objective end of a continuum ranging from subjective to objective" (Lawton, 1997, p.93). Although raising some concern about the ability of people with dementia to make subjective judgements, Lawton argued that the experiencing individual is the only one capable of deciding whether life is favourable or unfavourable in any relevant domain.

### **Including the perspectives of people with dementia**

Although Kitwood's work was highly influential in a move towards Person Centred Care, Goldsmith (1996) noted that he did not incorporate the opinions of people with dementia in his research. It appeared that at this time, asking the opinion of the person with dementia was a relatively new concept and that most research had considered other people's perspectives. Mozley, Huxley, Sutcliffe, Bagley, Burns, Challis and Cordingley (1999) described how a number of studies which interviewed older people about their care had excluded those deemed 'unable to participate'. These were

primarily people who were described as ‘confused’ or having dementia. Instead, staff or other third-party views were utilised.

Goldsmith (1996) reviewed the small number of qualitative studies available at the time, which asked people with dementia about the services they receive or their experiences of them (e.g. Sutton and Fincham, 1994; Gillies 1995). He highlighted themes which emerged including the social rather than physical aspects of care being of greatest importance, and said: “The need to belong, the desire for companionship, the need to feel valued and the desire to be engaged in stimulating activities or those which arouse pleasant memories were the concerns which surfaced time and time again” (Goldsmith, 1996, p.17). More broadly, the *Health of the Nation* report (DoH, 1992) emphasized the importance of consulting service-users in planning and implementing services. Additionally, Downs (1997) described how the academic community has been challenged to elicit the views of people with dementia and for these to be included in both research and service design and evaluation. Hence from various perspectives, hearing the views of people with dementia is becoming increasingly valued.

### **Residential care: Environment and context**

It is important to discuss the environment and context of residential care settings, in considering the QoL of those living there. It has been estimated that approximately 75% of older people in residential care in the UK have dementia (Martin, Hancock, Richardson, Simmons, Katona, Mullan et al, 2002). It has been suggested that increasingly high dependency rates in local authority homes has resulted in staff doing a job very different from that to which they had been appointed (Moniz-Cook,



Millington and Silver, 1997). For example, there may be more emphasis on intimate physical care and dealing with problematic behaviour than there had been in the past.

Two decades ago, common problems in institutions for people with dementia were highlighted: “Lack of activity continues to be a predominant feature, residents continue to have little in the way of meaningful social interaction, choices continue to be denied, not enough is done to help the person maintain their sense of identity...” (Woods & Haugen, 1987, p.304). Unfortunately, more recent research identified further obstacles: hierarchical organisation of staff, care assistants having little opportunity to contribute their opinions and experiences, an absence of any induction, lack of training and lack of feedback about their work (Lintern and Woods, 2000). These definitions can be linked to Kitwood’s (1997) description of two types of care settings (see Table 1), type A bearing many similarities to the ‘Old Culture of dementia care’ and type B, the ‘New Culture’. Kitwood described an ‘old culture of dementia care’ as denying the existence of psychological needs and minimal interaction between people with dementia and their carers. He proposed the ‘new culture of dementia care’ which should be aspired to, involving commitment to engaging with psychological needs, interaction as the truly healing component of care; and a focus on understanding people’s abilities, tastes, interests and values (Kitwood, 1997).

The quality of care provided by staff, which is closely linked to the care setting in which they work, is likely to have an important impact on QoL. For example, care in which the status of clients is equal to staff and communication is personal and two way (Type B) is likely to have a more positive influence on QoL than care involving

high power differentials between staff and residents, and impersonal communication (Type B). The relative impact of quality of care on QoL might vary according to how dependent the person with dementia is on others. Dementia Care Mapping (Bradford Dementia Group, 1997) has been used to assess quality of care (e.g. Kitwood and Bredin, 1992). This method of structured observation involves collecting detailed data over time of what each person with dementia is doing, an estimate of their relative well being / ill-being, a record of episodes in which a person is demeaned or discounted and instances of good practice. The process of feedback following observation is considered an important way of teaching staff ways of improving quality of care.

In the UK, staff employed as care workers in residential care homes are not required to have any former experience of nursing or indeed caring. Typically, they have received limited training at best (Moniz-Cook et al, 1997) Hence, many staff caring for people with dementia will have no training about what dementia is or how to care for people with dementia. Due to limited resources, homes are often understaffed. This results in an enormous pressure to attend to people's physical needs, with psychological needs often undervalued. Moniz-Cook et al (1997) examined psychological well-being, perceptions of the work environment and job satisfaction in 48 members of staff from two local authority homes. They found that that levels of stress were comparable to that found in professional nurses in the NHS. Apart from two people, care staff did not believe that there were opportunities for promotion. They also found that high levels of emotional exhaustion were significantly related to low job satisfaction. They concluded that the low sense of personal accomplishment emphasised the need for staff development within a career structure.

*Table 1: Two types of care settings (Kitwood, 1997, p.106)*

	Type A	Type B
Manager's role	Authoritarian, remote	Exemplary, accessible
Status divisions among staff	Large rigid	Small, flexible
Status of clients	Lowest of all	Equal to staff
Communication	One way, impersonal	Two-way, personal
Feelings and vulnerabilities	Concealed, not dealt with	In the open, dealt with
Power differential	High	Low

### **QoL in residential care**

Some of the problems identified above have led to the idea that residential care settings can encourage anonymity between staff and residents, and negative stereotypes regarding dementia (Woods and Haugen, 1987; Pietrukowicz and Johnson, 1991). However, Kitwood's concept of a Malignant Social Psychology did not imply evil intent on behalf of care staff. In contrast, Kitwood said that most work is done with good intent and that the malignancy is part of our cultural inheritance. He talked about the need to improve the quality of interaction between staff and people with dementia: "When all the conditions are advantageous, it is still common to find that interactions are brief and superficial; when staff have done their essential duties they tend to chat with each other or find something 'practical' to do." (Kitwood, 1997, p.87). This supports the concept of the depersonalised, routine-orientated way in which care can be provided, discussed by Moniz-Cook et al (1997). In summary, one might expect lower levels of QoL for residents living in homes where problems exist within the general culture of the institution.

One way of monitoring the quality of the care environment is to directly question staff and use their attitudes as a way of evaluating the standard of care they are providing. The Approaches to Dementia Questionnaire (ADQ, Lintern & Woods, 2001) attempts to quantify staff's approaches to dementia using two sub-scales: hope and person-centredness. Much of what has been discussed above can be linked to these two factors. For instance, staff working in an environment which puts emphasis on physical care to the exclusion of psychological care might become less person-centred. Those receiving little support for the work they are doing may become less hopeful over time. A question in the hope sub-scale is "nothing can be done for people with dementia, except for keeping them clean and comfortable". Staff agreeing with this statement might make little effort to engage in psychological care, which Kitwood identified as essential in improving the care environment. Similarly, if a person agrees with the statement "It is important for people with dementia to have stimulating and enjoyable activities to occupy their time" (part of the 'person-centred sub-scale'), they are more likely to initiate activities and create a stimulating environment for residents.

Lintern, Woods and Phair (2000) showed how staff performances on the ADQ can be linked to observable phenomena in the care environment. After giving the staff team in a residential home extensive training and feedback using Dementia Care Mapping, they observed the development of relationships between staff and residents, improved communication amongst staff, a sense of team cohesion and a much greater awareness of the necessity for psychological care alongside physical care. This coincided with improvements on the ADQ in both hope and person-centredness. Therefore, one might predict a link between staff attitude to dementia (hope and person-centredness)

and QoL in residents. Lintern et al (2000) showed that staff with more positive attitudes to dementia allowed residents more choice, freedom, opportunities to express themselves and a more relaxed and stable environment. All these factors could be considered contributory to improvements in QoL. This current study hypothesises that higher levels of hope and person-centredness in staff are associated with increased resident QoL (see hypotheses).

### **Different perceptions of QoL**

A major question for this thesis asks why there might be a discrepancy between a) the person with dementia's perception of their QoL and b) their care staff's perception of it. This seems important because (1) measures have been developed which place value on both evaluations (or rely solely on proxy evaluations), (2) research suggests that staff factors (e.g. stress, hope and person-centredness) might impact on their perception of and relationship with people with dementia, (3) research suggests that the severity of dementia might impact on people's self assessment, e.g. of their memory (see next section).

### **People with dementia: factors which might affect their own perception of their QoL**

There is a vast and complex literature on how 'awareness' might impact on symptoms in dementia and the person's interpretation of them. Some authors have found evidence that the level of a person's cognitive impairment affects their awareness of it. For example, Lopez, Becker, Somsak, Dew & DeKosky (1994), using a sample of 181 people with probable dementia, found that awareness of deficits declined as dementia severity (as rated by the Mini-Mental State Examination) increased. They

also found that depression and psychosis had no impact on people's awareness of their cognitive decline. This study supported earlier research (Reisberg, Gordon, McCarthy & Ferris, 1985) which showed that people with moderate to severe dementia rated their memory impairments as less severe than their spouses. Because the people with dementia showed relative awareness of their spouses' cognitive functioning, the authors concluded that their own lack of awareness was due to the operation of a defence mechanism. However, their sample was small and this was based on their own interpretation.

Other research has shown that awareness can fluctuate greatly over time and circumstances. Phinney (2002) conducted a qualitative analysis using a small sample of people with dementia, asking them about their understanding of their symptoms. She found that descriptions of symptoms may be salient, vague or forgotten, concluding that it might be difficult for people to articulate a narrative of what is happening in their lives. Further, there is some evidence that people with dementia have a decreased awareness of their ability to perform everyday tasks. Giovannetti (2002) found that when performing a series of tasks, such as toast preparation and gift wrapping, people with dementia were aware of and corrected significantly less errors compared to 'healthy' controls. However, the sample was skewed in that there were 54 people with dementia and only 10 controls. Similarly, Demarest (1996) concluded that people with dementia have impaired awareness of their overall functional abilities. However, he found that less 'aware' people were not more cognitively impaired, as might be expected, although they were significantly more impaired in functional daily living skills. Although the above only provides a brief introduction to the complex literature on awareness, it is important to be mindful of how awareness might impact

on ratings of QoL by people with dementia, especially as many measures of QoL contain questions on memory and functional ability.

Brod et al. (1999) argued that awareness of one's own feeling states may be preserved, even when awareness of cognitive deficits is impaired. This implies that ratings of more subjective areas of QoL, such as mood, can be made by those at any stage of dementia, provided that some degree of communication ability remains. Ratings on more 'objective', as opposed to 'subjective' domains, are more likely to be compared to the outcomes of objective tests, hence subject to scrutiny if there is a difference. Such comparisons might be harder to make for more subjective items. However, it is important to be aware of difficulties surrounding the very construct of 'objective', as outlined earlier. Individual characteristics such as cultural background, education, socio-economic status, age and gender may make different areas of QoL more or less important to that person. Logsdon et al (2002) suggested that the stage of dementia might impact on what is important in QoL, for example preservation of intellectual capacity may seem important in early stages yet comfort and safety more important in later stages.

### **Care staff: factors which might affect their perception of QoL in people with dementia**

The care environment and job satisfaction in care staff can influence their stress and burnout, and can impact on the quality and quantity of their interactions with residents. It follows that such factors might influence staff members' perception of individuals QoL, with interaction or burnout (for example) being mediating factors. Logsdon et al (2002) found that family carers' rating of QoL in people with dementia

significantly correlated with the carer's level of burden and depression. The authors suggested that: "Caregivers who are highly burdened or depressed may rate their patient's QoL lower because they have a negative bias that influences their perspective. It is likely that this is not limited to QoL assessment in cognitively impaired individuals" (p.517). They concluded that caregiver ratings do not substitute for patient ratings and that future research should address factors that affect both patient and caregiver ratings.

Moniz-Cook et al (2000) examined staff factors associated with perception of behaviour as 'challenging' in residential and nursing homes. They used a number of staff measures including demographics, experience, stress, burnout, job satisfaction, knowledge of dementia and management practices in the home. They asked staff to rate 'ease of management' on 14 vignettes of challenging resident behaviour, finding that only supervisor support, staff anxiety and the potential to relate to people as individuals predicted 'perceived management difficulty.' They also found that in any given home, there was great variation in staff perception and that overall, qualified staff appeared to have greater difficulty in managing challenging behaviour than care assistants. These findings mirrored previous research which showed that problematic behaviour in a given resident is often perceived differently by different staff, and that its impact on different staff can vary widely (Everitt, Fields, Soumerai & Avorn, 1991).

To date, no studies have considered factors in staff which may contribute to their perception of a person's quality of life. However, one might hypothesise that factors which influence staff perceptions of people's behaviour may similarly impact on their



interpretation of the person's quality of life. Knowledge of individuals might affect staff's perception of them and hence their perception of their QoL. Woods and Haugen (1987) stated that staff should be encouraged to systematically obtain information about the person's life and interests, giving them the opportunity to see the person behind the diagnosis. Pietrukowicz and Johnson (1991) asked staff in two nursing homes to complete a scale on residents which measured positive and negative stereotypes, giving half their sample a brief life history of the resident. At post-test, controlling for individual differences such as prior work experience and knowledge about ageing, those who received life histories reported significantly more positive attitudes on instrumentality, autonomy and personal acceptability of the residents. Their ratings of willingness to work with the residents were not significantly different. The authors suggested that providing more information about individual residents could have not only a positive impact on staff attitudes but also on the self-esteem of both residents and staff, both groups who might be routinely devalued.

Jenkins and Allen (1998) found that longer-serving staff had lower levels of perceived involvement in decision-making and a higher quantity of negative staff-resident interactions. An association between longer-serving staff and the number of negative staff-resident interactions was also found in people with long-term mental health problems (Shepherd et al, 1995, reported by Jenkins and Allen). Shepherd et al suggested that staff may become institutionalised and less resident-orientated over time. Hence the amount of time spent working in the home may have implications as to how staff perceive the QoL of residents.

### **Staff burnout and stress**

There is substantial literature on the effects of burnout and stress on those caring for people with dementia (e.g. Chappell and Novak, 1992; Baillon, Baldwin, Modlin & Lewis, 1996). Maslach defined burnout as “a syndrome of emotional exhaustion, depersonalisation and reduced personal accomplishment that can occur among individuals who do ‘people work’ for some time” (Maslach, 1982, p.3). Baillon et al (1996) examined factors that contribute to stress for care staff in residential homes. Stressful events strongly related to anxiety, with staff rating “insufficient staff on duty”, “too many things to do at once” and “too little time to spend with residents” as particularly stressful. Organisational factors were perceived as equally stressful as aspects of caring for confused residents. Of particular concern, 32% of the staff scored sufficiently highly to indicate minor psychiatric symptoms associated with stress. The authors found that attitudes towards residents in the home did not impact on stress.

Jenkins and Allen (1998) examined the relationship between staff burnout and interactions with residents in two residential homes. They found that staff who reported lower levels of burnout exhibited significantly more interactions with residents. Additionally, staff who perceived themselves as more involved in decisions relating to their work showed significantly fewer negative interactions. The quality or quantity of staff-resident interaction was not significantly related to staff distress, emotional exhaustion and depersonalisation, or the level of dementia in residents. However, results should be interpreted with caution due to the small sample.

**Staff job satisfaction**

Job satisfaction has been linked to stress in care staff. For example, Baillon et al (1996) found that intrinsic, extrinsic and general job satisfaction was negatively correlated with anxiety. Further, satisfaction has been linked to staff-resident interactions. Robertson, Gilloran, McGlew, McKee, McKinley and Wight (1995) observed the 'quality of care' between staff and people with dementia in four psychiatric hospital wards in Scotland. Accumulating the results of staff ratings of their job satisfaction, two wards were classified as 'high satisfaction' and two as 'low satisfaction'. Twenty-four patients in high satisfaction wards and twenty-four in low satisfaction were included, with observations including length of time required for activities of daily living and the 'quality' of the interaction. The results showed that staff on wards with higher levels of satisfaction were more likely to initiate interactions with patients and that patients were offered more choice, independence, personal attention, supervision, information and privacy during physical care tasks. Finally, Jenkins and Allen (1998) found that staff who perceived more involvement in decisions relating to their work showed significantly fewer negative staff-resident interactions. Because job satisfaction might link to the quality of relationships between staff and residents, one might expect it to have some impact on how staff rate resident QoL, and how the residents rate their QoL.

**Staff attitudes towards dementia**

Kitwood (1997) stated that although it is relatively easy to help a person gain knowledge and skills, attitudes (such as ageism, rigidity and arrogance) are often difficult to change. Stating that "attitudes are key", he suggested that they can be evaluated by asking staff to describe examples of good and bad practice. As

mentioned earlier, attitudes towards dementia in staff can be evaluated by the “Approaches to Dementia Questionnaire” which has two subscales: hope and person-centredness. Using this measure, Lintern and Woods (2001) found that hopeful attitudes towards dementia in staff was predictive of more positive behaviour, including engagement in social interactions, purposeful activity and stimulation with residents. There is a substantial narrative literature linking person-centred care with better attitudes in staff and better care environments, e.g. Kitwood (1995, 1997). Moniz-Cook et al (2000) found a significant relationship between person-centredness in staff and appraisal of behaviour as challenging in people with dementia. Aside from this, the author was unable to identify any literature directly linking person-centredness to staff perceptions or appraisal of people with dementia.

### **Proposed conceptual model**

Figure 1 shows a model which proposes to outline the factors contributing to perception of QoL in people with dementia and staff. Following the literature discussed (e.g. Moniz-Cook et al, 2000; Robertson et al, 1995), the staff factors hypothesized as contributing to their perception of resident QoL are job satisfaction, person-centredness, hope, stress, anxiety and support received. Due to constraints of this study, only job satisfaction, person-centredness and hope will be investigated. The main factors in people with dementia proposed to influence their perception of QoL are level of cognitive impairment, mood and personality. Only cognitive impairment will be investigated in this study, as it is likely to have the most clinical relevance. Some of the literature has suggested that caregiver ratings of QoL are influenced by cognitive impairment (Gonzalez-Salvador et al, 2000) and one would expect a greater dependence on proxy ratings of QoL for those who are more cognitively impaired.

Decisions, for example regarding the effectiveness of an intervention, might be made using proxy ratings. Hence it is important to understand how closely staff perceptions of QoL in those more cognitively impaired match the person's own (i.e. the nature of the discrepancy as a function of cognitive impairment).

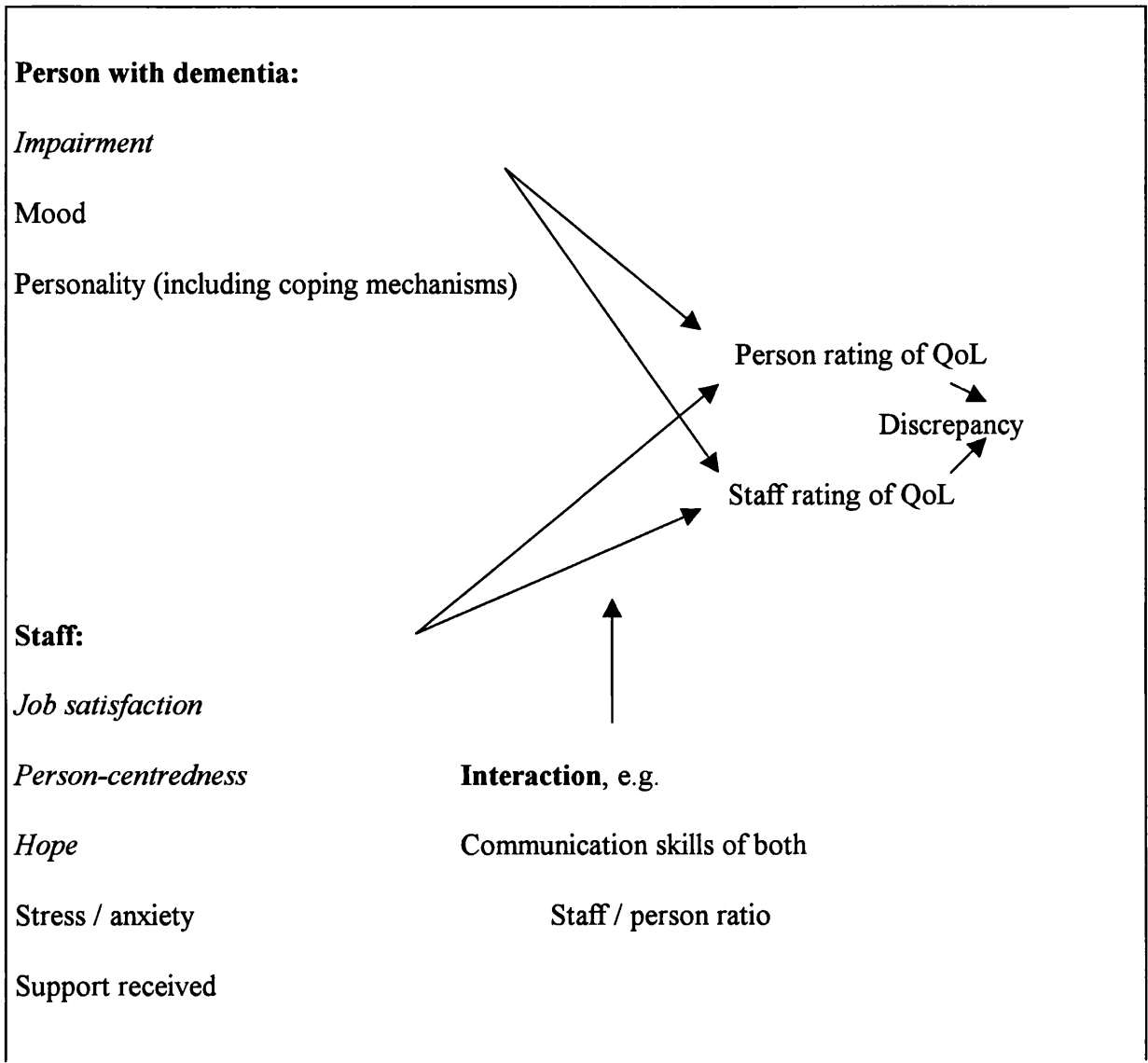
The model also proposes that there are interactive factors between people with dementia and staff, which might impact on the perception of QoL in staff. This includes the communication skills of both and the amount that they communicate and listen to each other. The latter might be affected by the ratio between staff and residents. For example, if the person with dementia is withdrawn and communicates minimally, or if the staff member does not prioritise communication with residents, the discrepancy between ratings of QoL may be greater. These interactive factors will not be investigated in this study, again due to time limitations. Finally, the model shows an overlap in that staff factors may have an influence on QoL in people with dementia. For example, QoL might be higher for residents whose staff are more satisfied with their jobs, person-centred and hopeful. Additionally, factors in people with dementia might influence staff ratings of their QoL. For example, the literature suggests that QoL might be rated by proxies as lower in those who are more impaired (Gonzalez-Salvador et al, 2000) and personality factors, such as coping style, might influence others' perception of their QoL. The discrepancy between the two scores (assuming that a quantitative measure such as the QoL-AD were used) would be calculated by subtracting one score from the other. Hence this study begins to investigate some of the factors which might influence perceptions of QoL.

### **Rationale for comparing person and proxy ratings of QoL**

Proxy measures are the most common methodology employed to collect data about people with dementia (Brod et al, 1999). This is probably due to reservations about people with dementia's ability to comprehend questions and provide reliable accounts. Many research studies have used staff measures to evaluate outcome (e.g. Breuil, De Rotrou, Forette, Tortrat, Ganansia-Ganem, Frambourt et al, 1994). An example is the Depressive Signs Scale (Katona & Aldridge, 1985), a proxy rating scale for depression in dementia. There are two types of potential discordance between person and proxy ratings of QoL: disagreement about what is important to include and disagreement in measurement.

Since staff are frequently asked to make ratings on behalf of people with dementia, one might expect an increase in the use of staff-rated QoL measures over time. Nonetheless, some argue that any appraisal of QoL should rely where possible on the perception of the individual person (Thorgrimsen et al, 2003). With this in mind, an understanding of how the two ratings compare seems important. An advantage of using proxy ratings is that they can be used throughout the course of the dementia. They may be quicker to gather and there is reduced concern about whether or not the person understands the question. However, proxy reports are likely to be influenced by their own expectations and belief system, nature of relationship with the person with dementia, time spent with person, objectiveness of the questions and issues in their own life.

*Figure 1: Proposed conceptual model highlighting factors affecting perception of QoL in people with dementia and care staff*



N.B. Items in italics will be investigated in this study.

(such as stress and hope) which affect their perception of the person's QoL. The most obvious advantage of asking the person with dementia to report on their QoL is that their rating is more meaningful than someone else's perspective on it. It might be argued that a person's own perception of their QoL is what their QoL really is, regardless of how much it relates to 'objective' outcomes. The disadvantage of person

ratings is that there may be some doubt about their ability to understand the questions and that the dementia may cloud their awareness and hence their ability to answer some of the questions accurately.

### **Research comparing person / proxy ratings**

Person-proxy comparisons within dementia populations have considered various outcomes. Teri and Wagner (1991) assessed the concordance of ratings of depression between 75 people with dementia, their caregivers and geriatric clinicians. Using the Hamilton Rating Scale, they found that people with dementia perceived themselves as less depressed than did caregivers or clinicians. Level of dementia, as assessed by the Mini-Mental-State-Examination, did not affect the ratings. Earlier studies (Miller, 1980; Burke, Rubin, Morris and Berg, 1988) also showed that people with dementia rated themselves as less depressed than their clinicians, friends or family did. In contrast to Teri and Wagner (1991), Burke et al. (1988) found that ratings of depression were less similar to proxy ratings for people with more severe dementia, with proxies rating people as more depressed, the more their dementia progressed. They concluded that the ability of caregivers and clinicians to estimate depression declines as cognitive impairment increases. Finally, Parmalee, Katz and Lawton (1989) found no significant differences between patient and proxy ratings on the Geriatric Depression Scale in cognitively impaired people.

Kiyak, Teri and Borson (1994), in a two-year longitudinal study, found that 40 people with Alzheimer's consistently rated their functional abilities as higher than did their family members. The authors suggested two possible explanations for this discrepancy, both of which have been presented earlier on this chapter. First, that



intrinsic to dementia is a decrease in awareness of one's abilities. Second, that increasing family burden may negatively skew caregivers' reports of the person's functioning. Because ratings of functional status by 'healthy elderly' and their families were more concordant, the authors concluded that the first explanation was more likely. However, this argument does not rule out their second explanation, as family burden in the healthy elderly would be lower. Further, people with dementia's reports did show declines over time, thus suggesting that they did have an awareness of their functional deterioration. They concluded that there is a need to interview both people with dementia and their caregivers to get a clearer picture, and suggested the role of observational methods.

Research comparing person-proxy ratings of QoL has been conducted in other populations. For example, Sainfort, Becker and Diamond (1996) compared judgements of QoL between 37 schizophrenia patients and their primary clinicians, finding moderate agreement on symptoms and function, less agreement on physical health and little or no agreement on social relations and occupational aspects of QoL. These latter areas might be considered to be more 'subjective' and therefore harder to rate by proxies. The authors' suggestions for this discrepancy were that patients might adapt to their symptoms and use a different yardstick to measure them, or that some clinicians may be more / less knowledgeable than others. These ideas could also be applied to a dementia population.

Some studies have begun to compare scores on QoL measures between people with dementia and proxies. Selai et al (2001) compared scores on the QOLAS in ten patient – carer dyads. They found that carers rated patients as having poorer QoL in

all domains of the QOLAS than the patients rated themselves. Thorgrimsen et al (2002), comparing 38 person-proxy ratings on the QoL-AD, also found that people with dementia appeared to have a more positive outlook on their lives and roles than their carers or health care professionals did. Using the same measure, Logsdon et al (2002) found that the level of agreement between 155 patient and caregiver ratings was 'modest'. They argued that this is likely to reflect a real difference in the way they perceive QoL rather than a lack of reliability of the measure. Prior to this, Logsdon, Whitehouse and Teri (1996) had reported good person-carer correlations on some individual items ('mood', 'energy', 'physical health' and 'self as a whole'), whereas correlations on 'memory' and 'ability to do chores' were lower.

### **Description of study**

This study examines the rating of QoL (using the QoL-AD) in 76 dyads of people with dementia and their care staff, recruited from nine residential care homes in greater London. Additionally, care staff are given measures of job satisfaction, hope and person-centredness and the people with dementia are assessed for severity of cognitive impairment. The primary research questions are:

1. Is there a relationship between person and staff-rated QoL?
2. Which items of the QoL-AD are more similarly rated between people with dementia and staff?
3. Which staff factors (e.g. support, hope and person-centredness) are associated with a discrepancy between staff rated and person-rated QoL in people with dementia?
4. Is severity of cognitive impairment associated with the discrepancy between staff rated and person-rated QoL?

5. Is there a relationship between job satisfaction, hope and person-centredness in staff, and QoL in residents?

The hypotheses are as follows:

1. In line with past research, the items 'memory' and 'ability to do chores' will be rated more discrepantly between people with dementia and staff. Other items which might be rated more differently might be the more 'subjective' domains, such as 'mood' and 'life as a whole'.
2. Low job satisfaction, hope and person-centredness in staff will be associated with a higher discrepancy between ratings of QoL, with staff underestimating QoL.
3. Increased severity of dementia will be associated with a higher discrepancy between ratings of QoL, such that increased cognitive impairment will be associated with lower perceived QoL by the staff.

## **Chapter 2: Method**

### **Overview**

This study involved recruiting 76 people with dementia and 76 staff members from nine residential homes in greater London. People with dementia were interviewed to obtain a measure of their QoL and their level of cognitive impairment. Each staff member was required to complete the QoL-AD on behalf of one person with dementia, in order for comparisons in ratings to be made. Staff were also asked to complete questionnaires on their job satisfaction, hope and person-centredness.

### **Power analysis**

A power calculation was performed using Cohen's table of statistical power (Cohen, 1992). Using multiple regression with three predictors, a type I error rate of .05 and a medium effect size, 76 person-staff dyads were required.

### **Sample**

The researcher had links with residential homes through previous research. Twenty-three homes in Essex, Hertfordshire, Barnet and Haringey were invited to participate. Letters were followed up with a phone call and nine homes (39%) agreed to take part. Reasons for non-participation were not returning calls (22%), too busy (9%), few or no people with dementia (26%) and feeling that the study would be too intrusive (4%). Of the participating homes, seven were Local Authority run and two were run by charitable trusts. They each had between 32 and 60 residents (mean = 48).

**Procedure: People with dementia**

In participating homes, a meeting was arranged with the manager. The aim was to discuss the research, answer any questions and compile a list of residents who might be suitable to participate. The inclusion criteria were the provision of consent (see below) and the presence of dementia according to the DSM-IV criteria (APA, 1994). This was based on clinical information from the notes and discussion with the manager and was confirmed by the researcher during the resident's assessment interview. The exclusion criteria was an inability to complete the QoL-AD, according to the guidelines ("instructions for interviewers", see Appendix 2). These guidelines helped to avoid influencing the person's responses, but also provided clarity as to whether or not people were suitable for interview. For example, it is suggested that if the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued.

In each home, all potentially suitable participants were interviewed individually in a quiet room, sometimes with a member of staff present. This meeting involved the following:

- 1) Requesting informed consent. People were given an information sheet outlining the nature and purpose of the study and giving them the opportunity to ask any questions. They were then asked to sign a consent form before participating in the study. If the researcher felt that the person was unable to understand the nature of the research, they would automatically be excluded. It usually followed that they would not understand the questions in the QoL-AD (see: 'Measures' section). However, due to their dementia, it was not always clear what people had understood. Obtaining consent was considered an ongoing process. For example,

people were reminded that they could withdraw at any time and if they appeared uncomfortable answering questions, the interview was terminated immediately. Due to the potential power differential, care was taken not to pressurise anyone to participate.

- 2) Using the Mini Mental State Examination (Folstein, Folstein and McHugh, 1975: see measures) and observations during interaction, as evidence that they met the DSM-IV criteria for dementia.
- 3) Interviewing with the QoL-AD. Residents completed the QoL-AD in an interview format.

Ninety-five people were invited to participate. Nineteen (20%) were excluded, due to being unable to comprehend and/or respond to two or more items on the QoL-AD (7), not having dementia (6) or refusing to consent to participate (6). Seventy-six residents were included. The mean age was 85.2 years ( $sd = 7.4$ ), with a range from 60 to 98 years. There were 67 women (88%) and 9 men (12%). The mean MMSE score was 13 (standard deviation = 4.8), with a range from 3 (severe dementia) to 25 (mild dementia).

### **Procedure: Staff**

Once the residents had been selected and interviewed, the manager was asked to identify a key worker or other member of staff who knew the person well and could comment on the individual's QoL. Typically, staff who were working that day were interviewed and the researcher arranged to come back one or more times to interview other staff. Allocated staff were given an information sheet explaining the nature and purpose of the study and were asked to sign a consent form. The staff interview

involved collecting demographics and the use of three measures (see below for details): The QoL-AD, Job Satisfaction Index (Barkham, Firth-Cozens, Reynolds, Shapiro and Bachman, 1979) and the Approaches to Dementia Questionnaire (Lintern and Woods, 2001). For the QoL-AD, staff were asked to think about how they perceived the QoL of the resident, not how the resident perceived his/her own QoL. They were given the choice of reading and completing the questionnaires alone (whilst the researcher sat with them to answer any questions) or to be interviewed. It was made clear that staff had the right to refuse or withdraw at any point if they wished. Only one staff member did not wish to participate and nobody withdrew from the study.

The mean age of staff was 40.3 (sd = 12.6), with a range from 16 to 67 years. There were 72 women (95%) and 4 men (5%). Four (5%) were management, twelve (16%) were senior carers and sixty (79%) were care assistants. The mean duration of working in the home was 5.3 years (sd = 4.3), with a range from 0 to 17 years. The mean duration of working with older people was 8.5 years (sd = 5.5), with a range from 0.5 to 21 years. Finally, the mean number of person-staff dyads recruited in each home was 8.4 (sd = 2.8), with a range from 4 – 14.

### **Measures** (see Appendix 2)

#### *Person with dementia:*

*Quality of Life – Alzheimer's Disease* (QoL-AD: Logsdon et al., 1999) is a brief, self-report measure with 13 items covering the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. Items are scored on a four-point Likert scale, ranging from 1 (poor) to 4

(excellent). It was designed so that people with dementia and their carers may both complete it (these scores may be combined to produce a single score). Although the measure was developed using data from home carers, a subsequent validation study (Thorgrimsen et al, 2003) using data from paid care staff showed that the QoL-AD had excellent inter-rater reliability and internal consistency, and good content validity, criterion concurrent validity and construct validity. This measure was selected because it is brief, easily administered and can be completed by people with a mini-mental state score as low as 3 (severe dementia). The latter is particularly important when interviewing people in residential care, who are often extremely cognitively impaired and hence other measures of QoL may be too complex (Thorgrimsen, et al, 2003).

*Mini-Mental State Examination* (MMSE: Folstein et al., 1975) is an internationally recognised, 11-item set of simple tasks presented informally to the participant. It involves orientation to time and place, registration of three words, attention and calculation, recall, language and visual construction. It has a maximum score of 30 points, with 24 or less suggesting cognitive impairment. Reliability and validity are satisfactory. The MMSE is helpful in assessing the person's level of cognitive impairment without subjecting them to extensive neuropsychological tests.

*Demographics.* Details of peoples' age (obtained from files) and gender were recorded.

*Staff measures:*

*QoL-AD.* Staff were given the family version of the QoL-AD, which is identical to the resident version except that it asks the respondent to complete the measure on behalf of someone else. The form was amended to say "staff version" rather than "family version" (see Appendix 2). Staff completed the QoL-AD in interview format, or by



themselves but with the researcher present (to answer any questions).

*Job Satisfaction Index* (Aspects of Work Inventory (AWI): Barkham et al., 1979). An 18-item Likert scale in which respondents rate their satisfaction with different aspects of their job on a scale from extremely dissatisfied (1) to extremely satisfied (7). Inter-rater reliability and validity are good.

*Approaches to Dementia Questionnaire* (ADQ: Lintern and Woods, 2001). A 20-item compound Likert scale in which staff rate their extent of agreement with different statements about dementia. Ratings range from (5) 'strongly agree' to (1) 'strongly disagree'. A total score and two sub-scores, 'hope' and 'person-centredness', can be calculated. The sub-scales were derived from factor analyses from data from over 200 care staff and have been cross-validated. Test-re-test reliability is good (total = 0.76, hope = 0.70, person-centredness = 0.69). Predictive validity is good for the 'hope' sub-scale, which predicts staff engagement in social interaction, purposeful activity and stimulation with residents. It was chosen as it appeared to be the only available measure of hope and person-centredness.

*Demographics*. Staff were asked to complete a demographics sheet which included their age, gender, job title, length of time working in the home (to the nearest half year) and with older people in general.

### **Ethical issues**

Ethics approval was obtained from the joint UCL/UCLH ethics committee (Appendix 1). Information sheets and consent forms both for people with dementia and staff (see appendix 1) were given in. Each participant was asked to sign the consent form which the researcher also signed, confirming that they had explained the nature of the research to the participant. Care was taken to make the forms brief and simply

worded, due to difficulties experienced by people with dementia in understanding complex information. I attempted to continually evaluate whether or not I believed the person to understand this information, through comments or responses they made, in order for people to make informed decisions as to whether or not to participate. The term 'memory difficulties' (as opposed to 'dementia') was used because many of the residents had never had a formal diagnosis and it would have been unethical to present them with this label. Typically, a diagnosis of dementia is made following detailed assessments and is more likely to be determined if, for example, it might have useful implications for the person's care.

### **Chapter 3: Results**

#### **Statistical analyses**

Data was analysed using SPSS (version 10). Preliminary analyses involved checking of variables for normality, outliers, skewness and kurtosis. Subsequently, Pearson's correlations between person and staff ratings on the QoL-AD were calculated. Individual item correlations and comparisons of means were performed using non-parametric tests. Hierarchical linear regression was used to examine predictors of the discrepancy between person and staff rated QoL, both with and without the direction of the discrepancy taken into account. Finally, correlations were performed between homes to investigate any links between resident QoL and staff hope, person-centredness and job satisfaction.

#### **Data checking**

Prior to analysis, the skewness and kurtosis and the overall distributions of all variables were inspected to ensure that they approximated to a normal distribution. Unless mentioned otherwise, it can be assumed that variables approximated to normality (Tabachnik and Fidell, 1996).

#### **Results of research questions:**

##### **Relationship between person and staff-rated QoL**

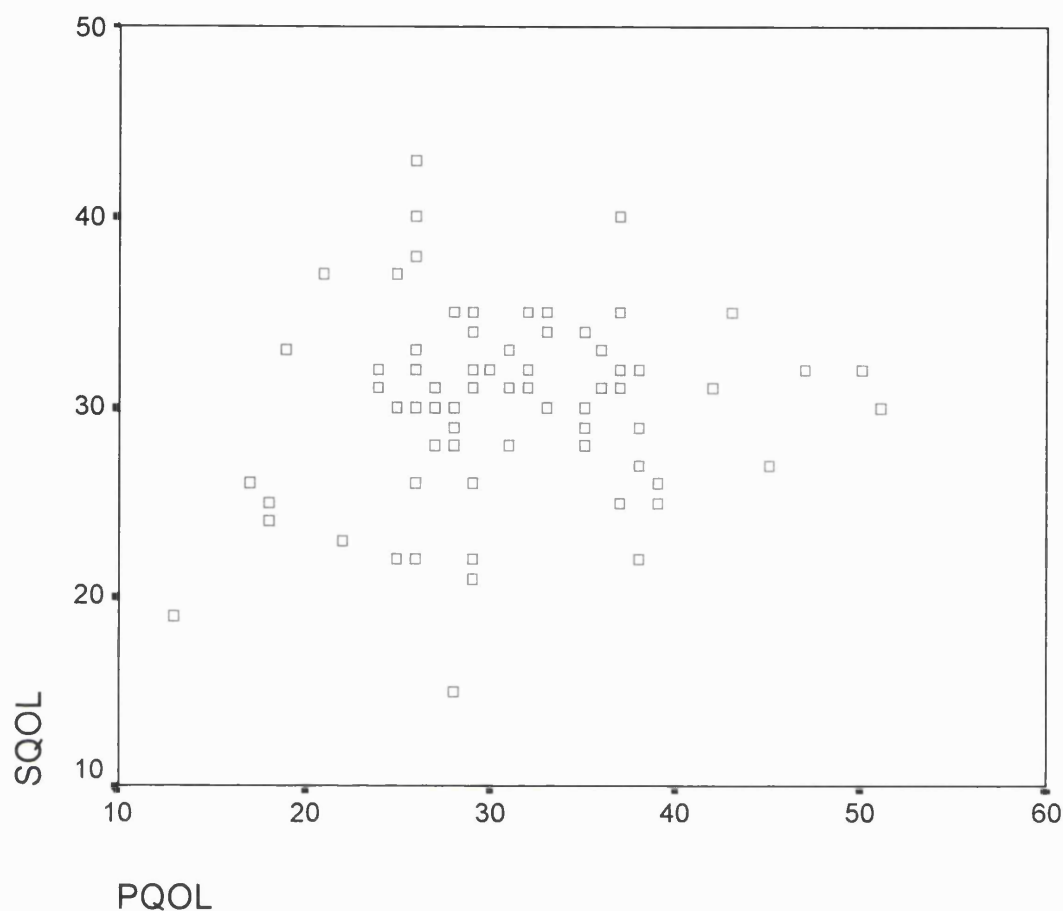
Figure 2 gives a scatter plot showing the relationship between person-rated QoL (PQoL) and staff rated QoL (SQoL). Person-rated QoL is slightly higher (mean PQoL = 30.9, SD = 7.4; mean SQoL = 30.2, SD = 5.0). A paired samples t-test showed that

there is not a significant difference between the means of the two groups:  $t(75) = 0.72$ ,  $p = 0.48$ . There is no significant correlation between PQoL and SQoL ( $r = 0.15$ ,  $p = 0.21$ ). There are no outliers. There is a slightly wider range in PQoL [13 - 51] than SQoL [15 - 43].

### **Rating of individual items on the QoL-AD**

The level of agreement between person and staff ratings of individual items of the QoL-AD were examined in two ways. Firstly, level of agreement between dyads was examined using Spearman's rank correlation, as data for individual items of the QoL-AD (rated from 1-4) should be treated as ordinal, hence the need for non-parametric analysis. Secondly, Wilcoxon tests were used to compare the person and staff means on each item. Table 2 shows results of the Wilcoxon tests and correlations for each item. 'Physical health', 'family' and 'friends' were rated similarly between the two groups, indicated by the significant correlations and lack of differences between the means. 'Memory', 'ability to do chores', 'marriage / closest relationship' and 'life as a whole' were rated differently, due to the significant difference between the means in the Wilcoxon tests.

Figure 2: Scatter plot showing the relationship between person-rated QoL (PqoL) and staff-rated QoL (SqoL)



#### Association between staff factors and the discrepancy in QoL ratings

A new variable, 'QoLDIF' was created by subtracting staff QoL (SQoL) from person QoL (PQoL). Positive scores on QoLDIF indicated that the person rating was higher than the staff rating. Negative scores indicated that the staff rating was higher than the person rating. The scores ranged from -17 to 21. Prior to planning this analysis, whether or not there were systematic differences between homes in QoLDIF was examined. This was necessary to ascertain, in order to decide whether or not to employ an analysis which allowed entry of 'home' as a random factor.

Table 2: Individual item comparisons of means and correlations between staff and person ratings on the QoL-AD.

QUESTION	PERSON SCORE: MEAN (SD)	STAFF SCORE: MEAN (SD)	COMPARISON OF MEANS: WILCOXON Z, P (significance)	CORRELATION: SPEARMAN'S Correlation coefficient, P (sig)
1. Physical health	2.33 (0.91)	2.30 (0.63)	-0.36, 0.716	0.29, 0.01*
2. Energy	2.20 (0.89)	2.08 (0.71)	-1.03, 0.30	0.12, 0.29
3. Mood	2.42 (0.79)	2.58 (0.66)	-1.13, 0.26	- 0.16, 0.17
4. Living situation	2.74 (0.81)	2.91 (0.66)	-1.48, 0.14	0.19, 0.16
5. Memory	2.20 (0.83)	1.93 (0.87)	-2.18, 0.03*	0.20, 0.09
6. Family	2.68 (0.97)	2.51 (0.96)	-1.17, 0.24	0.23, 0.04*
7. Marriage / closest rel.	2.78 (0.87)	2.49 (0.92)	-2.03, 0.04*	0.12, 0.30
8. Friends	2.30 (0.94)	2.11 (0.89)	-1.56, 0.12	0.24, 0.04*
9. Self as a whole	2.36 (0.89)	2.50 (0.64)	-1.12, 0.26	0.30, 0.80
10. Ability to do chores around house	2.08 (0.89)	1.62 (0.78)	-3.63, 0.00*	0.23, 0.03*
11. Ability to do things for fun	2.20 (0.88)	2.17 (0.85)	-0.18, 0.86	0.08, 0.44
12. Money / finances	2.30 (0.83)	2.53 (0.72)	-1.76, 0.08	0.03, 0.83
13. Life as a whole	2.32 (0.90)	2.57 (0.64)	-1.94, 0.05*	0.08, 0.50

\* = significant (p < 0.05)

Using an ANOVA which considered QoLDIF as the dependent variable and home as a random factor, there were no significant differences between homes in the way QoL was measured by staff and people with dementia ( $F(8,67) = 1.06, p = 0.40$ ). Subsequently, multiple regression was used as the main method of analysis and differences between homes was not considered. Two analyses were performed:

*Analysis 1: Relative change*

This first analysis considered the direction of disagreement (as well as the amount) to be of importance. Hence the direction and not simply that absolute degree of discrepancy was tested in this analysis. Hierarchical multiple regression was performed, with QoLDIF as the dependent variable. Because there were so few male staff members (4 compared to 72 females), gender was not considered as a factor. Staff were ranked according to seniority where 3 = management, 2 = senior care staff and 1 = care staff.

The first set of independent variables entered (Model 1) were staff age, staff seniority, staff duration in the home and staff duration working with older people. The second set (Model 2) consisted of staff satisfaction, hope and person-centredness. This method was used to see whether the key predictors (those entered in model 2) added to the variance explained over and above other factors (those entered in model 1). The change in  $R^2$  between model 1 and model 2 was small (.05) and not significant ( $F_{7,67} = .08, p = .59$ ). 3% of the variance was accounted for by staff age, seniority, duration in the home and in working with older people, and this only increased to 8% when adding satisfaction, hope and person-centredness. Thus, the hypothesised staff variables did not appear to predict discrepancies in ratings. This can be seen in Table

3, as none of the individual variables reach significance.

*Table 3: Staff factors and QoL ratings - relative change*

Hierarchical Regression Statistics					
	Regression terms	Rsquared	F	Beta	p
Model 1	--	.03	.57	--	--
	Age	--	--	-.15	P = .29
	Seniority	--	--	.06	P = .64
	Duration: home	--	--	.19	P = .27
	Duration: older people	--	--	-.04	P = .81
Model 2	--	.08	.80	--	--
	Satisfaction	--	--	-.16	P = .19
	Hope	--	--	-.01	P = .95
	Person- centredness	--	--	.15	P = .25
Model 2		.05	1.10		P = .36
-- Model	--			--	
1					



*Analysis 2: Absolute change*

This second analysis took the discrepancy between scores as important, regardless of its direction. Hence, the analysis examined factors which might be associated with the absolute value of the discrepancy. A new variable was created (QoLDIF2) which made all negative values positive on QoLDIF, ie. -3 and 3 became equal as they both represented a discrepancy of 3 points between person and staff ratings. An identical regression analysis was performed as above, but using QoLDIF2 as the dependent variable. The change in  $R^2$  between model 1 and model 2 was small (.01) and not significant ( $F_{7,67} = .28$ ,  $p = .96$ ). 2% of the variance was accounted for by staff age, seniority, duration in the home and in working with older people, and this only increased to 3% when adding satisfaction, hope and person-centredness. Thus, the hypothesised staff variables did not appear to predict discrepancies in ratings. This can be seen in Table 4, as none of the individual variables reach significance.

**Association between severity of cognitive impairment and the discrepancy in QoL ratings***Analysis 1: Relative change.*

This considered the direction of disagreement (as well as the amount) to be of importance, hence the direction and not simply that absolute degree of discrepancy was tested in this analysis. Hierarchical regression used QoLDIF as the dependent variable. Gender was not examined, as only 12% of the participants were male. Model 1 included the person's age. Model 2 included the person's MMSE. The change in  $R^2$  between Model 1 and Model 2 was small (.02) and not significant ( $F_{2,73} = 1.55$ ,  $p = .22$ ). 2% of the variance was accounted for by the person's age and this only increased to 4% when adding MMSE. This can be seen in Table 5, where the results

do not reach significance.

*Table 4: Staff factors and QoL ratings - absolute change*

Hierarchical Regression Statistics					
	Regression terms	Rsquared	F	Beta	P
Model 1	--	.02	.35	--	--
	Age	--	--	-.14	P = .35
	Seniority	--	--	.07	P = .57
	Duration: home	--	--	-.05	P = .77
	Duration: older people	--	--	.09	P = .61
Model 2	--	.03	.28	--	--
	Satisfaction	--	--	-.25	P = .80
	Hope	--	--	-.74	P = .46
	Person-centredness	--	--	.47	P = .64
Model 2 – Model 1	--	.01	.21	--	P = .89

*Table 5: Person factors and QoL ratings - relative change*

Hierarchical Regression Statistics					
	Regression terms	Rsquared	F	Beta	p
Model 1	Age	.02	1.56	-.14	P = .22
Model 2	MMSE	.04	1.55	-.14	P = .22
Model 2 – Model 1	--	.02	1.52	--	P = .22

*Analysis 2: Absolute change.*

This considered the discrepancy between scores as important, regardless of its direction. Regression analyses were identical to that above but using QoLDIF2 in the hierarchical regression. The change in  $R^2$  between Model 1 and Model 2 was small (.003) and not significant ( $F_{2,73} = .14$ ,  $p = .87$ ). Hence less than 1% of the variance was accounted for by both age and MMSE score. This can be seen in Table 6, where the results do not reach significance.

*Table 6: Person factors and QoL ratings - absolute change*

Hierarchical Regression Statistics					
	Regression terms	Rsquared	F	Beta	P
Model 1	Age	.001	.08	-.03	P = .79
Model 2	MMSE	.004	.14	.05	P = .66
Model 2 – Model 1	--	.01	.20	--	P = .66

#### **Association between cognitive impairment and person and staff-rated QoL**

Pearson's correlation showed no relationship between severity of cognitive impairment (MMSE score) and person-rated QoL ( $r = -0.12$ ,  $p = 0.30$ ). Further, there was no correlation between severity of cognitive impairment and staff-rated QoL ( $r = 0.02$ ,  $p = 0.89$ ).

#### **Association between staff factors and resident QoL.**

Any given individual's QoL was unlikely to be affected by one staff member's level of hope, person-centredness and job satisfaction, because the link was too tenuous. Instead, within each home, a possible association between the overall level of hope, person-centredness and job satisfaction in staff and QoL in residents seemed more likely. Therefore, an analysis comparing staff factors and resident QoL was not

possible using the full dataset as it stood. Instead, the mean level of hope, person-centredness, job satisfaction and resident QoL (PQoL) was calculated for each home. These means were then used to calculate correlations between homes, as seen in Table 7.

*Table 7: Pearson's Correlations between staff factors and resident QoL between homes*

	Staff Job Satisfaction	Staff Hope (ADQ sub-scale)	Staff Person-Centredness (ADQ sub-scale)
Person-rated QoL	R = -.36, p = .35	R = .72, p = .03*	R = .37, p = .33

\* Significant ( $p < 0.05$ )

There was a significant\* correlation between ADQ (hope) and person-rated QoL, suggesting that there might be an association between hope in staff and QoL in people with dementia. Because of this finding, hope was investigated further by looking at whether it correlated with person-centredness or job satisfaction. Both were insignificant (hope and person-centredness:  $r = 0.66$ ,  $p = .054$ ; hope and job satisfaction:  $r = 0.18$ ,  $p = 0.64$ ).

## **Chapter 4: Discussion**

### **Summary of results**

This is the first study to compare ratings of QoL between people with dementia and their care staff and examine factors which might contribute to such evaluations. The main finding was that people with dementia and their care staff generally rated QoL differently. This was shown through the lack of correlation between the scores of the two groups, and the marginally higher mean person-rated QoL score. Some items on the QoL-AD were rated more similarly between staff and people with dementia than others ('physical health', 'family' and 'friends'). There was a significant difference between the way in which 'ability to do chores', 'marriage / closest relationship', 'memory' and 'life as a whole' were rated between the two groups. People with dementia rated all but the latter more positively than staff, rating their 'life as a whole' slightly lower.

Furthermore, it was unclear what might be associated with a person-staff dyad having a discrepant view. None of the staff factors measured (hope, person-centredness, job satisfaction, age, seniority and duration of time working in the home or with older people) predicted the small discrepancy in staff and resident scores. No association was found between age and severity of cognitive impairment in people with dementia and this discrepancy. However, when the data was aggregated within residential settings, a relationship between hope in staff and QoL in the residents emerged. Person-centredness and job satisfaction in staff were not related to QoL in residents within that home.

## **Interpretation of results:**

### **Relationship between person and staff-rated QoL**

The findings, like earlier research with family carers, suggest that care staff rate QoL less favourably than do people with dementia (Thorgrimsen et al, 2002; Selai et al, 2001). Logsdon et al (2002) quoted a 'modest' level of agreement between patient and caregiver ratings on the QoL-AD, quoting a low intraclass correlation coefficient of 0.19. In line with the hypothesis, 'memory' and 'ability to do chores' were rated significantly differently between the two groups. Kiyak, Teri and Borson (1994) also found that people with dementia consistently rated their functional abilities as higher than their family carers did and Reisberg et al (1985) found that people with dementia rated their memory as better than their spouses did. Research was not identified that linked to the way in which other items were rated similarly or differently in this study.

Selai et al (2001) stated that poor person-proxy agreement in ratings might be due to a number of factors, including (i) errors in the measuring instrument, such as ambiguous wording of an item; (ii) that the patient and carer might have different views on whether something is relevant to QoL and (iii) that eccentricity identified by the carer might be acknowledged by the patient but not perceived as a problem, e.g. choosing to wear orange trousers with a pink shirt. Some further possible explanations will be presented:

#### *1) Difficulties in any one individual rating the QoL of another.*

Callahan (1992) argued that subjective consciousness stems from an individual's standpoint. He said that due to the ever changing nature of subjectivity, it is extremely difficult to make reliable and valid assessments of another's consciousness or potential

competencies. Hence even if the proxy knows the person who they are rating really well, that person's subjective state might change, for example, due to their mood or physical health that day. It might be unlikely that the proxy could have such a level of insight that would enable them to adapt their own ratings in the same way. The difficulty in any one person rating another's QoL can be seen in the person-proxy literature, reviewed in the introduction. For example, it has been shown that there are conceptual difficulties in proxy ratings on behalf of people suffering from schizophrenia (Sainfort et al, 1996) and such problems may well extend to the general population.

On the other hand, there is an assumption that QoL remains reasonably stable over time, hence the design of measures which interview a person about their QoL on a single occasion. Further, if it was as hard for one person to rate another's QoL as Callahan stated, one might presume that proxies would be better at rating 'objective' rather than 'subjective' states. Selai et al (2001) reported that published studies suggest less agreement for non-observable things, such as pain and psychological problems, compared to concrete, observable items such as ability to walk. However in this present study, there was a mixture of more subjective and objective items rated similarly between people with dementia and staff ('physical health', 'family' and 'friends') and differently ('ability to do chores', 'marriage', 'memory' and 'life as a whole'). This lack of consistency goes against Callahan's suggestion that more subjective states are harder to evaluate.



2) *Care staff ratings of QoL in people with dementia.*

As mentioned earlier, care staff often lack any formal training or previous experience of dementia. A lack of understanding into what dementia is, what causes it and what to expect may lead to ignorance in attempting to understand the subjective experience of it. Care staff typically experience high levels of stress (Baillon et al, 1996). It has been suggested that burden and stress for families might negatively skew reports of the person with dementia's functioning (Kiyak, Teri and Borson, 1994) and this might similarly apply to care staff. As Logsdon (2002) noted, depressed or burdened caregivers might have a negative bias that influences their perspective of QoL in people with dementia. Such burden is likely to be experienced with constant pressure, low wages, long hours and high levels of burnout.

Menzies (1972), using psychodynamic thinking, talked about 'organisational defences' occurring in nursing environments. She stated that because nurses are continually faced with situations which might provoke extreme anxiety, such as dealing with death, they distance themselves from the situation and exert an almost inhuman self-control. This prevents them from experiencing the pain involved in much of their work. This concept might be applied to staff in residential care. Being so defended might prevent them from having quality relationships with residents and hence understanding how that person is really experiencing different areas of their QoL.

It is possible that health care professionals might hold a different view on QoL in people with dementia than do the people themselves. Health care professionals (including staff in residential care), through focus groups, have described QoL for people with dementia as encompassing the same elements as QoL for other people

(Thorgrimsen et al., 2003). However, when considering what to include in a measure of QoL, they omitted some items which they regarded as important in their own QoL, such as fulfilling one's ambitions, experiencing beauty and perfecting new skills. These were still regarded as important by people with dementia, suggesting that health care professionals had lower expectations of the future for people with dementia and more pessimistic views of their QoL. Some health professionals felt that people with dementia should 'settle for being content' rather than aiming for happiness. This indicates an assumption in many that QoL automatically decreases with the onset of dementia.

3) *People with dementia appraising their own situation.*

Another argument is that confusion resulting from dementia might lead people to overestimate what they can do (e.g. memory, ability to do chores) or what they have (family, friends, money). This might account for the significantly different ratings on 'memory' and 'ability to do chores' between people with dementia and staff. These results correspond to some of awareness literature reviewed in the introduction, suggesting that people with dementia might have a reduced awareness of their cognitive (e.g. Lopez et al., 1994) and functional abilities (Giovannetti, 2002). However, seven of the thirteen items ask about the person's feelings towards more subjective states (e.g. energy, mood), highlighting that much of the QoL-AD is about subjective assessment rather than factual knowledge.

Sainfort, Becker and Diamond (1996) suggested that people with schizophrenia might adapt to their symptoms and use a different yardstick to measure them as compared to

proxies. This might also apply to many people with dementia, who come to terms with their losses over time and simply see their QoL in a different way to others.

An alternative hypothesis is that some people with dementia might be in denial about the reality of their QoL. Cheston and Bender (1999) stated that as a coping mechanism, denial can be functional and adaptive for people with dementia, protecting them from things that are too traumatic to deal with. For those who had used denial successfully in the past, there is no reason why this would change with the onset of dementia. Denying the existence of a failing memory and increasing dependence, for example, might be easier than dealing with the pain of its presence. The protective aspect of denial is illustrated by Greer, Morris and Pettingale's (1979) finding that women who showed denial after a diagnosis of breast cancer had a significantly higher survival rate than those who responded with hopelessness and depression.

The question of whether level of cognitive impairment affects the ability of people with dementia to appraise their situation has received some attention. Mozley, Huxley, Sutcliffe, Bagley, Burns, Challis and Cordingley (1999) attempted to determine the extent to which the MMSE succeeded in sorting people with dementia into those who were and those who were not able to be interviewed on their QoL. This was determined by i) the person's ability to answer the questions and ii) the interviewer's confidence rating of whether the response was 'reliable'. For example, if a person said that s/he was satisfied with where s/he lived but then talked about living with their mother (who was dead), this would be deemed an 'unreliable' response. A problem with this method is a dependency on the skills of the interviewer. More importantly, it assumes that if the person *feels* that s/he is satisfied where s/he

lives, this feeling can only be accepted as real if it corresponds with objective reality. However, these authors did find that people with lower MMSE scores (9 to 10 - severe dementia) could reliably report on their QoL than what had previously been recognised (17 to 18 - moderate dementia). In this present study, level of cognitive impairment did not impact on the discrepancy between person and staff ratings of QoL. Hence there was no evidence that level of impairment affected people with dementia's appraisal of their situation.

#### 4) *The experience of dementia*

Dementia can result in complex behaviour in an individual. For example Woods (2001, p.12) noted that: "Shouting out may reflect a physical pain that cannot be adequately communicated or a need for contact in a person who feels abandoned...wandering may reflect a search for something or someone familiar and safe, in a place that appears strange and frightening". The implications of this are that it might be difficult for others to appraise certain aspects of QoL in people with dementia, such as mood, due to different ways of communicating their feelings and needs.

In reality, many people with dementia might adapt well to the cognitive and behavioural changes that they experience, and find new ways of experiencing QoL. Poetry has sometimes been used to capture the subjective experience of people with dementia:

“...when words get in the way of knowing

- a touch, a smile -

You make me mindful of what humanness entails.

You have no cogent thought, and yet

Your muddled words

Are full of thoughtfulness”

(De Luca, unpublished, cited in Goldsmith, 1996, p.24)

This poem suggests that the author, who had dementia, had found a new, more mindful way of understanding others, with no indication that his QoL had been affected. Yet having not had the experience of dementia, it might be hard to comprehend how such losses could be experienced without a corresponding loss in QoL

Whilst there is likely to be a level of error in any proxy rating of QoL for any person, this does not warrant discarding such methods of investigation. Much psychological research involves asking people to make ‘subjective’ evaluations on behalf of others. A pattern has emerged in this study, like all the research described earlier, in that proxies consistently rated QoL differently to how people with dementia did. This suggests that the two groups hold different attitudes, rather than the difference being purely the result of confounding variables.

Brod et al (1999) noted that studies of concordance have failed to identify whether people with dementia are poor reporters or if proxy measures themselves are biased. This study has not answered this question, but has attempted to address it further in this chapter. It remains unclear as to why some individual items on the QoL-AD were

rated more similarly between the two groups and others more differently. No clear patterns emerged, for example relating to the rating of more 'subjective' or 'objective' items. There was some overlap in item-agreement to that identified by Logsdon et al. (2002, see Introduction). The lack of overlap in other items suggests that staff and family raters might evaluate certain areas of QoL differently. Finally, all the suggestions made in this section might be applied to an understanding of why people with dementia and staff rated different areas of QoL differently, in addition to the overall discrepancy in QoL.

The above research does not consider how culture might impact on the way that QoL is perceived by both people with dementia and their carers. I was unable to identify any literature relating to this question, although various authors have described the impact of culture on dementia care. Cox (1997) discussed how culture and religion might impact on whether people rely on family or formal care, the shame and stigma related to dementia and guilt regarding one's ability to meet care-giving needs. She reported that within Hispanic-American and African-American cultures, for example, there is a reluctance to use formal caregivers, with an emphasis on family and extended family care. This might imply an assumption by Hispanic-American and African-American care staff that QoL is lower for those not cared for by their families. Similar beliefs may be held by Hispanic-American or African-American people who have dementia.

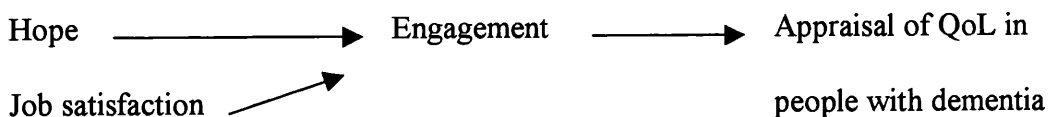
### **Staff factors and QoL ratings**

The thinking behind this hypothesis was that hope, person-centredness and job satisfaction might affect how staff relate to, feel about and understand the residents

they are working with. If this were the case, such factors might influence their appraisal of QoL. Past research has not considered factors which might contribute to staff's perception of QoL in people with dementia. However, Moniz-Cook et al (2000) found that person-centredness impacted on staff's perception of challenging behaviour.

The literature has linked both hope and job satisfaction to engagement in social interaction with residents (Lintern & Woods, 2001; Robertson et al, 1995). Although, in theory, level of engagement might be linked to appraisal of QoL, the results suggest that a link between hope, person-centredness, job satisfaction and appraisal of QoL is too tenuous. It might be that the 'engagement', as a construct, is a mediating factor, as illustrated in figure 3:

*Figure 3: Possible link between hope, job satisfaction and appraisal of QoL*



The lack of association between the three staff factors and the discrepancy in QoL might also be due to weaknesses in the measures or with the theoretical model used in this study. This will be addressed further in the section on limitations, see below.

### **Cognitive impairment and QoL ratings**

Some of the awareness literature (reviewed in the introduction) indicates that as dementia progresses, people's evaluations of their memory and functional skills become more discrepant from the results of objective tests (e.g. Lopez et al, 1994). One might therefore expect a similar pattern to follow on other items of the QoL-AD. There is evidence that caregivers rate QoL less favourably, the more cognitively impaired the person with dementia is (Gonzalez-Salvador et al., 2000). In contrast, Thorgrimsen et al. (2003) found that QoL ratings were sometimes higher by people with more severe dementia, compared to those at earlier stages. The discrepancy between these two findings might be more of an indication of how people *without* dementia hold a belief that some cognitive ability is necessary in order to experience QoL. In contrast, cognitive ability appears to be less important in the experience of QoL when judged by people with dementia themselves. Further, it might be expected that communication difficulties between people with dementia and staff would worsen as cognition declines further, perhaps making it harder for staff to appraise QoL. Cognitive impairment might therefore impact on the rating of QoL by both staff and the people with dementia.

However, in this study, no association was found between cognitive impairment and either staff or person ratings of QoL (and hence the discrepancy). These findings support the notion that level of cognitive impairment does not impact on how people with dementia generally rate and view their QoL. Additionally, it might be that care staff are affected differently to family carers by the extent of cognitive impairment. Perhaps care staff become accustomed to working with a client group for which cognitive deterioration is the norm, hence might be less sensitive to how it impacts on



their QoL. In contrast, having known the person with dementia for a much longer period of time and watched them decline, decreasing cognitive skills, in the eyes of family carers, may have a greater emotional impact. Finally, these results indicate that communication between the person with dementia and staff was not affected by the person's level of cognitive impairment, due to the absence of more discrepant ratings as the dementia progressed. However, it is unclear how much 'communication' actually impacted on ratings of QoL as this was not formally assessed in the study.

### **Relationship between staff factors and resident QoL**

'Hope', which was significantly related to resident QoL, was identified as one of Kitwood and Bredin's (1992) 'global sentient states', implying its importance in the QoL of people with dementia. There might be a link between having more hopeful staff, on which people with dementia are so dependent, and their own feelings of hope. I was unable to identify any previous literature relating to hope in care staff and QoL in people with dementia, making it hard to understand how the two might be related. However, hopeful staff might engage more with residents, create a happier care environment and be more encouraging of residents to develop and use their remaining skills.

On examination, some statements on the Hope sub-scale of the ADQ (see Appendix 2), for which staff were asked to indicate their level of agreement, may be linked to what has previously been defined as important in QoL for people with dementia. For example, Brod et al (1999) identified self-esteem as one of the five domains of dementia-specific QoL. Staff agreeing with the statements "People with dementia are very much like children" and "People with dementia are unable to make decisions for

themselves”, might hold an attitude which could be damaging to the esteem of residents. Barnett’s (2002) interviews with people with dementia identified feelings regarding care relationships as important to them. Staff agreeing with the statement “It is important not to become too attached to residents” might have more distant relationships with residents.

Similar links can be made with the person-centredness questions and the hypothesised elements of QoL. For example, Kitwood and Bredin’s (1992) emphasis on ‘sense of agency’ may be linked to the statement “People with dementia are unable to make decisions for themselves”. It is therefore of interest as to why person-centredness in staff did not impact on resident QoL. However, Lintern and Woods (2001) found that the hope subscale had greater predictive validity than the person-centredness one, finding that the former predicted staff’s engagement in social interaction, purposeful activity and stimulation with residents. It may be that such factors are closely linked to resident QoL, making the hope subscale as a measure more predictive of resident QoL than the person-centredness scale.

As higher job satisfaction has been linked to improvements in staff-resident interactions (Robertson et al, 1995), a relationship between job satisfaction and resident QoL might have been expected. Robertson et al suggested that job satisfaction may increase staff’s motivation and interest in their work, resulting in higher quality care. Further, staff working in higher quality care environments may feel more satisfied in their work. It might be that quality of care and QoL have some overlap, but that job satisfaction as a construct is too distantly linked with resident QoL.

### **Revised model**

The model outlined in Chapter 1 (page 37) suggested that there were aspects within the person with dementia, the staff rater and the interaction between the two which might impact on both ratings of QoL and the discrepancy between them. Owing to the limited scope of this thesis, it was only possible to begin looking at some of these factors. The results show that the factors investigated did not impact on the discrepancy between the ratings. This might have been due to the constructs not being relevant or too distantly linked to QoL. Alternatively, the measures themselves might not have picked up on factors which were predictive of people's appraisal of QoL. As a consequence, the model has been revised, removing factors which have shown not to be effective and incorporating ideas which have emerged in this discussion (see Figure 4).

The new model suggests that there are stable individual characteristics which might impact on the person with dementia's QoL, including age, gender, personality, education, philosophy, beliefs and coping mechanisms such as denial and humour (some of these being suggested by Brod et al., 1999). There are other factors which may be more changeable, such as mood and physical health. For example, the person may be experiencing pain on the day of assessment. These less stable factors might make it more challenging for staff ratings to mirror person ratings. It might be that although staff do notice daily changes in people, these are more likely to be in external signs rather than internal states.

Within factors relating to the staff themselves, hope remains in the model as it has been shown to link with QoL in people with dementia. Person-centredness has been

removed, as it had no impact on ratings of QoL. Stress has been kept in the revised model, as there was not the opportunity to examine its influence in this study. Job satisfaction has been replaced by 'attitude towards job', because what people are satisfied about (i.e. how they regard their job), rather than satisfaction per se, might be a more useful concept. To illustrate, one person could be satisfied with their job, yet regard it as being an entirely practical as opposed to caring job. Another person might be dissatisfied because they do not have the scope to develop relationships with residents. These two types of satisfaction (or lack of) are likely to have different influences on staff appraisal of QoL. Finally, the staff section also includes the amount of time spent between the staff member and person they are evaluating, with past research suggesting that knowing more about individuals can affect staff attitudes (Pietrukowicz & Johnson, 1991). Duration of time in the job, which was in the model previously, might not relate to how well they know the individual who they are evaluating.

The interaction section includes the type and quality of relationship. For example, a task-focused relationship might involve the staff member focusing on the physical care of the resident, whereas an emotionally focused relationship might place more emphasis on getting to know the person as an emotional being. The communication skills of both remain in the model, as communication between staff and people with dementia has been shown to be important. For example, Dijkstra, Bourgeois, Burgio and Allen (2002) trained nursing assistants in effective communication techniques and in using memory books as a way of talking to residents with dementia. Using a control group of staff who had not been trained, the results of discourse analysis showed a variety of improvements in discourses as a result of the intervention, such as

encouragement and cues from staff. Linking to communication skills, 'language barriers' have been added to the model, as some staff did not speak English as their first language. This might have made it harder for them to understand how the person with dementia felt about different areas of their QoL.

### **Limitations**

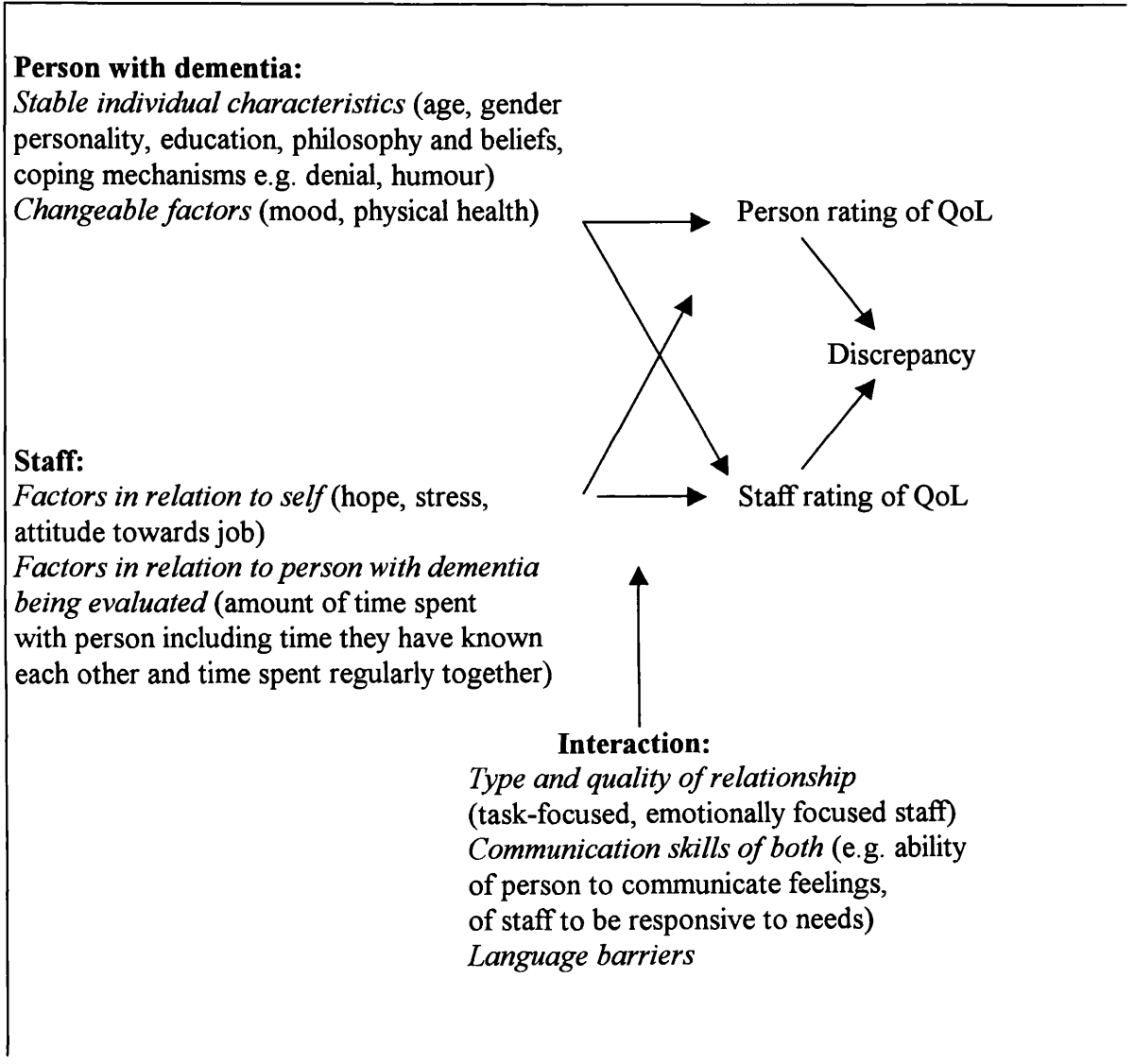
There were several areas in which this study could have been improved. One limitation might be due to problems within the conceptual framework being followed, which have been highlighted in the previous section. However, the model was designed to include factors which could be tested empirically, i.e. for which quantitative measures had been developed. A new model had been suggested, yet some consideration would be required into how to test some of these new hypotheses. For example, a way of quantifying the amount of time spent between the person with dementia and staff member would need to be developed.

There were also limitations regarding the measures used. The MMSE can have a ceiling effect and it relies on verbal responses and the ability to read and write, hence some people who had lost their vision or use of hands received an erroneously low score. Nonetheless, it is a quick way of evaluating the presence or absence of cognitive impairment and in conjunction with clinical information, is a useful screen for dementia. The Job Satisfaction Index was not designed specifically for care staff and may not have tapped in to factors which are important in relation to working with older people. For instance, there are no questions on any aspect of their relationships with residents, a fundamental part of their job. Further, satisfaction regarding relationships with residents (rather than, for example, organisational issues) may be

more crucial when thinking about attitude towards QoL. Hence the scale might have tapped into areas of job satisfaction which were not clearly linked to the hypotheses of this study. For the QoL-AD, reliability and validity checks were made using a sample of family carers as proxy raters (Logsdon et al., 1999). The scale may be less valid for paid caregivers. The scale places equal weight on different areas of QoL by adding them together. These facets may differ in importance to the individual, resulting in a less accurate overall picture of QoL. Such problems may be reduced by using measures of QoL which yield both qualitative and quantitative data, for example the QOLAS (Selai et al, 2001). However, this is time-consuming to administer and with the large sample used in this study, the QoL-AD was more suitable.

Individual and staff ratings of QoL are likely to be affected by numerous, changeable factors. These include characteristics and experiences of the individual and the duration and quality of the person-staff relationship. Varying deficits in memory, attention, judgement, insight and communication might influence the individual's ability to understand questions. Behavioural or non-cognitive symptoms of dementia, such as depression and agitation, may impact on QoL ratings. Although the QoL-AD asks the person to rate QoL "within the past few weeks", person ratings will be strongly influenced by how the person is feeling on the current day. In contrast, the staff member may have only seen the person a few days ago, when their mood may have been totally different. If variability of response is a problem, this points to an argument for the measurement of QoL over a period of time rather than on one occasion. Further, Selai et al (2001) noted that an apparently identical question, phrased in a slightly different way, can lead to quite different responses.

Figure 4: Revised model highlighting factors affecting perception of QoL in people with dementia and staff



Although the sample was large, only small numbers of person-staff dyads were recruited from each home (mean = 8.4). When looking at how staff factors impacted on resident QoL, the sample from each home was used to estimate the overall levels of hope, person-centredness, job satisfaction and resident QoL in that home. This small sample might not have been representative of the whole population in the home (particularly in the one home in which only four participants were recruited), possibly resulting in error. QoL might vary according to type of dementia. For example people with frontotemporal dementia have alterations of personality which might impact on the appraisal of QoL in both the person and their carer (Selai et al, 2001). Information about type of dementia may have been useful, although was rarely available for the participants used in this study.

All the people with dementia recruited were white British, with the exception of one person who was Afro-Caribbean and one Asian. Further, it was a predominantly female sample. Whilst the latter is typical of this age group, the results may not easily be generalised across ethnic groups and cultures. Data was not recorded on the ethnic group or primary language of staff raters. Whilst it would have been interesting to know such information, it may also have allowed the question of whether language barriers impact on QoL ratings to be explored. This was suggested in the 'interaction' section of the revised model. Further, there is evidence that cultural background might impact on the experience of burden in care giving (Cox, 1997). It might be, therefore, that culture is linked to some of the areas explored in this study. Having more information about cultural background might have allowed further exploration of such ideas.



Finally, this study has looked at aspects within the person with dementia and staff, but has not considered the interaction between the two. One way of evaluating the interaction between staff and residents might have been the use of Dementia Care Mapping. Thorgrimsen et al (2003) found that the correlation between the QoL-AD score and the Dementia care Mapping 'well-being' score in people with dementia approached significance.

### **Strengths**

The strengths of this study were that it used a large sample of both people with dementia and staff in nine residential homes, achieving the numbers required following power analysis. There were limited exclusion criteria, hence the results may be generalised to other people with dementia living in residential care in the UK. To my knowledge, this is the first UK study comparing ratings of QoL between people with dementia and their care staff, with previous research having focused on family carers. This thesis begins to address empirically some important issues which have been discussed theoretically, such as the complex relationship between staff and residents in care homes (Kitwood, 1997). Kitwood argued that a Malignant Social Psychology projected by staff, due to adverse work environments and attitudes to care, can have detrimental effects on the QoL of people with dementia.

### **Implications for research**

This research shows that people with dementia and staff rate QoL differently. One argument might be that variations in individual cases and numerous confounding variables always make it difficult to make broad conclusions about why these differences occur (Thorgrimsen et al, 2003). Using outcome measures which involve

preconceived ideas about what may or may not be influential may never fully encapsulate the complexity of individual processes. Therefore qualitative research, examining individual cases in more of an exploratory way, might be an alternative route of investigation. This would allow new concepts to emerge, pointing to categories which could then be investigated quantitatively.

Alternatively, future research could follow a similar design to the one used here, but consider some of the other predictors suggested in the new model (Figure 4). This would require developing ways of measuring factors such as staff attitude towards their job and the type, intensity and quality of relationship between staff and people with dementia. It would be useful to further explore the link between hope in staff and QoL in people with dementia, using qualitative or quantitative investigation. Finally, it would be interesting to investigate how staff and family carers' ratings of QoL compare. In any future research on QoL in people with dementia, the way in which data is collected needs to be considered. Brod et al. (1999) said that the quality of data obtained from people with dementia can be improved by more attention to clarity and simplicity and limiting the demands on their attention span, with questionnaire formatting, administration and comprehension being important.

### **Implications for practice**

The results show that there are problems using care staff as proxy raters for measuring QoL in people with dementia. To rely exclusively on them might give an inaccurate measure of the person's QoL. Although some people with severe dementia can rate their QoL using the QoL-AD, one concern is that as dementia deteriorates, many people lose the verbal skills to report on their QoL. Fortunately, this research

showed that proxy ratings did not become less accurate for people with more severe cognitive impairment. However, it is important to consider alternative ways of measuring QoL in severe dementia, without having to use on proxies, such as the 'Positive Response Schedule for Severe Dementia' (Perrin, 1997).

These results raise similar issues for other groups of people who might have a limited ability to express themselves, such as people with learning disabilities. It is likely that their care staff are also asked to make evaluations on their behalf, which could subsequently impact on the care that they receive.

Finally, the relationship between hope in staff and the QoL of residents is a note for practice. This points to consideration of ways to improve and maintain hope in care staff who may often be working in what feels like a hopeless environment. Kitwood and Woods (1996) suggested eight ways of improving the quality of life of staff: pay and conditions of service, induction, creation of a team, supervision, in-service training, individual staff development, accreditation and promotion and effective quality assurance. One might consider these important goals if wanting to improve people's hope and when striving towards a 'new culture of dementia care' (Kitwood, 1997).

## **Conclusions**

This study addresses a fundamental issue in dementia research, with improving QoL defined as "one of the primary goals for the treatment of Alzheimer's" (Ready et al., 2002). The main reason for using 'objective' measures or proxy reports to assess QoL in dementia is the belief that people with dementia, due to their cognitive deficits, lack

insight and cannot reliably report on internal states. Thorgrimsen (2003) argued that the belief about whether someone possesses insight is typically based on what is defined as reality by another person with greater power or status, such as health professionals. For example, if a person with dementia in a wheelchair states that their ability to do chores is good, they might be described as lacking in insight, yet their ability to do chores might feel good to them, at their point of reference, and have no negative impact on their QoL. As health professionals, we do not have the right to conclude that a person's reference point for QoL is inferior or faulty. At times, it might be necessary to accept that QoL, as rated by people with dementia, is going to be different to the results of 'objective' assessments. Their rating could be criticised as being inaccurate, due to denial or decreased 'awareness'. However, returning to the summary of when QoL evaluations are important, such as in evaluating service programs (Brod et al., 1999), it is evident that the QoL with real clinical significance in these situations is based on the individual's own assessment.

This study highlights the importance of asking people with dementia to rate their own QoL, even those with severe levels of cognitive impairment and high dependency. This approach follows the principles of person-centred care. This thesis was unable to identify factors in people with dementia or care staff which impact on ratings of QoL, but suggestions are offered as to how this might be investigated further. Finally, a link between hope in staff and higher QoL in residents was identified. This has important clinical implications, with more thought and planning required into ways of instilling hope in a group so often undervalued and under trained.

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## **Appendix 1**

Co-Chairs:  
Mr M Harrison and Dr R MacAllister

Please address all correspondence to:  
Ms Sabrina Balendra – Ethics Administrator  
Email: [sabrina.balendra@uclh.org](mailto:sabrina.balendra@uclh.org)

The UCL/UCLH Joint Research Committee A  
Research & Development Directorate  
1st floor, Vezey Strong Wing  
112 Hampstead Road, London NW1 2LT  
Tel. 020 7380 9579 Fax 020 7380 9937  
Website: [www.uclh.org](http://www.uclh.org)

1 April 2003

Our ref: RM/SB/03A247

Dr Linda Clare  
Lecturer in Clinical Psychology  
Dept of Clinical Health Psychology  
Torrington Place

Dear Dr Clare

**REC Ref No:** 03/0072 (please quote in all correspondence)  
**REC Name:** Committee A (please quote in all correspondence)  
**Study Title:** Factors contributing to the perception of quality of life (QoL) in dementia: a comparison of people with dementia and staff in residential care

The Joint UCL/UCLH Committees on the Ethics for Human Research reviewed your application on 20 March 2003. The documents reviewed were as follows:

REC application form  
Patient information sheet  
Patient consent form  
Research Protocol

The members of the committee present gave approval for your research on ethical grounds providing you comply with the conditions of approval set out below:

- You do not recruit any research subjects unless you have received a notification of no objections from the R&D office.
- You do not undertake this research until the relevant Trust management approval has been received (via the R&D office).
- You do not deviate from, or make changes to, the protocol without prior written approval of the REC, except where this is necessary to eliminate immediate hazards to research participants or when the change involves only logistical or administrative aspects of the research. In such cases the REC should be informed within seven days of the implementation of the change.
- You complete and return the standard progress report form to the REC one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the REC when your research is completed and in this case should be sent to this REC within three months of completion.
- If you decide to terminate this research prematurely you send a report to the REC within 15 days, indicating the reason for the early termination.



- You advise the REC of any unusual or unexpected results that raise questions about the safety of the research.
- The project must be started within three years of the date of this letter.

NHS REC is compliant with the International Conference on Harmonisation/Good Clinical Practice (ICH GCP) Guidelines for the conduct of trials involving participation of human subjects.

**Your application has been given a unique reference number please use it on all correspondence with the REC.**

Yours sincerely

*Dr Raymond MacAllister*  
**Dr Raymond MacAllister**  
**Chair**

Enclosure: REC Response Form  
 REC Progress Report

Name and address of REC: The UCL REC Committee on the Ethics of Human Research, Research & Development Directorate, 1<sup>st</sup> Floor, Veroxy Building Wing, 112 Hampstead Road, London NW1 2EJ

REC Reference Number: 030002

Noted below is a complete record of the review undertaken by the UCL REC Committee on the Ethics of Human Research Committee A with the decisions made, dates of decisions and the requirements of each stage of the review.

Date of review, date of approval, date of expiry - this information should be included in all correspondence to this office.

0300003 - Study 2/00000

THE FINAL DOCUMENTS AND APPROVALS ARE APPROVED BY THE REC:

- The following documents have been approved:
- REC application form
- Participant information sheet
- Participant consent form
- Research protocol

Date of REC approval: 03/01/01

Signature of REC Administrator: *[Signature]*

Name (printed): *Raymond MacAllister*





**REC RESPONSE FORM**

**DETAILS OF APPLICANT:**

1. Name and Address of Principal Investigator:

Dr Linda Clare  
Lecturer in Clinical Psychology  
Dept of Clinical Health Psychology  
Torrington Place

Title of Project: **Factors contributing to the perception of quality of life (QoL) in dementia: a comparison of people with dementia and staff in residential care**

2. Name and Address of Sponsor: n/a:

**DETAILS OF REC:**

Name and address of REC: **The UCL/UCLH Committees on the Ethics of Human Research; Research & Development Directorate; 1<sup>st</sup> Floor, Vezey Strong Wing; 112 Hampstead Road; London NW1 2LT**

REC Reference Number: 03/0072

Listed below is a complete record of the review undertaken by the Joint UCL/UCLH Committees on the Ethics of Human Research: Committee A with the decisions made, dates of decisions and the requirements at each stage of the review:

Date of review, decision made, issues raised – this information should be provided for each review in date order:

20/03/03 – Study to proceed

**THE FINAL DOCUMENTS AND ARRANGEMENTS APPROVED BY THE REC:**

The following items have been approved:

- REC application form
- Patient information sheet
- Patient consent form
- Research Protocol

Date of REC approval: 20/03/03

Signature of Chair/Administrator: Sabina Kalendra Date: 20/03/03

Name (please print) Sabina Kalendra



Sub-Department of Clinical Health Psychology

**UNIVERSITY COLLEGE LONDON**

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Version 1

18<sup>th</sup> February 2003

Project ID:

Investigators:

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**CONFIDENTIAL**

Factors contributing to the perception of quality of life in people with memory difficulties: a comparison of people and staff in residential care.

### **Participant Information Sheet**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with me so I can be sure that it makes sense to you. Ask me if you would like more information.

This project is designed to see how your opinion of your quality of life compares with a member of staff's opinion of it. It will involve me asking you some questions about your quality of life and have you rate different aspects of it. I will also ask you some more general questions, such as asking you to repeat some words and copy a picture. This will help me to see how your memory is. In total, it will take about 10-15 minutes. Additionally, I will ask one of the staff here – someone who knows you well – the same questions about your quality of life and some other things about them. I will then



compare both ratings of your quality of life, and look at factors which might affect any differences.

It is up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and be asked to sign a consent form. You may withdraw at any time, without giving a reason. A decision to withdraw or a decision not to take part will not affect the standard of care you receive. The information we get from this study may help us to understand how people like you and your staff think about quality of life, and may point to ways in which services can develop. We hope to publish the results of this research in an academic journal. This study has been reviewed by the UCLH Ethics Committee.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the home will have your name and all identifiable information removed so that you cannot be recognised. The information will only be accessible to me, Aimee Spector, and other members of the research team. The forms which you sign will be kept separate to the information you give. If you have any concerns or questions about this research, please contact Aimee Spector on 01708-796464.

*Thank-you for taking part in this study!*



Sub-Department of Clinical Health Psychology

**UNIVERSITY COLLEGE LONDON**

GOWER STREET LONDON WC1E 6BT

**CONFIDENTIAL**

Version 1

18<sup>th</sup> February 2003

UCLH Project ID:

Patient identification number for this study:

Name of principal investigator: Linda Clare

**PARTICIPANT CONSENT FORM**

Title of project: Factors contributing to the perception of quality of life in people with memory difficulties: a comparison of people and staff in residential care.

Please initial box

1. I confirm that I have read and understood the information sheet dated 18<sup>th</sup> February 2003 (version 1) for the above study and have had the opportunity to ask questions.
  
2. I confirm that I have had sufficient time to consider whether or not want to be included in the study
  
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
  
4. I agree to take part in the above study.

\_\_\_\_\_  
Name of patient                      Date                      Signature

\_\_\_\_\_  
Name of Person taking consent      Date                      Signature

Aimee Spector                      01708-796464  
Researcher (to be contacted      Email/phone number  
if there are any problems)

Comments or concerns during the study

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.



Sub-Department of Clinical Health Psychology

**UNIVERSITY COLLEGE LONDON**

GOWER STREET LONDON WC1E 6BT

Version 1

18<sup>th</sup> February 2003

Project ID:

Investigators:

*Aimee Spector*, Dept of Clinical Health Psychology, UCL, 1-19 Torrington Place,

London WC1E 6BT. Tel: 01708-796464. *Linda Clare*, Dept of Clinical Health

Psychology, UCL, 1-19 Torrington Place, London WC1E 6BT Tel: 020-7679-1844.

*Martin Orrell*, Dept of Psychiatry and Behavioural Sciences, UCL, Wolfson Building, 48  
Riding House St, London W1N 8AA. Tel: 020-7679-9418.

**CONFIDENTIAL**

Factors contributing to the perception of quality of life in people with memory  
difficulties: a comparison of people and staff in residential care.

### **Staff Information Sheet**

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask me if there is anything that is not clear or if you would like more information.

This project is designed to see how your opinion of a resident's quality of life compares to their opinion of it, and factors that might affect this. It will involve you answering some questions about their quality of life and have you rate different aspects of it. I will also ask you to complete two further questionnaires about your job satisfaction and more general questions about dementia. In total, it will take about 10-15 minutes. I will then compare both ratings of your quality of life, and look at factors which might affect any differences.

It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. You may withdraw at any time, without giving a reason. A decision to withdraw or a decision not to take part will not affect the standard of care you receive. The information we get from this study may help us to understand how quality of life is perceived by different people and may point to ways in which services can develop. We hope to publish the results of this research in an academic journal. This study has been reviewed by the UCLH Ethics Committee.

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the home will have your name and all identifiable information removed so that you cannot be recognised. The information will only be accessible to me, Aimee Spector, and other members of the research team. The forms which you sign will be kept separate to the information you give. If you have any concerns or questions about this research, please contact Aimee Spector on 01708-796464.

*Thank-you for taking part in this study!*



Sub-Department of Clinical Health Psychology

**UNIVERSITY COLLEGE LONDON**

GOWER STREET LONDON WC1E 6BT

**CONFIDENTIAL**

Version 1

18<sup>th</sup> February 2003

UCLH Project ID:

Patient identification number for this study:

Name of principal investigator: Linda Clare

**STAFF CONSENT FORM**

Title of project: Factors contributing to the perception of quality of life in people with memory difficulties: a comparison of people and staff in residential care.

Please initial box

1. I confirm that I have read and understood the information sheet dated 18<sup>th</sup> February 2003 (version 1) for the above study and have had the opportunity to ask questions.
  
2. I confirm that I have had sufficient time to consider whether or not want to be included in the study
  
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
  
4. I agree to take part in the above study.

\_\_\_\_\_  
Name of staff member  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of Person taking consent  
Signature

\_\_\_\_\_  
Date

Aimee Spector  
Researcher (to be contacted  
if there are any problems)

01708-796464  
Email/phone number

Comments or concerns during the study

If you have any comments or concerns you may discuss these with the investigator. If you wish to go further and complain about any aspect of the way you have been approached or treated during the course of the study, you should write or get in touch with the Complaints Manager, UCL hospitals. Please quote the UCLH project number at the top this consent form.

## **Appendix 2**



## Quality of Life-AD

### Instructions for Interviewers

The QOL-AD is administered in interview format to individuals with dementia, following the instructions below.

Hand the form to the participant, so that he or she may look at it as you give the following instructions (instructions should closely follow the wording given in bold type):

I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: **poor, fair, good, or excellent.**

Point to each word (**poor, fair, good, and excellent**) on the form as you say it.

When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas. We want to find out how you feel about your current situation in each area.

If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.

It is usually apparent whether an individual understands the questions, and most individuals who are able to communicate and respond to simple questions can understand the measure. If the participant answers all questions the same, or says something that indicates a lack of understanding, the interviewer is encouraged to clarify the question. However, under no circumstances should the interviewer suggest a specific response. Each of the four possible responses should be presented, and the participant should pick one of the four.

If a participant is unable to choose a response to a particular item or items, this should be noted in the comments. If the participant is unable to comprehend and/or respond to two or more items, the testing may be discontinued, and this should be noted in the comments.

As you read the items listed below, ask the participant to circle her/his response. If the participant has difficulty circling the word, you may ask her/him to point to the word or say the word, and you may circle it for him or her. You should let the participant hold his or her own copy of the measure, and follow along as you read each item.

1. First of all, how do you feel about your physical health? Would you say it's **poor, fair, good, or excellent?** Circle whichever word you think best describes your physical health right now.
2. How do you feel about your energy level? Do you think it is **poor, fair, good, or excellent?** If the participant says that some days are better than others, ask him or her to rate how she/he has been feeling most of the time lately.
3. How has your mood been lately? Have your spirits been good, or have you been feeling down? Would you rate your mood as **poor, fair, good, or excellent?**

4. How about your living situation? How do you feel about the place you live now? Would you say it's poor, fair, good, or excellent?
5. How about your memory? Would you say it is poor, fair, good, or excellent?
6. How about your family and your relationship with family members? Would you describe it as poor, fair, good, or excellent? If the respondent says they have no family, ask about brothers, sisters, children, nieces, nephews.
7. How do you feel about your marriage? How is your relationship with (spouse's name). Do you feel it's poor, fair, good, or excellent? Some participants will be single, widowed, or divorced. When this is the case, ask how they feel about the person with whom they have the closest relationship, whether it's a family member or friend. If there is a family caregiver, ask about their relationship with this person. If there is no one appropriate, or the participant is unsure, score the item as missing. If the participant's rating is of their relationship with someone other than their spouse, note this and record the relationship in the comments section.
8. How would you describe your current relationship with your friends? Would you say it's poor, fair, good, or excellent? If the respondent answers that they have no friends, or all their friends have died, probe further. Do you have anyone you enjoy being with besides your family? Would you call that person a friend? If the respondent still says they have no friends, ask how do you feel about having no friends—poor, fair, good, or excellent?
9. How do you feel about yourself—when you think of your whole self, and all the different things about you, would you say it's poor, fair, good, or excellent?
10. How do you feel about your ability to do things like chores around the house or other things you need to do? Would you say it's poor, fair, good, or excellent?
11. How about your ability to do things for fun, that you enjoy? Would you say it's poor, fair, good, or excellent?
12. How do you feel about your current situation with money, your financial situation? Do you feel it's poor, fair, good, or excellent? If the respondent hesitates, explain that you don't want to know what their situation is (as in amount of money), just how they feel about it.
13. How would you describe your life as a whole. When you think about your life as a whole, everything together, how do you feel about your life? Would you say it's poor, fair, good, or excellent?

**SCORING INSTRUCTIONS FOR THE QOL:**

Points are assigned to each item as follows: poor=1, fair=2, good=3, excellent=4. The total score is the sum of all 13 items.

<b>Quality of Life: AD (Participant Version)</b>				
<b>Subject Number</b>		<b>Assessment Number</b>		<b>Interview Date</b>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
				Month Day Year
<b>Interviewer administer according to standard instructions. Circle responses.</b>				
<b>1. Physical health.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>2. Energy.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>3. Mood.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>4. Living situation.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>5. Memory.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>6. Family.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>7. Marriage/closest relationship.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>8. Friends.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>9. Self as a whole.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>10. Ability to do chores around the house.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>11. Ability to do things for fun.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>12. Money / financial situation.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>13. Life as a whole.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>

**Quality of Life: AD**  
(staff Version)

<b>Subject Number</b>	<b>Assessment Number</b>	<b>Interview</b>
<b>Date</b>		
<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/> <input type="text"/>
<input type="text"/>		Month    Day    Year

***The following questions are about your resident's quality of life. When you think about your resident's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relative's current quality of life in each area using one of four words: poor, fair, good, or excellent. Please rate these items based on your relative's life at the present time (e.g. within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance.***

***Circle your responses.***

<b>1. Physical health.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>2. Energy.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>3. Mood.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>4. Living situation.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>5. Memory.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>6. Family.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>7. Marriage/closest relationship.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>8. Friends.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>9. Self as a whole.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>10. Ability to do chores around the house.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>11. Ability to do things for fun.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>12. Money/financial situation.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>
<b>13. Life as a whole.</b>	<b>Poor</b>	<b>Fair</b>	<b>Good</b>	<b>Excellent</b>

## APPENDIX 1

Clinical Report on Ageing  
VOLUME 1 NUMBER 1 1987

## Mini-Mental State Examination

Patient's Name: \_\_\_\_\_ Patient# \_\_\_\_\_

Examiner's Name: \_\_\_\_\_ Date: \_\_\_\_\_

Patient Score	Maximum Score	
		<b>Orientation</b>
_____	5	What is the (year) (season) (date) (day) (month)?
_____	5	Where are we (country) (state) (county) (city) (clinic)?
		<b>Registration</b>
_____	3	Name three objects, allotting one second to say each one. Then ask the patient to name all three objects after you have said them. Give one point for each answer. Repeat them until he hears all three. Count trials and record number.
		APPLE TABLE PENNY                      Number of trials _____
		<b>Attention and Calculation</b>
_____	5	Begin with 100 and count backward by 7 (stop after five answers): 93, 86, 79, 72, 65. Score one point for each correct answer.
		<b>Recall</b>
_____	3	Ask the patient to repeat the objects above (See Registration). Give one point for each correct answer.
		<b>Language</b>
_____	2	<b>Naming:</b> Show a pencil and a watch and ask the patient to name them.
_____	1	<b>Repetition:</b> Repeat the following: "No ifs, ands, or buts."
_____	3	<b>Three-Stage Command:</b> Follow the three-stage command, "Take a paper in your right hand; fold it in half; and put it on the table."
_____	1	<b>Reading:</b> Read and obey the following. "Close your eyes" (show the patient the item written on reverse side).
_____	1	<b>Writing:</b> Write a sentence (on reverse side).
_____	1	<b>Copying:</b> Copy the design of the intersecting pentagons (on reverse side).
_____	30	Total Score Possible

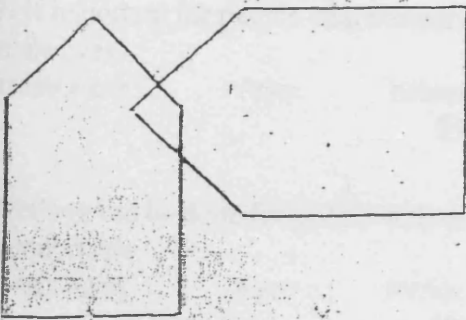
# CLOSE YOUR EYES

---

# WRITE A SENTENCE

---

# COPY DESIGN



Please indicate to what extent you agree or disagree with each of the following statements:

1. It is important to have a very strict routine when working with dementia sufferers.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

2. People with dementia are very much like children.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

3. There is no hope for people with dementia.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

4. People with dementia are unable to make decisions for themselves.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

5. It is important for people with dementia to have stimulating and enjoyable activities to occupy their time.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

6. Dementia sufferers are sick and need to be looked after.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

7. It is important for people with dementia to be given as much choice as possible in their daily lives.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

8. Nothing can be done for people with dementia, except for keeping them clean and comfortable.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

9. People with dementia are more likely to be contented when treated with understanding and reassurance.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree

10. People with dementia should be treated just like any other person.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree



11. Once dementia develops in a person, it is inevitable that they will go down hill.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

12. People with dementia need to feel respected, just like anybody else.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

13. Good dementia care involves caring for a person's psychological needs as well as their physical needs.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

14. It is important not to become too attached to residents.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

15. It doesn't matter what you say to people with dementia because they forget it anyway.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

16. People with dementia often have good reasons for behaving as they do.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

17. Spending time with people with dementia can be very enjoyable.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

18. It is important to respond to people with dementia with empathy and understanding.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

19. There are a lot of things that people with dementia can do.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree

20. People with dementia are just ordinary people who need special understanding to fulfil their needs.

Strongly Agree      Agree      Neither Agree nor  
Disagree      Strongly Disagree  
Disagree



SATISFACTION INDEX

Please tick the appropriate box:

How satisfied are you with:

7 - Extremely Satisfied

6 - Very Satisfied

5 - Quite Satisfied

4 - Not sure

3 - Quite Dissatisfied

2 - Very Dissatisfied

1 - Extremely Dissatisfied

1	The physical work conditions?								
2	The freedom to choose your own method of working?								
3	Your fellow workers?								
4	The recognition for good work?								
5	The supervision you receive?								
6	The amount of responsibility you are given?								
7	Your rate of pay?								
8	The opportunities to use your abilities?								
9	Your chance of promotion?								
10	The way your organisation is managed?								
11	The attention paid to suggestions you make?								
12	Your hours of work?								
13	The amount of variety in your work?								
14	Your job security?								
15	The training you receive								
16	Relationships in your workplace?								
17	The quality of relationships between your workplace and other departments?								
18	Now taking everything into consideration how do you feel about your job as a whole?								
		7	6	5	4	3	2	1	