

# **My name is not dementia**

Literature review

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# Executive summary

## Background and introduction

This literature review forms the first part of a research project which sets out to establish key quality of life indicators for people with a diagnosis of dementia using evidence that draws directly on their own views and experiences. A central aim in developing these indicators is to provide commissioners, service providers, unpaid carers and people with dementia themselves the means to evaluate quality of life and well-being in relation to the services they are providing or receiving.

The project took place shortly after the publication by the government of the first 'National Dementia Strategy for England' (Department of Health 2009). This sets out three key steps in terms of improving quality of life for people with dementia and their carers: public education; proper and timely diagnosis of dementia; and development of appropriate services for people who have dementia and their carers. It is likely that the indicators developed through the research of which this review forms a part will include measures that reflect these three key elements of the dementia strategy and may help in monitoring its effectiveness.

Dementia is an umbrella term used to describe a group of brain disorders that involve a progressive deterioration in cognitive function resulting eventually in severe cognitive impairment. The individual with dementia experiences a gradual decline in their ability to understand, remember, reason, communicate and use learned skills; mood changes are also common as the part of the brain that controls emotion is affected by the disease (Alzheimer's Society 2007).

In the UK there are currently 750,000 people who have dementia, although this figure is expected to double to 1.4 million in the next 30 years (Alzheimer's Society 2007). People with mild to moderate dementia constitute the larger proportion of this figure whereas people with severe dementia make up approximately 12.5 per cent of the total (Alzheimer's Society 2007). It is anticipated that the current annual costs associated with dementia in the UK will almost treble during the same period, to over £50 billion (Department of Health 2009).

The growing interest in quality of life and dementia reflects a wider ranging interest in quality of life as a concept. However, there is no definitive consensus about exactly what quality of life is, what it means and therefore, how it might be measured or assessed. In

simple terms, there are three ways of approaching quality of life that are each reflected in the literature we have reviewed. Firstly, it can be viewed as something that can be 'measured' objectively by others, such as clinicians or carers; secondly, it can be regarded as something that is by definition a subjective phenomenon and therefore can only be meaningfully evaluated through self-report by the person concerned; thirdly, there is the approach to quality of life which tries to synthesise these two broad approaches to develop relevant and meaningful indicators based on self-report, observations and other evidence.

For a definition of quality of life that appears to capture its complexity and the importance of the interplay between various factors, the following from Bowling and Gabriel (2004) is more than adequate for our present needs:

Quality of life, then, is a multidimensional collection of objective and subjective areas of life, the parts of which can affect each other as well as the sum. It is also a dynamic concept, reflecting values as they change with life experiences and the process of ageing. (p3)

The trend towards greater involvement of people with dementia in service planning and delivery and in research is mirrored in an increased focus on capturing their perspectives on quality of life. At the same time, confidence in the possibility of obtaining reliable information directly from people with dementia has increased significantly. As the idea of subjective evaluations of quality of life have gained currency, the question of how to assess it when the person concerned is unable to provide a self-report, such as when they have severe dementia, becomes central. The literature that addresses these key issues forms a central focus of this review.

## **Defining and measuring quality of life in dementia**

There are two broad categories of relevant literature in terms of approaches to defining and measuring quality of life. The first is largely medical or health-related and tends to take a traditional approach to measuring quality of life. This means the emphasis is often on 'objective' measures using clinician or carer observations, where reports by proxy respondents often replace self-reports. Where the self-report of the person with dementia is incorporated, it is more often as an adjunct to the objective measure of their quality of life. More often than not however, such self-reports are not included and this is especially true where the quality of life of people with severe dementia is concerned.

The implicit working assumption that often underpins this literature is that someone's quality of life will correspond closely to the state of their health and to what they can do in terms of everyday living. It is often assumed that living with a chronic condition of any form will correspondingly mean a reduced quality of life. Objective instruments have been developed that appear to show moderate to good levels of reliability and validity in research terms. However, questions remain about the extent to which such measures can provide a 'true' reflection of an individual's quality of life if they do not incorporate an account by the individual concerned. One major basis for this doubt is the fact that agreement between proxies and the person with dementia is often rated as poor to moderate, and that the gap widens as dementia becomes more advanced. Quality of life is generally rated as being lower by carers than by the person with dementia themselves. It is therefore debatable whether it is appropriate to substitute proxy-reports for self-reports at all.

The second category of literature implicitly or explicitly conceptualises quality of life as a subjective phenomenon. In this literature, the first-hand accounts of people with dementia are often regarded as providing the most authentic account of that individual's quality of life. This increased focus on capturing the perspectives of people with dementia on their quality of life is a reflection of the wider trend towards greater involvement of people with dementia in service planning and delivery and in research.

The core dilemma inherent in assessing quality of life in people with dementia from this perspective is the fact that dementia is defined by deterioration of the means to comprehend and communicate. For this reason, assessing quality of life in people with severe dementia is usually considered a very different undertaking compared to assessing it in people with mild to moderate dementia because of the effect that severe dementia is assumed to have on the ability to comprehend and communicate. Despite the challenges however, a growing body of research evidence suggests that people with severe dementia can indeed provide meaningful self-reports about their quality of life.

Evidence based on assessing quality of life from the perspective of the person with dementia suggests that what is important for quality of life for someone with dementia is in many respects the same as that for someone who does not have dementia. Positive social relationships, psychological well-being, independence and financial security are things that most of us need in order to feel we have a good quality of life. However, some research highlights certain areas that appear to have greater significance for someone with dementia. These areas include being of use and giving meaning to life, security and privacy, and self-determination. Also included in one study is a domain of 'self-concept', which is believed to be unique to dementia and which incorporates stigma-related concepts such as embarrassment and self-esteem.

There is also a range of psychosocial issues that are thought to be relevant to understanding the experience of people with dementia and quality of life. The concept of psychosocial well-being, the different coping styles that individuals might adopt in response to developing dementia, the degree of resilience they have, social comparison theory, stigma and self-stigmatisation have all been found to be important and have added to our understanding.

## **Outcomes and quality of life indicators**

There is an important, albeit limited, literature based on research carried out in relation to a range of groups that have relevance for understanding quality of life from the perspective of people with dementia. People with dementia from seldom heard groups are frequently marginalised and their voices silenced, as the phrase suggests. However, there are sufficient studies to indicate that quality of life is mediated in complex ways by an individual's 'race', ethnicity, social class, age and gender. In simple terms, quality of life for a woman with dementia may mean something quite different compared to a male counterpart. Similarly, quality of life for someone of limited financial means may be defined differently compared to someone who is well off. What this literature demonstrates is the serious problem with the fact that dementia, once diagnosed, is all too quickly perceived to be the all-consuming feature of a person's identity. The reality is that people remain complex and multi-faceted and their quality of life is no less complex. The literature reviewed here suggests that the development of appropriate domains and indicators to assess quality of life needs to reflect this diversity and complexity rather than assume a degree of homogeneity which does not exist.

In terms of service settings, the review focuses on two main areas: early interventions for diagnosis and care home settings. A great deal of attention has recently been paid to the importance of early diagnosis of dementia and the improvements that can be made to people's quality of life if diagnosis is made early. This emphasis is reflected in the 'National Dementia Strategy for England' (Department of Health 2009), where the widespread adoption of memory services is intended to lead to improvements in people's experiences of services at this stage. There is clearly strong evidence that improving the process through which people are diagnosed and widening access to a high level of support at a relatively early stage of the illness is beneficial.

At the same time, the literature on developing quality of life measures for people with dementia in care homes is significant. The treatment of people in care home settings has been found to be sub-standard in a number of important respects, with evidence that this is a widespread problem rather than restricted to small areas. Studies that are reviewed demonstrate the central importance of understanding the subjective experience of the person with dementia as a fundamental dimension of enhancing care practice, developing appropriate interventions and increasing understanding.

In addition to the work reviewed here on quality of life and dementia, there have been significant developments in exploring the quality of life of people in other key groups that are relevant for this review, including older people, people with mental health needs, and people with learning disabilities. An important range of studies has investigated quality of life in older people, particularly from the perspective of older people themselves. Some of the most significant studies emphasise the importance of considering inequality between groups in understanding quality of life and how it should be assessed. More specifically, it is the consequences of inequality that are of concern; in particular, the capacity of inequality to constrain and limit quality of life.

The orientation of the research reviewed from the mental health field comes from a different evidence base compared to that from people with dementia and older people, with a focus on patient outcome measures rather than quality of life. However, its specific contribution is an important one as it serves to highlight the importance of user perspectives and participatory approaches. The concept of quality of life has become an increasingly important feature of the learning disability field. It is characterised by a rights based approach where quality of life issues are viewed in the context of a strong tradition of user involvement and giving 'a voice' to service users. This strong value base reflects the history of the learning disability movement.

## **Conclusion and key recommendations**

The focus of this review has been the development of quality of life indicators in relation to dementia. What has become clear in the process of reviewing the relevant literature is that we still know very little about quality of life in this area.

From the evidence reviewed it is clear that the perspective of the person with dementia has for too long been omitted or ignored compared to other perspectives on quality of life, particularly formal, theoretical or medical perspectives. The disease-oriented measures that have been dominant are not as helpful as once thought and, specifically, the assumption that dementia inevitably results in poor quality of life from the perspective of the person with dementia is faulty.

From the evidence reviewed, it should be emphasised that quality of life is not just multi-dimensional, it is multi-perspectival. In other words, how quality of life is understood depends on where you are looking from.

The idea that a single instrument could be used to assess quality of life at each stage of development of an illness such as dementia is almost certainly redundant and much more dynamic approaches to the task are required. In particular, the development of methodologies to enable the assessment of quality of life from the perspective of

someone with severe dementia is of central importance. Any steps to make further progress in developing this work should be welcomed.

Positive social relationships, psychological well-being, independence and financial security are things that most of us need in order to feel we have a good quality of life. These factors have been found to be no less important for people with dementia. Being of use and giving meaning to life, security and privacy, and self-determination are some of the areas that appear to have greater significance for someone with dementia. The domain of 'self-concept' in one study is of great interest and work in this area could be developed further, particularly as it incorporates stigma-related concepts such as embarrassment and self-esteem.

The evidence is clear that stigma and discrimination have a serious and detrimental effect on the quality of life of people with dementia. The impact of 'personhood' in dementia has led to a paradigm shift in the way the perspectives of people with dementia are understood and increasingly incorporated. The argument that a further shift towards incorporating notions of citizenship for people with dementia may help address stigma and discrimination is compelling.

The population of people with dementia, like any other population, is heterogeneous in terms of individual biography, life course factors, 'race', social class, gender and sexuality. There is strong evidence that such factors mediate in significant ways in terms of the individual experience of quality of life. Some of the most significant studies stress the importance of considering inequality between groups in understanding quality of life and how it should be assessed. The future development of approaches to assessing quality of life must engage with and reflect this diversity if they are to be effective and experienced as authentic and meaningful by people with dementia.

# Introduction

This literature review forms the first part of a research project which sets out to establish key quality of life indicators for people with a diagnosis of dementia using evidence that draws directly on their own views and experiences. A central aim in developing these indicators is to provide commissioners, service providers, unpaid carers and people with dementia themselves the means to evaluate quality of life and well-being in relation to the services they are providing or receiving.

The project took place shortly after the publication by the government of the first National Dementia Strategy for England (Department of Health 2009). This sets out three key steps in terms of improving quality of life for people with dementia and their carers. Firstly, improving public knowledge about dementia and reducing the high levels of stigma currently associated with it; secondly, proper and timely diagnosis of dementia; and thirdly, the development of a range of appropriate services for people who have dementia and their carers (p9). It is likely that the indicators developed through the research of which this review forms a part will reflect these three key elements of the dementia strategy and may help in monitoring its effectiveness.<sup>1</sup>

Dementia is an umbrella term used to describe a group of brain disorders that involve a progressive deterioration in cognitive function, resulting eventually in severe cognitive impairment. The individual with dementia experiences a gradual decline in their ability to understand, remember, reason, communicate and use learned skills; mood changes are also common as the part of the brain that controls emotion is affected by the disease (Alzheimer's Society 2007). Dementia shortens the lives of those who develop the condition. Although the estimated median survival for those with Alzheimer's disease is 7.1 years and for vascular dementia, 3.9 years, there is much individual variability (Fitzpatrick et al 2005). The risk of developing dementia increases significantly with age, with prevalence rates of one in six people with dementia in people over the age of 80 compared to one in 1,400 in the 40–64 age group.

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1 Quality of life indicators are the individual items used to indicate quality of life. They usually include statements or questions such as 'How satisfied are you with your personal relationships?' Respondents are often asked to respond to each item using a rating scale (such as from 1 to 5 with 1 being 'very dissatisfied'). Indicators are normally organised under domains or themes, such as 'social relationships' or 'financial security', and these groups of indicators are all incorporated into a single questionnaire or schedule, which might be referred to variously as an instrument, tool, scale or measure.

The impact of dementia on the individual concerned and on those close to them is profound and it is a major cause of disability worldwide. In the UK there are currently 750,000 people who have dementia although this figure is expected to double to 1.4 million in the next 30 years (Alzheimer's Society 2007). It is anticipated that the current annual costs associated with dementia in the UK will almost treble during the same period, to over £50 billion (Department of Health 2009). The size of the population affected by dementia, the scale of the costs and the complexity of the issues involved in providing care and support means that dementia has become a policy priority area, as indicated by the publication of the 'National Dementia Strategy for England'. It is useful to view the population with dementia as being pyramid shaped in that people with mild to moderate dementia constitute the larger part of the population whereas people with severe dementia make up approximately 12.5 per cent of the total (Alzheimer's Society 2007). The majority of people with severe dementia are women. Approximately one third of all people with dementia live in care homes and at least two thirds of the population who live in care homes have some form of dementia (Department of Health 2009).

The growing interest in quality of life and dementia reflects a wider ranging interest in quality of life as a concept. It has come under increasingly close scrutiny by the World Health Organization (WHO) over recent years. The WHO established a working group on quality of life, which identified its core domains as follows: physical, psychological, level of independence, social relationships, environment and spirituality, religion or personal beliefs (WHOQOL 1998). Quality of life as understood by the WHO is a broad concept which is affected in complex ways by factors from each of these core domains and it is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHOQOL 1995). For the WHO then, quality of life at its core is about the subjective experiences of the individual concerned and how their life compares with their hopes and expectations.

However, there is no definitive consensus about exactly what 'quality of life' is, what it means and therefore, most crucially for our purpose, how it might be measured or assessed. The concept has been variously described as confusing, elusive, controversial, and lacking clarity (Ettema et al 2005). In simple terms, there are three ways of approaching quality of life that are each reflected in the literature we have reviewed. Firstly, it can be viewed as something that can be 'measured' objectively by others, such as clinicians or carers, through structured observations and/or interviews using instruments, normally in the form of questionnaires, checklists and/or rating scales. Secondly, it can be regarded as something that is by definition a subjective phenomenon and therefore can only be meaningfully evaluated through self-report by the person concerned – as implied in the WHO definition above. Within this approach,

there are differences in terms of the degree to which subjective experiences can be measured. Thirdly, there is the approach to quality of life which tries to synthesise these two broad approaches to develop relevant and meaningful indicators based on self-report, observations and other evidence. For a definition of quality of life that appears to capture its complexity and the importance of the interplay between various factors, the following from Bowling and Gabriel (2004) is more than adequate for this review:

Quality of life, then, is a multidimensional collection of objective and subjective areas of life, the parts of which can affect each other as well as the sum. It is also a dynamic concept, reflecting values as they change with life experiences and the process of ageing. (p3)

Objective instruments have been developed that appear to show moderate to good levels of reliability<sup>2</sup> and validity<sup>3</sup> in research terms. However, questions remain about the extent to which such measures can provide a true reflection of an individual's quality of life if they do not incorporate a subjective account, such as a self-report from the person with dementia (Thompson and Kingston 2004). It has been suggested that the argument about the role of self-reports in assessing quality of life in dementia is largely ideological because it is based on assertion or inference rather than empirical evidence (Smith et al 2005b: p8). The notion of a true reflection of quality of life is a central one in that it helps to demarcate between the different approaches to the way quality of life is conceptualised and, consequently, which indicators are considered important for assessing it.

In relation to attempting to measure the quality of life of people with dementia, the relevant literature on indicators has traditionally been dominated by a focus on health-related or utility-related measures of quality of life. Furthermore, the amount of attention that quality of life as a theme has received in the relevant medical literature has increased sharply, especially since the 1990s (Dröes et al 2006). This growth in part reflects the need to evaluate the efficacy of new medical treatments as they have been developed (Hoe et al 2005). The implicit working assumption that often underpins this literature is that someone's quality of life will correspond closely to the state of their health and to what they can do in terms of everyday living:

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- 2 A measure can be considered reliable when it consistently shows the same results. If weighing scales are reliable, they will consistently give a reading of eight stones for a person who weighs eight stones.
  - 3 A measure can be considered valid if it actually measures the attribute it is designed to measure. A weighing scale can be reliable but invalid if it consistently gives an incorrect reading for the weight of a person who weighs eight stone, for example, by consistently giving a reading of eight stone two pounds.

Implicit within the medical model is the notion that there is an optimum level of functioning to which all people should aspire, whereby those who are impaired or disabled have, by definition, a poorer QoL [quality of life]. This leads to the questionable assumption that one cannot achieve positive QoL in the presence of physical deficits. (Trigg et al 2007: p790).

This assumption has meant that quality of life for people with significant health problems has routinely been underestimated (Livingston et al 2008). Specifically, some measures of quality of life in dementia are based on the faulty assumption that it will inevitably deteriorate as the severity of dementia increases (Ready and Ott 2003). As Hoe et al point out, the fact that quality of life does not decrease as cognition worsens (2005: p134) is counter-intuitive and is an important finding, not least because of the increased use of living wills where people effectively make predictions concerning how they may feel in the future about living with certain types of conditions.

As explored later in this review, the assumption that deteriorating cognition should result in reduced quality of life is at odds with the disability paradox (Albrecht and Devlieger 1999), in which people with serious disabilities report a good quality of life where to external observers their quality of life may be judged to be poor. The idea that successful ageing is primarily determined by good health status has been recently challenged in empirical work, which has shown that the main predictors, including for people with dementia, are mental health and social factors rather than physical illness, pain or global dementia severity (Livingston et al 2008).

Whilst there have been major advances in the development of individual measures of quality of life in dementia, these approaches by no means address the whole picture. 'Good' and 'bad' quality of life is also determined at population level in terms of the nature of services provided for people with dementia and frameworks for evaluating these have more recently been developed (Banerjee et al 2006; 2004). This issue will be explored later in this review.

Views about what quality of life means and how it can consequently be measured depends very much on the perspective and knowledge-base of the researcher or clinician concerned (Thompson and Kingston 2004). In addition to the dementia literature, this review draws upon relevant sources from different fields such as learning disability and the general mental health literature. It is worth highlighting the fact that these literatures reflect the different ideological standpoints and discourses that have evolved within these fields, including a growing emphasis on the direct involvement of service users. For example, the rights based approach has become a central feature of learning disability discourse where quality of life issues are viewed in the context of giving 'a voice' to service users (Plimley 2007) and user involvement. This strong value

base reflects the history of work in the learning disability field – specifically the influence of the eugenics movement and the assumption that people with learning disabilities would have a poor quality of life. This has historically been used to justify oppressive and abusive treatment of people with learning disabilities. Discussion about quality of life issues in this field often includes a strongly expressed value base (Plimley 2007). Value statements in this context stress that all people, with and without disabilities, share the human experience together and that every human being is entitled to live a good life within his or her environment (Schalock 2002: p461).

The direct involvement of people with dementia in their care, treatment, and aspects of service delivery has been relatively slow to develop compared with the involvement of people with other mental health problems or learning disabilities. This is partly due to a lack of investment in developing user involvement, which in turn has resulted from a somewhat nihilistic and ageist view of dementia as being an illness that is primarily a product of old age. Lack of user involvement is also an unforeseen consequence of the active role that carers have played in advocating on behalf of service users as well as for their own needs. The lack of user involvement has also been a reflection of the progressive nature of dementia combined with the strong tendency – until recently – for diagnosis to occur at a relatively late stage of the disease, when impairment is likely to be great. However, over the last ten years or so, there has been a shift towards earlier diagnosis and improvements in pharmacological treatments to slow the rate of memory loss, resulting in people retaining their cognitive faculties for longer. This, combined with the influence of concepts such as ‘personhood’ in dementia work, has led to a significant increase in the direct involvement of people with dementia in research and other initiatives aimed at eliciting their views and experiences.

The work of Harris and Stein (1998) identified how the social interactions of people with dementia affected their sense of self, and also highlighted the different types of coping strategies adopted by them. Research by the Mental Health Foundation (Pratt and Wilkinson 2001) explored the effect of being told the diagnosis of dementia from the perspective of 24 people who had dementia. Most recently, Alzheimer’s Society published ‘Dementia: out of the shadows’ (Alzheimer’s Society 2008). This research explored the perspectives and experiences of people with dementia before, during and after receiving a diagnosis, as well as the different ways they had adjusted and coped, and the effect of stigma.

Alongside the shift in approaches to researching dementia there have been developments involving people with dementia with a more overt focus on campaigning. This can be seen with the establishment of national groups of people with dementia such as the Scottish Dementia Working Group (supported by Alzheimer Scotland) and the Living With Dementia programme in England (supported by Alzheimer’s Society).

Perhaps most significant is the involvement of people with dementia in the development of the 'National Dementia Strategy for England' (Department of Health 2009). The strategy involved people with dementia in the various working groups that contributed to its development, contains personal stories and a substantial number of quotes from people with dementia, and includes a specific recommendation emphasising the importance of peer support and learning networks.

Developments such as these suggest that the involvement of people with dementia is beginning to mirror the levels of user involvement and participation seen in mental health services for younger adults. Issues that are familiar in these arenas, such as support, training and paying people with dementia for their participation, are actively being addressed by people with dementia:

If we don't offer payment we are saying that we do not value the voice of people with dementia. You can have as many professionals in a room as you want, but the real expert is the person with the condition. (Ashley and Savitch 2009: p16)

The publication in 2007 of 'Strengthening the involvement of people with dementia' (Care Services Improvement Partnership, 2007) also highlights a number of deficits shared by the user involvement agenda in other aligned fields. The challenge of involving people with dementia from seldom heard groups, such as people from black and minority ethnic communities, is an issue for service user movements across the piece. This review addresses some of these concerns in Chapter 3. Despite the common issues this review has identified, there are a number of other issues in relation to involving people with dementia that may be particular or unique to them and that require special attention. These include the language and terminology used; methods of communication; involvement of carers; applicability of the concept of recovery and rehabilitation; and the separation of dementia services from mainstream mental health services.

The trend towards greater involvement of people with dementia in service planning and delivery and in research is specifically reflected in an increased focus on capturing their perspectives on quality of life. At the same time, confidence in the possibility of obtaining reliable information directly from people with dementia has increased significantly. In contrast with quality of life as measured by external observers or clinicians is the development of a conceptualisation of quality of life as a subjective evaluation by the person themselves:

The individual's own perspective is very important in the assessment of QoL [quality of life] and it is the person with dementia who is the expert on their QoL and not society, researchers or clinicians. (Thompson and Kingston 2004: p36)

As the idea of subjective evaluations of quality of life has gained currency, the question of how to assess it when the person concerned is unable to provide a self-report, such as when they have severe dementia, becomes central. Smith et al (2005b: p8) summarise the main complications associated with assessing quality of life in dementia as they see it:

- Memory problems may lead to problems in generating accurate self-assessment.
- Problems with maintaining attention may make it difficult for a person with dementia to focus on the interview.
- Language disorders, which often feature in dementia, can limit the scope for full participation in discussion.
- Lack of insight may mean some people with dementia are unaware of their impairments or deny or minimise them.
- The capacity to make judgements can be impaired in people with dementia, making it difficult to produce a valid judgement about quality of life.
- Accurate self-assessment may also be compromised by challenging behaviour such as agitation or anxiety.
- The progressive nature of dementia means that the nature of quality of life, and therefore the means to assess it, is likely to vary over time.

This pinpoints the core problem with assessing quality of life in people with dementia. If quality of life is understood as being fundamentally a subjective evaluation of the quality of one's own life, then the fact that dementia is defined by deterioration in the means to identify and communicate is a primary and pivotal challenge. Assessing quality of life in people with severe dementia is usually considered a very different undertaking compared to assessing it in people with mild to moderate dementia because of the effect that severe dementia is assumed to have on the ability to comprehend and communicate:

Cognitive impairment is a diagnostic criteria [sic] for dementia ...and increases in severity as dementia progresses. Patients eventually lose the ability to communicate effectively. Thus, measures of QOL [quality of life] for patients in the moderate to severe stages of the disease must inevitably rely more on proxy reports than on patient self-report. (Ready and Ott 2003: p6)

Assessing quality of life in someone who has advanced dementia clearly presents great challenges. Despite these challenges, a growing body of research evidence strongly suggests that people with severe dementia can indeed provide meaningful self-reports about their quality of life (see for example Hoe et al 2005) and the evidence for this will be examined later in the review.

The review is divided into two parts. The first part outlines the way in which quality of life has been defined and measured. It begins in Chapter 1 by presenting the evidence drawn largely from reviews and studies about indicators from the more traditional approach to the objective measurement of quality of life. Chapter 2 describes studies in which quality of life is conceptualised as being rooted in the subjective experience of people with dementia, many of which have used qualitative approaches to research. The second part of the review is more concerned with outcomes and quality of life from the perspectives of different groups. The population of people with dementia is not only diverse in terms of the wide spectrum of cognitive abilities that it encompasses. It is also heterogeneous in terms of individual biography, life course factors, 'race', social class, gender and sexuality. Assessing quality of life in people with dementia therefore presents different challenges in relation to different groups and this review reflects that diversity. Chapter 3 reviews the evidence on quality of life indicators for people with dementia who belong to seldom heard groups, including people with learning disabilities; people from black and minority ethnic groups; lesbian, gay, bisexual and transgender people and people who live in rural as opposed to urban areas. Chapter 4 considers the evidence about the outcomes that are most important for people with dementia in terms of their contact with health and social care services. Finally, Chapter 5 reviews the literature on relevant quality of life indicators developed by other key groups, including older people as a broad population, people with mental health needs who do not have dementia, and people with learning disabilities.

## Methodology

Searching was carried out using a range of approaches:

- Electronic databases were searched using MEDLINE, PsychINFO, PSYCHLIT and the Cochrane Library Database (covering the period 2004-2009). Indexing and abstracting services including EBSCOhost, JSTOR and Springerlink were also searched and cross-referenced with Academic Search Complete and article linking services to ensure as full coverage as possible of material that did not fall within the academic journal domain specifically, but which linked with journals and periodicals that are specific to service professionals.
- Specialist sources of evidence were searched. This included the database at the National Institute for Health and Clinical Excellence, Social Care Institute for Excellence, the Royal College of Psychiatrists, the Royal College of General Practitioners and the Kings Fund. Relevant work from Carers UK, the Mental Health Foundation, Age Concern and Help the Aged were also included. The Bradford Dementia Group (at Bradford University) database and Alzheimer's Society database and catalogue were also searched.

- Hand searching was undertaken of relevant journals (not online) such as the Journal of Dementia Care, guidance documents such as the 'National Institute for Health and Social Care/Social Care Institute for Excellence Dementia guidelines', and reviews or papers which are not published but were nevertheless relevant. These were more likely to be sources for testimonies of service users which related to the issues under review.
- Book titles published within the timeframe, authored or edited by well known academics with expertise in this field, were also sourced for examination.
- Documents published by the Department of Health were also searched to provide an up-to-date position on policy concerning quality of life measurement scales, and service accepted features of measurement for service user outcomes.

The search focused on social care databases as well as those defined under the auspices of 'health' and 'health care'. All searches were limited to English language articles reporting on issues relevant to quality of life indicators for people with a diagnosis of dementia, their carers, family or friends. Material published before 2004 was only identified if it was particularly significant, relevant or ground breaking.

The key words 'dementia', 'Alzheimer's disease' or 'cognitive impairment' combined with 'quality of life' and 'service user and patient defined outcomes' were used. The search was underpinned by clear definitions of 'quality of life', and 'patient-defined outcomes/indicators'. Specific types of dementia - other than Alzheimer's disease - were searched for including: 'vascular or stroke related dementia', 'mixed dementia', 'frontal temporal dementia', 'dementia with Lewy bodies', 'Korsakoff's syndrome', dementia in Parkinson's disease' and 'AIDS dementia complex'. Very rare types of dementia linked to metabolic or neurological disorders such as CJD or were not specifically searched for but were not excluded. Evidence relating to mild cognitive impairment (MCI) – which does not lead to a dementia diagnosis – was excluded. Evidence linked to those with early onset dementia was included.

As part of the wider project will focus on seldom heard groups, these were included in the search. These groups include people with learning disabilities who develop dementia, people from black and minority ethnic communities who develop dementia, lesbian, gay, bisexual and transgender people who develop dementia and people in the later stages of dementia.

The search was extended from a meta-review of research literature (including international literature) to include individual studies in areas where less research has been undertaken and reviews are not yet available. The rationale for including studies was limited to those studies which contained comparative measures of either quality of life measurement scales or comparative groups such as patients, carers, relatives, service

staff. Studies were also an important source of testimonies where interviews were reported in detail.

Also included in the search were reviews relating to quality of life indicators and measurements from either patient or service perspective from other life threatening or life shortening conditions. This was to investigate whether the importance of individual quality of life indicators for dementia patients may differ from other illnesses.

# **PART ONE**

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## **Defining and measuring quality of life in dementia**



# 1. Quality of life measures and their development

The need to develop instruments for measuring quality of life in dementia was established in the early 1990s (Karim et al 2008). Since then a number of measuring scales and instruments have been created that aim to measure quality of life and each of these reflects different ways of conceptualising it. The early work of Kitwood and Bredin (1992) for example, conceptualised quality of life in relation to four different domains:

- sense of personal growth
- sense of agency
- social confidence
- hope.

As the number and type of measures have proliferated, several attempts have been made to compare and review them in order to assist those who might use them in selecting the optimum tool for their needs or setting. For our purposes, it is important to distinguish between measures that are dementia-specific and those that are generic but are routinely employed in populations of people with dementia (Ettema et al 2005). Generic measures focus mainly on health domains and tend to use cognitive function in the operational definition of quality of life. They are therefore based on the assumption that quality of life will deteriorate as cognitive function declines. At least two reviews of the relevant literature recommend that dementia-specific measures should be used in preference to generic ones (Banerjee et al 2009; Ettema et al 2005). This view is echoed by another review of the literature by Ready and Ott (2003), who state that generic quality of life scales are unlikely to be the most sensitive and specific measures of domains of quality of life that are relevant to dementia patients (p2). They argue that this is because generic measures assess physical illnesses that are not related to dementia and they may not capture unique and important aspects of dementia patients' experiences (ibid: p2). As we discuss in the next chapter, the 'uniqueness' of the experience of people with dementia in terms of what is important for quality of life is open to debate.

Lawton's work on dementia in the 1980s and 1990s has been particularly influential in quality of life and dementia research (Lawton 1994; 1997; 1999). In one review of instruments designed to measure quality of life in dementia over the ten year period

prior to 2003, the authors note that the greatest similarity between the range of instruments found was the utilisation of Lawton's model (Ready and Ott 2003), (although there were differences in the interpretation of how the model should be applied). Lawton's work provided a conceptual framework that incorporates four dimensions with both objective and subjective components:

- psychological well-being
- objective environment
- behavioural competence
- perceived quality of life.

This model and the key elements in it continue to provide the basic framework for the development of new quality of life measures. (Thompson and Kingston 2004). However, it has been noted that despite Lawton's model and the hypothesised links between quality of life and other factors derived from it being so widely cited in the literature, there is a lack of empirical evidence to support them (Byrne-Davis 2006).

Of key importance in conceptualising quality of life is whether key factors such as those in Lawton's model are understood as defining features, predictors or indicators of quality of life (Ready and Ott 2003). These decisions are critical in terms of how an instrument ultimately translates into a measure of quality of life. If, for example, cognition and functioning are incorporated as defining features, then a person's quality of life (as measured by the instrument) will inevitably decline as their cognitive function declines (Ready and Ott 2003). Woods et al (2006) conducted a study that found quality of life to be independent of cognitive function and regarded it as a largely independent variable, which needs to be measured in its own right, rather than using other variables as proxy measures in order to make estimates of the person with dementia's quality of life. Bowling (2005) highlights the distinction that might be made between causal and indicator variables and how traditional approaches to the measurement of quality of life have tended to assume only indicator variables – how quality of life is manifested – rather than what may add or detract from it. Conceptualisations of what quality of life is and the role of different variables in relation to it are therefore of central importance in the debate about how quality of life should be measured or assessed.

The review by Ettema et al (2005) identifies six dementia-specific quality of life measures and Ready and Ott (2003) identified nine. The same five measures were identified in both reviews and a further five were identified in only one of the two reviews. The five that were identified in both reviews are summarised here:

**Dementia Care Mapping** was developed by Kitwood and Bredin (1992) for use in care homes with people with dementia who were unable to provide self-reports. It involves using specially trained observers to perform systematic observation over a period of several hours to record levels of ill- or well-being on the part of the person with dementia. Kitwood, who developed the early prototype of Dementia Care Mapping, described it as a serious attempt to take the standpoint of the person with dementia, using a combination of empathy and observational skill (1997: p4). This approach to assessing quality of life is still used primarily in formal care settings and is based on the philosophy of person-centred care. The approach can be used with people in all stages of dementia and it is now used as an aid to clinical practice, care home inspection processes and as a research tool. In a review of the research literature relating to Dementia Care Mapping, Brooker (2005) points out that the original development work is unavailable in the public domain and that other key details about the development of the tool have not been published. However, it remains a very popular tool, partly because it explicitly adopts an orientation which respects people with dementia and this is rare among such tools.

The UK version of the **Dementia-Quality of Life (D-QOL)** questionnaire has been developed by Karim et al (2008) from the US original (Brod et al 1999). It explicitly conceptualises quality of life as experienced subjectively. The measure is based on self-report by the person with dementia through interview and incorporates five domains:

- the ability to appreciate beauty, surroundings and nature (aesthetics)
- feelings of happiness, hopefulness and good humour (positive affect)
- the absence of negative affect such as anxiety, sadness and loneliness
- feeling useful and loved (belonging)
- self-esteem.

(Karim et al 2008)

The questionnaire is intended for use with people who have mild to moderate dementia. The original tool was developed through an extensive literature review and consultation with focus groups (which included care providers, people with dementia, as well as professionals), as part of an iterative conceptual and statistical process (Ready and Ott 2003: p4).

The **Cornell-Brown Scale for Quality of Life in Dementia** was developed by Ready et al (2002) and is a modified version of the Cornell Scale for Depression in Dementia (Alexopoulos et al 1988). To develop the dementia scale, the depression scale was adjusted so that it incorporated positive aspects of quality of life as well as negative features. The scaling system was also adjusted so that it better expressed a measure for

quality of life. The instrument conceptualises quality of life as the presence of positive affect, self-esteem and satisfaction with the relative absence of negative affect. The Cornell-Brown scale uses joint interviews with a person with dementia and their carer by a clinician. It includes statements about physical complaints. It is intended for use with people who have mild to moderate dementia.

The **Quality of Life in Alzheimer's Disease (QOL-AD)** measure (Logsdon et al 1999) is based on self-report by the person with dementia and also their carer through interview. It was developed through a literature review of quality of life domains in the general population of older people, followed by a review of potential items by people with dementia, carers, older people without dementia and professionals. It is intended for use with people who are in the mild to moderate stages of dementia. It involves an appraisal of the person's:

- physical condition
- mood
- interpersonal relations
- ability to participate in meaningful activities
- financial situation.

This measure has also been found to be valid and reliable when used with people with severe dementia (Hoe et al 2005).

The **Alzheimer's Disease Related Quality of Life (ADRQL)** instrument (Rabins et al 1999) was developed using focus groups with carers and expert panels. It includes a weighting system for different indicators, which were arrived at through a rating exercise with 61 carers. The scale incorporates five domains:

- social interaction
- awareness of self
- enjoyment of activities
- feelings and mood
- response to surroundings.

The instrument involves an interview of a carer by a trained interviewer rather than direct reports from the person with dementia and as such is intended for use across all stages of dementia.

The review by Ettema et al (2005) also identified the **Quality of Life for Dementia (QOL-D)** (Terada et al 2002), which is a Japanese measure that involves interviews with a carer only and does not involve self-reports by the person with dementia. It can be

used across all stages of dementia. The domains it incorporates are: positive and negative affect; ability to communicate; attachment to others; spontaneity and activity, and restlessness.

The literature review by Ready and Ott (2003) identified a further four dementia-specific instruments for measuring quality of life as follows:

The **Activity and Affect Indicators of Quality of Life** measure (Albert et al 1996), as its name suggests, involves rating the activity levels and observable affect (through body language and facial expression) of the person with dementia. It can be used with people at all stages of dementia and is conducted using proxy ratings by family members or carers rather than self-reports, based on the view that people with dementia cannot reliably self-report about subjective states. The measure was developed by selecting items from two other scales, one for the indicators for activity levels, and one for the indicators of affect.

The **Psychological Well-being in Cognitively Impaired Persons (PWB-CIP)** scale (Burgener et al 2002), as its name indicates, measures aspects of quality of life relating to psychological well-being, such as frustration and expression of discontent. It contains 11 items that measure positive and negative affect and engagement behaviour. It is considered appropriate for use with people with severe dementia because it uses observer ratings only, without self-reports. It is also considered to be a relatively narrow measure of quality of life because of its focus on affect and behaviour (Ready and Ott 2003).

The **Quality of Life in Late-stage Dementia (QUALID)** scale (Weiner et al 2000) utilises a sub-set of items from the Activity and Affect Indicators of Quality of Life (Albert et al 1996, see above). It is a very brief measure designed for use with people with severe dementia in residential settings. It uses ratings from staff in residential homes based on their observations of 11 behaviours indicating emotional states and activity levels.

The **Quality of Life Assessment Schedule (QOLAS)** (Selai et al 2001) utilises both qualitative and quantitative approaches to measuring quality of life and is designed to be tailored to the individual person with dementia. The person is interviewed and asked to identify which key issues they consider to be important for their quality of life, selected from five domains. Carers are also interviewed. The QOLAS is based on a technique called Quality of Life Assessment by Construct Analysis, which was originally used with people with epilepsy. This method was underpinned by four key concepts. Firstly, an extensive literature review identified five domains that are important for quality of life:

- physical functioning
- psychological or emotional status
- social and family life
- economic or employment status
- cognitive abilities.

Secondly, specific items within these domains will vary in their importance from individual to individual. Thirdly, levels of expectation are a crucial aspect of quality of life, in that any discrepancy between expectations and present life situation will determine quality of life. Finally, quality of life is considered a comparative phenomenon in that people compare themselves to others and to themselves at other points in their lives.

The recent emphasis on the importance of incorporating self-reports of people with dementia has led to the development of measures specifically to assess subjective quality of life through self-report. The **Bath Assessment of Subjective Quality of Life in Dementia (BASQID)** is designed for use with people who have mild to moderate dementia and was developed from the perspective of the person with dementia (Trigg et al 2007: p790). The measure incorporates fourteen items asking respondents about their levels of satisfaction with issues such as their health and independence, and the extent to which they, for example, feel useful or happy. The measure is designed to complement objective measures of health and quality of life.

As can be seen in some of the measures described above, reports by proxy respondents often replace self-reports. Of the nine instruments reviewed by Ready and Ott (2003), only four involve seeking a self-report from the individual concerned. The fact that it has been shown that agreement between proxies and the person with dementia is often rated as poor to moderate, and that the gap widens as dementia becomes more advanced, is a real concern (Thompson and Kingston 2004). Specifically, quality of life is generally rated as being lower by carers than by the person with dementia themselves. This may be explained by the fact that the caregiver experiences depression or weight of responsibility which colours their view of the quality of life of the person they are caring for (Ready and Ott 2003). It is also linked to the tendency, referred to above, to assume that impaired cognition will adversely affect quality of life.

In a qualitative study that specifically examines the differences between self-reports of quality of life in dementia and those of proxies, the authors conclude that it may not be appropriate to substitute proxy-reports for self-reports at all (Smith et al 2005a). Among the problems they found with proxy-reports was the tendency for carers to talk about their own reactions when asked how they thought the person with dementia felt. Such observations have led the authors to develop two separate but complementary

measures, one for people with dementia (**DEMQOL**) and one for carers (**DEMQOL-proxy**) (Smith et al 2005b). The conceptual framework on which the measures are based is derived from an extensive review of existing literature and qualitative fieldwork. The people with dementia that were interviewed included people with mild, moderate and severe dementia. The final conceptual framework incorporates five domains with descriptive components for each:

**Daily activities and looking after yourself included:** getting around, keeping yourself clean, getting dressed, keeping yourself looking nice, going to the toilet, using a knife and fork, getting the things you need from the shops, getting in touch with people when you need to, getting meals, taking care of the house, getting where you need to go, taking care of finances, using money to buy everyday things, choice about how you spend your time, things that you want to do but can't, being able to enjoy what you want to.

**Health and well-being included:** global health, happiness or depression, contentment or frustration, enjoying life or enjoying nothing, confidence, embarrassment, anxiety, feeling lively or weary, loneliness, somatic complaints, feeling safe, cheerful, relaxed, irritable, angry, resentful, sad, distressed.

**Cognitive functioning included:** memory for recent events, memory for distant events, concentration, memory for names, orientation in time, place and person, clarity of thought, making your mind up, communication.

**Social relationships included:** treatment by others, social interaction, reciprocity, social integration, companionship, social support, intimacy and physical affection, other emotional relationships.

**Self-concept included:** self-esteem, presentation of self, sense of independence, satisfaction with past life, satisfaction with present life, hopes and aspirations for the future, feeling useful.

(Smith et al 2005a: p892)

The authors argue that one of the domains - self-concept - appears to be unique to dementia (ibid). They also highlight the fact that some of the components in other domains, such as embarrassment, are considered important by people with dementia but are not often found in generic measures of quality of life. Significantly, the authors recommend that DEMQOL-proxy should be used with people with severe dementia.

In some instances, it is suggested that the difference between proxy-rated quality of life and the ratings given by the person with dementia can be attributed to loss of insight on the part of the person with dementia (see for example Naglie et al 2006). This suggestion underscores the widely held belief that accounts of quality of life by people with dementia are more dependable than those drawn from other more 'reliable' perspectives. However, low levels of knowledge about the nature of insight in relation to dementia and how it does, or does not, affect a person's ability to evaluate their own quality of life, suggests that we cannot assume a person with dementia's self-report is either invalid or unreliable (Ready and Ott 2003). Thorgrimsen et al (2003) held focus groups for people with dementia and their relatives and concluded that priorities may change for people with dementia over time, and that there may simultaneously be an increased loss of insightfulness. However the focus groups enabled people to reminisce about the past and also express views of 'making the best of it' and 'taking one day at a time'. This would suggest that some subjective insightfulness was intact, allowing for both reflection on the past and planning for the near future. The disability paradox (Albrecht and Devlieger 1999), referred to in the introduction of this review, suggests that lack of insight may not be the key factor, and that the central issue may be the failure of others to imagine how life can be enjoyed from a position of 'objective' suffering.

It is clear that there are differences between the measures described above in terms of the involvement of people with dementia in their development as well as their use. As this review has indicated, some measures, such as D-QOL, QOL-AD and DEMQOL have been developed using focus groups or qualitative fieldwork with people with dementia. Such work provides strong support for the argument that quality of life can be discussed in a meaningful way with people with dementia and that this can be the first step in developing new tools for assessing quality of life (Byrne-Davis 2006). The review now turns to consider in more detail the evidence concerning how people with dementia understand quality of life.

## 2. How people with dementia understand quality of life and the role of key psychosocial concepts

This chapter is concerned with research that has set out to understand more about the meaning of quality of life from the perspective of the person with dementia. Significant progress has been made in terms of conducting research into quality of life from the perspectives of older people, particularly through large scale projects such as the Growing Older Programme (Walker 2005). The growing interest in hearing directly from people with dementia about their quality of life is therefore part of a wider trend in this direction. This review briefly explores the research on older people and quality of life as a discrete group in Chapter 5 of this review. This chapter begins by considering how doubts about the use of the directly captured perspectives of people with dementia have been challenged. It identifies some of the specific domains that have been identified through research with people with dementia and considers how some of these differ from both the domains that tend to be the focus of traditional measures and those identified by proxies such as carers. The chapter also considers key psychosocial concepts such as coping, stigma and resilience, since understanding of these concepts has largely developed through research that has attempted to understand the world through the eyes of the person with dementia.

There is a tension between the objective evaluation of quality of life and the broader conceptual issue of how quality of life is defined and understood by older people - with and without dementia - themselves. As we have seen, this is reflected in part in the tendency for (most) quality of life measures to marginalise or even exclude the perspective of the person and instead rely on the proxy views of others, most commonly carers. More recently, attention has been paid to incorporating the perspectives of service users in assessments of quality of life and quality of care. However, as these currently depend on experiential methodologies (eg Clare, Rowlands and Bruce et al 2008), they are not easily included in instruments that tend to be conservative in nature and are underpinned by health related constructs. Where the subjective evaluation of the person with dementia is incorporated in such studies, it tends to be more as an adjunct to objective measurement rather than it being situated at the core of the process. Such studies are to be distinguished from those that see the assessment of

quality of life as being rooted in the subjective experience of the person with dementia. Campbell et al (2008) state that quality of life rests in the experience of life and its essence lies in the person's own evaluation. This supports the argument that all people are capable of evaluating their life through their own internal experience and that no person's experience can be invalidated because they have a disability or impairment.

The tendency to bypass subjective accounts of people with dementia when assessing their quality of life reflects an assumption that people, particularly those with severe dementia, may not be able to communicate their views. Whilst Lawton's influential model (see pages 13 to 14) incorporates both objective and subjective evaluations of quality of life, self-report is still considered problematic:

Necessary dimensions for QOL [quality of life] assessment include both subjective and objective components, specifically attributes falling into sectors of behavioural competence, self-assessed quality of domains of everyday life, environment, and generalised psychological well-being. None of these QOL facets should be excluded from assessment in people with dementia, but many such people require the use of indicators that do not depend on self-report. (Lawton 1997: p91)

This view is echoed by Ettema (2005) who states that there are doubts about people with dementia being valid and reliable informants about their life quality (p676). However, this assumption has been challenged. It has been argued that people with dementia, including people with moderate to severe dementia, can communicate meaningfully about their quality of life (Byrne-Davis et al 2006). Mozley et al (1999) specifically question the tendency to use MMSE (mini-mental state examination) scores in quality of life research to predict the 'interviewability' of people with dementia. They challenge the use of MMSE scores to exclude people as the MMSE cut-off of 17/18 commonly used to indicate severe impairment is a poor guide to quality of life interviewability (ibid: p782). They found that a large proportion of older people with significant cognitive impairments were in fact able to answer questions about their quality of life. Findings from studies with people with significant cognitive impairment highlight specific areas associated with better quality of life:

Our study suggests that in severe dementia, higher quality of life was predicted by better functional ability, lack of disability, improved mood status and increased engagement with the environment (Hoe et al 2005: p134).

A number of studies highlight the central importance of addressing the question of how people with dementia understand quality of life. This is fuelled in part by evidence that

people with dementia highlight different domains than those identified by their carers and those emphasised in current quality of life measures. In particular, the assumed strong link between disease-oriented issues such as cognitive difficulties and quality of life is brought into question by a number of these studies. Specifically, they challenge the emphasis in many traditional quality of life measures on cognitive elements (Byrne-Davis et al 2006). Selwood, Thorgrimsen and Orrell (2005) conducted a one year follow up study examining quality of life. They found that a decline in subjective quality of life is not inevitable despite a reduction in independence and cognitive ability:

...it seems that people with dementia adapt to this and continue to have positive experiences. (Selwood, Thorgrimsen and Orrell 2005: p236)

In fact they identified that the only major predictor of future quality of life was quality of life at baseline, saying that mood and personality have a strong influence on how we perceive our life and change of circumstances. In addition, they found that although lower levels of anxiety and depression correlated with higher quality of life, quality of life was not correlated with cognition. Based on their research using focus groups with people with dementia, Byrne-Davis et al (2006) found that people with dementia, including moderate to severe dementia, were able to talk about their quality of life in meaningful ways. Questions that were asked in the focus groups were:

- How would you describe your quality of life?
  - Why did you say that?
  - What things give your life quality?
  - What things take away from the quality of your life?
  - What would make the quality of your life better?
  - What would make the quality of your life worse?
- (Byrne-Davis et al 2006: p857)

The key issues people emphasised were not disease-oriented but were issues that could conceivably have been generated by many different groups of people (ibid: p861):

- social interaction
- psychological well-being
- church/god/religion/spirituality
- independence
- financial security
- health.

This evidence suggests that the domains of quality of life highlighted as important by people with dementia are similar, or even the same, as those emphasised by people

without dementia. More elements of quality of life may be shared than may be unique to people with dementia than has hitherto been identified (Byrne-Davis et al 2006). The questions used in the study were also used in a study of quality of life in older adults without dementia and this found that family relationships, social contacts and activities were considered as important as functional status and health (Farquhar 1995). Steeman et al (2006) identified social interaction as having a central function in facilitating or hindering an individual's capacity to cope with dementia, reflecting the importance given to social interaction in quality of life studies in general.

Dröes et al (2006) carried out an exploratory study with people with dementia living in nursing homes and in the community. The explicit aim of the study was to compare the quality of life domains identified by people with dementia with those derived from theoretical models and carer perspectives. The study concluded that most domains considered to be important by people with dementia were shared with carers and reflected in the literature. However, the study found some exceptions to this. Certain key domains were not mentioned by carers but identified by people with dementia, including:

- financial situation
- sense of aesthetics in living environment
- being of use or giving meaning to life.

Key domains that were left out of measurement instruments but emphasised by people with dementia included:

- security and privacy
- self-determination and freedom.

The article provides a useful table (pp545–547) which provides a detailed overview of the domains that were identified by people with dementia and carers and derived from the theoretical models and measures of quality of life. The measures considered by the Droes et al study include DQoL, ADRQOL, QOL-AD and Cornell-Brown, as described in Chapter 1 of this review.

The chapter now moves to considering the role of a specific range of psychosocial issues that are of particular relevance in terms of understanding the experiences of people with dementia and their quality of life. Psychosocial wellbeing is a synthesis of intrinsic, eg personal and emotional self, and extrinsic, eg the social self dimensions (Roelands et al 2008; Pratt and Wilkinson 2003). These two aspects of self interlink and interrelate and are affected by a whole set of variables which are themselves located both within

the person, such as personality, and in their immediate sphere, such as the quality of their personal relationships (Galvin et al 2007). This concept, along with coping styles, resilience and self stigmatisation, has been reviewed in relation to people in the early stages of dementia (Milne and Peet 2008). This work formed part of a wider project that explored the experiences of people with early dementia and their relatives (Alzheimer's Society 2008). In this review, our focus is on the psychosocial concepts of coping and resilience, social comparison theory, and stigma and self-stigmatisation as these are most relevant to the issue of quality of life. It should be noted that this section is based largely on evidence from research that focuses on people with mild to moderate symptoms of dementia.

## The role of key psychosocial concepts in relation to quality of life

### 1 Stigma and self-stigmatisation

Stigma is widely evidenced as a major source of social exclusion for people with mental health problems (Social Exclusion Unit 2004) and has specifically been identified as having a significant negative impact on the psychosocial well-being of people with dementia and their social experience (Banerjee 2006; 2004; Katsuno 2005). It is commonly identified in testimonies of people with dementia and their families as detrimental to their daily lives and sense of well-being (Bowling and Gabriel 2007; Betts Adams 2006; Clare, Rowlands and Quin 2008).

There is a particularly strong evidence base in relation to the experience of seeking and receiving a dementia diagnosis. This is largely a consequence of the deeply held fear of dementia, especially Alzheimer's disease. Fear of this disease appears to be more deeply ingrained in the public psyche than any other dementia. Katsuno's study (2005) for example, found that – almost unanimously – participants feared a diagnosis of Alzheimer's disease because they associated it with devaluation, mistreatment, social exclusion and loss of friends. They viewed it as creating both a social stigma and as undermining their internal sense of self; they anticipated they would feel a lesser person. The work of Clare (2003) also evidences a particular fear of the label of Alzheimer's disease; one participant said about her physician:

'I knew anyway, what Alzheimer's is...he didn't say Alzheimer, he didn't want to say that. Early ageing, that's what he said.' (Paula, Clare 2003).

Fear of being negatively viewed and labelled is reflected in the fact that many older people take proactive steps to prevent the onset of Alzheimer's disease. For example, in one of the Growing Older Programme projects, 60 per cent of participants stated that they deliberately undertake certain activities with the aim of preventing cognitive decline (McKee et al 2005).

Self-stigmatisation occurs as a result of the individual internalising negative descriptions of people with dementia including terms such as 'madness', 'losing it' or 'senility'. If these views are internalised by a person who then develops dementia, they tend to feel that they have entered a new socio-cultural group that is 'lower' and marginalised. This was noted by participants in Katsuno's study (2005), who reported experiencing social exclusion and devaluation. They not only feared the disease itself, but also the negative responses that they expected to receive from others, which they in turn internalised. For some this contributed to the hiding of their symptoms and avoidance of seeking help:

'I'm trying to guard that...the reputation, you know...don't want to be looked down on...like...don't want the feeling of being back in first grade or whatever...of going in the other direction. Decreasing instead of improving...and [I have] inward anger.' (participant, Katsuno 2005: p206)

In another study a physician stated:

'I get told all the time, "Please don't mention the A word". That's what it's called; it's called the A word. And I will be sensitive to that.' (physician participant, Kissel and Carpenter 2007: p277).

Kissel and Carpenter (2007) found that when pressed, physicians often described their diagnosis as 'memory problems' or 'thinking changes' instead of using a specific stigmatising label. This behaviour among physicians may serve to perpetuate the stigma and self stigma attached to dementia, as it can be reasoned that if professionals are unwilling to acknowledge the true status of the condition, then the person with dementia and the wider public may continue to misunderstand the meaning of the term. This not only discourages diagnosis but contributes to a view of people with dementia that is wholly negative and damaging.

## **2 Coping, resilience and social comparison theory**

Evidence from literature suggests that people with dementia adopt two main coping styles (Milne and Peet, 2008). These are a self adjusting style that is associated with awareness of cognitive change, help seeking behaviour and heightened emotion and a

self maintaining style which is associated with minimal reaction to diagnosis, lower levels of emotion and maintaining a 'life as usual' approach to illness (Clare 2003). Coping style is likely to have implications for the assessment and evaluation of quality of life. For example, if a person adopts a self maintaining coping style, diagnosis tends to be sought at a later stage in the illness, when opportunities for early intervention and practical help may be lost. This is likely to undermine or compromise quality of life (Aminzadeh et al 2007). Conversely the person who tends to adopt a self adjusting style is more likely to notice symptoms, seek help at an early stage and maximise their chances of accessing preventive treatments and being involved in decision making. This approach is more likely to enhance the quality of life of the person and their relatives (Milne and Peet 2008).

The psychological concept of stress inoculation (Kobasa 1979) could also impact upon self-reported levels of quality of life in relation to dementia. Broadly this concept proposes that if an individual has been exposed to stressors throughout the life span, they are more likely to develop a 'hardiness' to stress and develop methods to manage their stress levels effectively (Keady et al 2007). It seems reasonable to assume that if stress inoculation can help to moderate how an individual copes with the onset of symptoms, diagnosis, and the aftermath, then stress inoculation could play a positive role in self-reported quality of life.

This dovetails with the concept of psychological resilience, or the ability to quickly recover from negative experiences. Resilience is positively associated with optimism and extroversion, and this could lead to better adaptation to changed circumstances (Hamilton-West, in press). This supports the notion that the personality of the individual, as existing before the outset of dementia, influences psychosocial outlook and reported quality of life – the concept of the glass being half full or half empty.

Resilience has also been linked to the management of lifelong disadvantage and discrimination. Hulko (2009) for example argues that resilience is acquired by people from marginalised groups throughout their life course, and that this may equip them to better manage the onset and consequences of dementia than people from more privileged groups. Other authors have argued that for some marginalised groups the experience of dementia and the process of diagnosis may actively deconstruct people's coping mechanisms:

For older gay men and lesbians who may have felt the necessity to maintain a superficially heteronormative lifestyle, the onset of dementia in later life may be a minefield of potential 'outings'. The crises that may accompany the diagnosis of life-threatening disease or gradual development of disability mean that previously private matters can suddenly be open to public scrutiny. (Price 2008: p1,344)

This emerging evidence base demonstrates the importance of acknowledging a wide range of diverse and individualised experiences around dementia, in particular a need to appreciate the complexity of factors that might contribute to well-being and quality of life.

Another theoretical perspective suggests that if stressful events are accumulated over a relatively short period of time, for example two to three years, stress can have a detrimental impact on psychological health. Holmes and Rahe (1967) developed the Social Readjustment Rating Scale (SRRS) which measures the impact of stressful life events such as ill health, divorce or moving house, on people's health. It could thus be argued that the way in which a person with dementia manages the condition is, in part, related to extraneous variables and that it is the number and accumulation of stressful events that impacts negatively on well-being not the dementia per se. It is therefore important when evaluating quality of life to take account of dementia alongside the person's other, recent, life experiences. It also implies that the person with dementia copes better with having dementia if they are physically and psychologically robust at the time of, and following, diagnosis.

Social comparison theory (Festinger 1954) suggests that individuals assess their own attitudes, emotions, health etc, by comparing themselves to other people in similar situations. It is acknowledged as a mechanism to reduce anxiety especially when faced with a threat, and a potential route to finding reassurance. Evidence strongly supports the notion that individuals prefer to share a new or threatening experience with others and that this increases their chances of being reassured and supported (Hewstone and Stroebe 2001). Work with carers of people with dementia, for example, has shown not only that sharing caring experiences with others in a similar situation reduces the level of 'burden' and enhances quality of life for carers (Roelands et al 2008) but that advice and support given to a relative at an early stage in the dementia trajectory promotes the psychosocial well-being of both the carer and the person with dementia (Aggarwal et al 2003).

This is also evidenced directly in people with chronic health conditions such as dementia who attend support groups (Carmack-Taylor et al 2007). Bennenbroek et al (2002) showed that - particularly amongst those who view their illness negatively - seeking advice and information from others who are coping better enhanced a sense of being and of being in control of the condition. If people feel in control they tend to want to learn more about coping strategies and treatments and engage to a greater degree with relatives, support services and self help groups. Such evidence demonstrates the value of information, support and advice work with people with dementia, particularly that which includes some type of informal or formal group work.

# **PART TWO**

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## **Outcomes and quality of life indicators**



# 3. People with dementia from seldom heard groups

## Introduction

Reviews in this area are uncommon, as one might expect of seldom heard groups. We have therefore relied upon individual studies that have produced relevant findings, particularly those that suggest the need for further research in specific areas. Reasons for the dearth of studies include the self-evident fact that we are talking about groups that are by definition marginalised in both research and other spheres of life. Another significant reason is that dementia tends to become the all-consuming feature of a person's identity once they receive a diagnosis, rather than any other aspect of their identity such as 'race', ethnicity, or gender:

...once a person has dementia, the diagnosis and its presumed personal and public consequences somehow become a person's chief defining characteristics. Other social identities are perceived as less important, or at least less pressing, and are thus extinguished in the observer's eye - a response, perhaps, to the persuasiveness and power of the stereotypes, stigma and discrimination that surround the condition. (Price 2008: p1,341)

Yet there is also evidence that quality of life is mediated in complex ways by the socio-political location of individuals, including their 'race', ethnicity, social class, age and gender. Whilst the following observation is made in relation to older people in general and a key aspect of quality of life - opportunities to engage - it plainly includes people with dementia:

...we need to examine how the various social structures such as class, gender and ethnicity interplay to enable (or restrict) older people to engage with the opportunities available to them in general. (Higgs et al 2005: p29)

In particular, there appear to be important differences between groups in terms of their degree of social power and marginalisation. Hulko (2009) conducted an exploratory, qualitative study of the relationship between the experiences of older people with dementia and the intersection of social class, gender, 'race' and ethnicity. She found

that the extent to which dementia was conceptualised as a problem by her respondents varied according to their social location. Specifically, she found that privilege was linked with negative views of having dementia whereas people from more marginalised groups seemed better able to resist being regarded as the sum of his or her symptoms and dismiss the significance of the illness (Hulko 2009: p141). People from marginalised groups were more concerned with instrumental preoccupations relating to their physiological and safety needs compared with people from more privileged groups, who were more concerned with socio-emotional issues such as becoming a burden to others. These different preoccupations resulted in differential experiences of the condition itself:

Being more focused on instrumental than socio-emotional preoccupations correlated with viewing dementia as 'not a big deal' or a 'nuisance' rather than 'hellish', which was related to having socio-emotional preoccupations. (ibid: p138)

Hulko uses Maslow's hierarchy of needs (Maslow 1970), with its model of basic and higher order needs, as a conceptual framework. Her work foregrounds the heterogeneous, fluid and dynamic nature of experiences of living with dementia and highlights the need for sensitive and nuanced approaches to the interpretation of indicators and evaluations of quality of life in this multi-dimensional area. In particular, being aware that the conceptualisation of dementia that underpins current quality of life instruments - that it is a personal tragedy and an incurable negative disease - reflects the position of socio-economically privileged groups and not those whose voices are less powerful or off the radar.

The chapter now turns to considering issues relating to people with dementia from what are often termed 'seldom heard' groups, including people from: black and minority ethnic groups; people in rural communities; people with a learning disability; and lesbians and gay men, bisexual and transgender people.

## **Black and minority ethnic groups:**

The number of people with dementia from black and minority ethnic populations is predicted to rise significantly over the next 20 years. This is especially true amongst first generation migrants (those who came to the UK between the 1950s and 1970s), many of whom are now reaching the age at which the risk of developing Alzheimer's disease is considerably raised (Milne and Chryssanthopoulou 2005). People from the African Caribbean community and some Asian sub populations have been identified as being at an increased risk of vascular dementia due to enhanced levels of hypertension and diabetes (Parker and Philp 2004).

Both in real terms and as a proportion of the general population, the numbers of older people from black and minority ethnic groups have risen rapidly. Older people from black and minority ethnic groups have less access to pensions and benefits than their white counterparts and are more likely to face higher levels of poverty and live in poor quality housing (Joseph Rowntree Foundation 2004); factors that are known to have great bearing on quality of life experiences in the general sense.

The 'Dementia UK' report estimates that there are at least 11,860 people from minority ethnic groups with dementia; this is likely to represent a considerable under-estimate (Alzheimer's Society, 2007). Early diagnosis of dementia may be particularly difficult within minority groups for a variety of reasons. These include communication issues, the taboo nature of dementia and mental illness more widely, stigma, unfamiliarity of symptoms to patients and their families, a perspective that constructs dementia as a 'normal' part of the ageing process and a lack of diagnostic and screening instruments (Milne et al 2008).

There is some evidence that dementia may not be an acceptable diagnosis in some minority ethnic groups; there may also be a lack of information about available services or services may be viewed as inappropriate or racist in their orientation (Beattie et al 2005: p68). Doubts about whether GPs have the relevant skills for assessment and diagnosis in terms of cultural and language differences have been highlighted as one problem in relation to diagnosis (Beattie et al 2005). Fears about mislabelling are also an issue in terms of:

...a historical and pervasive racism in the mental health system that would lead black people to be mislabelled as having dementia when they really had a different mental health problem. (Beattie et al 2005: p71)

Specific issues relating to the whole process of cognitive testing and cultural diversity have been identified.

## **Cultural issues in cognitive testing**

Cognitive testing does not always translate across cultures or geographic boundaries (Black et al 2009). Different cultures may regard memory loss in different ways and may not consider dementia to be a disease, therefore dementia may not be reported in all cultures or countries in the same way; likewise, not all approaches to testing cognitive ability will be equally applicable.

Language may also heavily influence the validity of cognitive tests. Measures developed in English may not translate well. Languages with different grammatical structure, phonetic spelling and sentence structure for example, will not always allow for translation, or could imply a different meaning culturally. Written tests could also be a problem in areas of high illiteracy such as India, where a task to test initial letter fluency would be meaningless (Black et al 2009; Milne and Chryssantopoulou 2005). Technical problems include the fact that people for whom English is a second language often revert to their language of origin when they develop dementia. This clearly potentially impedes the identification of the symptoms of dementia (Milne and Chryssantopoulou 2005).

This cross-cultural sensitivity is also likely to be a problem in terms of unproblematically employing quality of life instruments or indicators. An item that is considered pivotal to good quality of life in one culture may not be appropriate in another. The Western notion of family caregiving being a 'burden' for example, is simply not in the linguistic or cultural cannon of most minority ethnic communities in the UK or US (Milne and Chryssantopoulou 2005). The term 'caregiver' is not widely understood in many black and minority ethnic communities either (ibid). If it is accepted that cognitive testing may not be reliable cross-culturally, then it is also reasonable to assume that quality of life assessment is unlikely to be sufficiently sensitive to capture culturally specific and often nuanced differences. Given the importance of culture in influencing and underpinning life experiences including those relating to ill health, stigma and family caring it is important to acknowledge that instruments developed (mainly) in the West are likely to fail to take account of those dimensions of quality of life that are not shared with mainstream Western culture. This point resonates with that made above about the dominance of a particular group in privileging a particular conceptual model of dementia and thereby our understanding of quality of life for those with the condition as well as quality of life instruments. There is a long established need for investment in designing culturally sensitive quality of life measures for those with dementia and their relatives that are valid and reliable (Seabrook and Milne 2009).

## People in rural settings

Just as the general population is ageing, the numbers of older people living in rural areas has increased. While 15 per cent of the urban population are aged 65 and over, more than 18 per cent of those living in rural areas are in this age group; approximately one third of the older population of England live in the countryside (Milne et al 2007). Inadequacy of service provision in rural areas compared to urban areas has been identified in recent research. Problems include limited access to rural premiums (extra sums allocated to rural authorities in order that they match services in urban areas) in terms of resource allocation, little understanding of disadvantage in rural locations and lack of inclusion of the perspectives of rural older people (ibid).

While rural life can enhance quality of life for many older people, it also carries a number of risks. Isolation, including lack of opportunity to develop a social network, is a primary risk of living in a remote setting such as a farm or hilltop hamlet. Chronic isolation has been implicated in late life depression including that linked to dementia, and is a contributor to the loneliness of long term dementia carers (Milne et al 2007). The stigma associated with mental health problems can be particularly evident and severe in a small community; a strong culture of self-sufficiency can also mean people are reluctant to seek help. Poorer health and quality of life outcomes for people with dementia are not only linked to limited availability of social and secondary care services in rural areas but also to the need to travel longer distances to visit their GP (ibid). Prohibitive transport costs are also an issue which specifically undermines the ability of those on low incomes to access care services, support groups, shops and post offices (Murphy et al 2009).

## People with learning disabilities

The life expectancy of people with learning disabilities has increased more quickly than that of their non-disabled counterparts. (Hatzidimitriadou and Milne 2005). For example, life expectancy for someone with Down's Syndrome is now estimated at over 50 years, an increase of ten years since the 1980s (Wilkinson et al 2006). The improved life expectancy that people now experience is due to improvements in standards of living and improved access to appropriate medical care (Hatzidimitriadou and Milne 2005). As the number of older people with a learning disability and specifically Down's Syndrome has grown, so too has the number of people with a learning disability who are diagnosed with dementia.

Few studies have addressed the issue of quality of life for this group explicitly. One study (Stalker et al 1999) explored choice-making for people with learning disabilities and dementia. It emphasised that people often had clear preferences which they could express clearly when given time to communicate effectively. Interestingly, this small-scale study identified what appeared to be a link between bereavement - particularly unresolved grief - and a diagnosis of dementia. A diagnosis of dementia appeared to occur shortly after the person experienced a primary bereavement. This is likely to be because people have come to the attention of agencies after years of being cared for at home.

In another study, Wilkinson et al (2006) identified the importance of the approach taken to disclosing a diagnosis in terms of the individual's capacity to meaningfully engage with the implications of the illness for their health and life. In addition, the study found that information about dementia was often not shared with others close to the individual concerned, such as those who co-reside in shared accommodation. This

meant that tensions could develop over a person's behaviour, or because of staff responses to their behaviour, because the causes of the behaviour were not understood by other residents. A detailed review of the issues relating to interventions and services for people with a learning disability who have dementia can be found in Kerr (2007).

## **Lesbian, gay, bisexual and transgender people with dementia**

A rough estimate suggests that there may be around 57,000 lesbian and gay people in the UK with a diagnosis of dementia (Price 2008). Just as in mainstream service provision and research, this group is largely invisible in dementia research. In fact the whole issue of sexuality has been absent from dementia discourses (ibid). In part, this simply reflects the dominant biomedical approach to dementia which, in its traditional form, allows little scope for a holistic view of the individual including their sexuality. It also reflects a deeper and widely prevalent ageist belief that older people are asexual and that considerations of sex and sexuality are irrelevant to assessments of need or quality of life (ibid). There is virtually no literature that deals specifically with the issue of quality of life of lesbian, gay, bisexual and transgender people with dementia. However, in relevant individual studies, choices about 'coming out' – revealing one's lesbian or gay identity – emerge as a particular stressor in dementia:

The anticipated loss of personal agency and control that may accompany dementia, resulting in the necessity to rely more heavily on others, may mean that personal living circumstances, the nature of which may have been closely guarded, are thrust into the public domain...and, as many lesbians and gay men will be acutely aware, the public gaze is not always benign. (Price 2008: p1,346)

Fears about coming out may intersect with the experience of lifelong and age related discrimination and dementia related stigma to increase the risk of social isolation and a reluctance to seek help, particularly a diagnosis.

The review now turns to the experiences of people with dementia in their contact with health and social care services.

## 4. People with dementia and their contact with health and social care services

This chapter focuses on two main areas in terms of quality of life: diagnosis in the early stages of dementia and the quality of life of people with dementia in residential care homes. The reason for this dual focus is that a great deal of attention has recently been paid to the former issue – as reflected in the ‘National Dementia Strategy for England’ (Department of Health 2009) – and the latter issue has been the subject of a relatively large number of studies. As discussed in the previous chapter, it is important to acknowledge the heterogeneous character of the population of people who have dementia. Within this heterogeneity are groups that are more or less marginalised and who have more or less power in society. For some groups, this means that their experience of dementia compounds and amplifies the disadvantage(s) they may already be facing. At the present time, there is evidence that this disadvantage is mirrored, rather than addressed, by the services they receive:

There is a massive underfunding of all services for people with dementia. The general absence of services on the ground does not bode well for marginalised groups, whose most important hurdles are seemingly the same ones faced by anybody with dementia, but magnified. Overall, the picture is of a care system which is not centred on the needs of marginalised groups with dementia.

(Beattie et al 2005: p77)

### Diagnosis in the early stages of dementia

A particular problem with lack of services has been identified at the early stages of dementia. Intervention at this stage is of crucial importance in terms of reducing, in the long-term, the harm that results from late diagnosis (Banerjee et al 2007). The introduction of a comprehensive model for early dementia assessment and care – the Croydon Memory Service Model – was found to have high acceptability, accessibility and effectiveness in increasing the numbers of people diagnosed and cared for in the community (ibid). In terms of quality of life, a follow-up study of people referred to the service using DEMQOL and DEMQOL-proxy (see Chapter 1) found statistically significant improvements in both self and proxy-ratings of quality of life (Banerjee et al 2007). The

follow-up study also found that the service was successful in achieving its goal of an increased referral rate for people from minority ethnic groups. The strategy involved building relationships with places of worship in order to reduce the stigma associated with mental health services and so make a referral more acceptable to the individual concerned. Such strategies clearly address the nature of some of the problems we identified in Chapter 3 of this review, concerning seldom heard groups. The Croydon Memory Service was a Department of Health funded pilot study; the 'National Dementia Strategy for England' (Department of Health 2009) acknowledges the need to commission new services of this type nationally.

### **Quality of life and quality of care for people with dementia in residential care**

While the care of people in the early stages of dementia is of vital importance, so too is consideration of the services received and the quality of life of people in care home settings.

One of the problems with assessing quality of care is that good care is a necessary but not sufficient ingredient for improving the quality of life of people who receive it:

Although good care may be a necessary condition for good quality of life, it is possible to provide good care without residents experiencing good quality of life. (Edelman et al 2005: p27)

As discussed later in this chapter, this leads to the further reinforcement of the argument that understanding the subjective experience of the person with dementia is of fundamental importance. A considerable amount of research in this area has been undertaken in care home settings.

Assessing quality of life amongst care home residents is a difficult task, not least because there are often differences between the ratings provided by residents, staff and carers. This is unsurprising, given the evidence reviewed in previous chapters. Each group tends to emphasise different aspects of quality of life; for example, staff ratings tend to be associated with dependency and challenging behaviour, whilst the quality of life scores of residents are most affected by the presence of depression and anxiety (Hoe et al 2006). A combination of measures that incorporates observations from all three groups may therefore be required in order to obtain a full picture of quality of life (Sloane et al 2005). Despite the challenges presented by measuring quality of life in care homes, evidence suggests that it is largely determined by a sense of subjective well-being and the existence, or not, of mental health problems (Smallbrugge et al 2006).

Like quality of life, the related concept quality of care is also complex and again, there are multiple perspectives to be incorporated into its assessment. The components of 'care' include those elements that are provided within the home as well as those offered by external sources, such as medical care. Dementia Care Mapping, as described in Chapter 1 of this review, has made an important contribution in this area as it gathers multiple rather than single sources of evidence. Good quality care depends on a range of macro level factors, such as financial stability of the provider, as well as micro factors, such as staff satisfaction. The fact that these interact makes the assessment of quality of care multi-faceted and far from straightforward. Spector and Orrell (2006) found a correlation between increased hope in staff at a care home and better resident assessed quality of life. The study examined factors that were associated with discrepancies between residents' self-assessments of their quality of life and staff assessments of it. Some items on the QoL-AD scale such as physical health, family and friends were rated similarly, but others differently, such as ability to do chores, marriage or relationship, memory and life as a whole. Neither staff factors such as job satisfaction and person-centeredness, nor severity of cognitive impairment of residents, explained the discrepancy. This seems to support the argument that cognitively impaired residents were able to rate their quality of life reliably as consistency was found, and that staff attitudes influence quality of life for residents.

A linked example of an observational tool used in the inspection of care homes is the Short Observation Framework for Inspection (SOFI). This draws heavily on Dementia Care Mapping and involves structured observation of a sample of five residents in a communal area and over an extended lunch period. SOFI is specifically designed to help observe and report on the quality of care experienced by people with communication difficulties such as severe dementia. It has a value base which is explicitly about treating people with respect and as individuals; it highlights the need to view the world from the perspective of the individual and it acknowledges the central importance of the social environment (Commission for Social Care Inspection 2007).

Evidence about the quality of care in homes is mixed, reflecting in part the different methodological approaches to measuring it. Direct observations of care home practices tend to produce less positive findings than those adopting a checklist approach (Ballard et al 2001). There is strong evidence of the negative impact on residents' quality of life of prescribing patterns and practices such as covert administration of medication, physical restraint, electronic tagging and abuse (Help the Aged 2007).

In terms of the experiences of people with dementia in care homes, a recent survey, 'Home from home' undertaken by the Alzheimer's Society (2007) found that people with dementia are not always afforded dignity and treated with respect. As already observed in this review, dementia appears to have become a label which eclipses all

other needs and which renders other aspects of the person's identity and history redundant or at least secondary. This tendency fosters a task-centred approach to care and undermines the development of more individualised, nuanced approaches. The survey also identified lack of stimulation and activities in care homes, particularly for those with severe dementia. This is of particular concern given the evidence that occupation is a major determinant of quality of life affecting depression, physical function and other factors.

These themes are echoed in the 'Commission for Social Care Inspection Report' (2008). The report noted that the quality of staff communication - both verbal and non-verbal - had a significant bearing on the well-being of residents. Perhaps unsurprisingly, the kinds of interaction identified as being important are the same as those that would be important for almost any human being in any context. Warm and friendly communication leave the person with dementia feeling relaxed and happy, whilst interactions that are neutral or negative leave residents feeling withdrawn and distressed. Whilst inspectors found examples of excellent practice in terms of one-to-one attention and care offered with understanding and warmth, impersonal assistance was also widely in evidence. This and other Commission for Social Care Inspection reports provide evidence that people with dementia in care homes do not always receive care that can be considered person-centred.

Clare, Rowlands and Quin (2008) recently conducted an important phenomenological study exploring the subjective experiences of people with advanced dementia in long-term care. Daily experience was found to be shaped by the losses resulting from dementia, which for most residents were characterised by distressing thoughts and feelings. Fear of being alone or lost was often paramount. Feelings of lack of control, limited self-determination and uncertainty, arising from 'being in the home' were compounded by multiple experiences of loss. The sense of lost memories, identity and ability resulted, for some, in feelings of worthlessness. However, the accounts from residents also identified them as agents actively seeking to cope with their situation (Clare, Rowlands and Quin 2008: p718). Being involved in supportive relationships appeared to be especially pivotal to maintaining a sense of well-being and a lack of such relationships added to any feelings of distress and alienation. What this study reinforces is one of the key themes of this review – that understanding the subjective experience of the person with dementia is a fundamental dimension of enhancing care practice, developing appropriate interventions and increasing understanding.

The final chapter of the review synthesises research evidence drawn from work conducted with other key groups, including the broad population of older people, people with mental health problems (other than dementia) and people with a learning disability.

# 5. Quality of life indicators and patient-defined outcomes from other key groups

## Older people and quality of life

There have been significant developments in exploring the quality of life of older people, particularly in terms of researching the concept from the perspective of older people themselves. The Growing Older Programme, referred to earlier, encompassed several relevant projects, the findings of which are reported in an edited volume (Walker 2005). This incorporates eight themes: meaning and measurement of quality of life; inequalities in quality of life; the environments of ageing; family and economic roles; social participation; social isolation and loneliness; frailty, identity and social support; and bereavement (Walker and Hennessy 2005). These themes resonate strongly with some of the issues already highlighted in this review; in particular, that it is the interplay between factors relating to both structure (such as social inequalities) and agency (such as the maintenance of health and identity issues) that produces quality of life (Walker 2005).

The significance of an individual's social position and the wider context in influencing older people's quality of life is also highlighted in the Walker volume (2005). In particular, structural differences in terms of social class (or more specifically socio-economic disadvantage), ethnicity, and gender have major implications for how quality of life is experienced. However, it is important to note that the processes by which inequalities influence quality of life are complex and that demonstrating inequalities in resources or health is not simply the same as demonstrating inequalities in quality of life (Higgs et al 2005: p47). It is therefore the consequences of inequality that are of concern and, specifically, the capacity of inequality to constrain and limit quality of life:

In such circumstances, the important inequalities are those that restrict access to good quality life rather than being sufficient 'reified' realities of their own. (ibid: p47-8)

The fact that it is the mediating impact of inequalities rather than the inequalities themselves that are important may explain the findings in some studies that

socio-economic indicators were less directly and strongly linked with self-ratings of quality of life (see for example Bowling et al 2002). In findings from a national interview survey of older people, Bowling et al (2002) found that the main predictors of quality of life were:

- social comparisons and expectations
- personality and psychological characteristics
- health and functional status
- social capital.

Research from the same study, but this time drawing on in-depth interviews with older people, established that the main themes relating to quality of life for them were:

- Having good social relationships, help and support.
  - Living in a home and neighbourhood that is perceived to give pleasure, feels safe, is neighbourly and has access to local facilities and services including transport.
  - Engaging in hobbies and leisure activities (solo) as well as maintaining social activities and retaining a role in society.
  - Having a positive psychological outlook and acceptance of circumstances which cannot be changed.
  - Having good health and mobility.
  - Having enough money to meet basic needs, to participate in society, to enjoy life and to retain one's independence and control over life.
- (Bowling and Gabriel 2004: p675)

The similarity between these themes and those reported as being important for people with dementia in the first section of Chapter 2 above is striking, albeit unsurprising. That the dimensions of quality of life identified by people with dementia are similar to those identified by people without dementia is an overarching finding of this review and an issue that needs to be taken on board in research, policy and practice arenas. It also underscores the need for quality of life to be seen as what Higgs et al (2005) describes as an expanding concept rather than a restricted one (ibid: p29).

## **Mental health and participatory research**

Significant work has been done in the mental health field on developing outcome measures that are generated by service users. In mental health the term 'patient relevant outcome measures' (PROMS) is more readily in use than that of 'quality of life' measures. The term itself suggests something important about the orientation of work in this field, given the emphasis on relevance for service users. In a recent study, Rose et al (2009) demonstrated that it was possible to construct an outcome measure of

continuity of care in mental health based exclusively on user perspectives. The measure, known as CONTINU-UM (CONTINUity of care – User Measure) was developed through the use of focus groups with mental health service users. The domains included: accessing services and the range of services available, choice, waiting times, out-of-hours support, hospital discharge, staff changes and information available. The final measure comprises 16 domains with two components: the experience of that domain for the service user and how satisfied they were with their experience. Most significantly for our purposes, the authors of this study explicitly identify the approach taken to the development of their measure with participatory research, which aims to reduce the power relations between researcher and researched. (ibid: p323).

Participatory research can be defined in the following way:

We argue that the key element of participatory research lies not in methods but in the attitudes of researchers, which in turn determine how, by and for whom research is conceptualised and conducted. The key difference between participatory and other research methodologies lies in the location of power in the various stages of the research process. (Cornwall and Jewkes 1995: p1,667)

In a qualitative review of user involvement in research, Trivedi and Wykes (2002) noted how the involvement of users in their research changed the design, content and focus of their study. They also highlighted the increased amount of time and extra financial costs involved in facilitating user involvement, and stressed the level of commitment required. Entwistle et al (1998) also highlight the resource implications and attempt to provide a framework for 'lay' input into health research. They identify two different reasons for incorporating lay perspectives: that it is politically mandated and that it will improve the quality of research. Where the political mandate is emphasised, involvement may be regarded as a goal in its own right. The focus is often on processes of decision making and the actual research may become a secondary consideration (ibid). In each case, they argue, a different approach to inclusion and different criteria for evaluating input is implied.

The orientation of the research reviewed comes from a different evidence base compared to that from people with dementia and older people, and has as its focus patient outcome measures rather than quality of life. However, its specific contribution is an important one as it serves to highlight the importance of user perspectives and participatory approaches.

## Learning disability services

The concept of quality has become an increasingly dominant feature of the learning disability field. However, an important distinction can be made between two manifestations of quality: quality of care and quality of life. Many agencies and services are in transition from the former to the latter (de Waele et al 2005). Whilst quality of life is conceptualised as a more value-based evaluation of person-referenced outcomes, quality of care is characterised by the notion of people with learning disabilities as clients or consumers of the care system rather than citizens; perspectives of professionals are more influential and there tends to be an emphasis on impairment and homogeneity (ibid).

Whilst not a review in the strictest sense, the work by Schalock et al (2002) is a report of an international panel of experts in the field of learning disability. It synthesises a number of the key issues regarding quality of life. The focus on quality of life in this field has shifted from a theoretical construct to become an instrument to guide policy reform:

Quality of life might best be viewed as a sensitising concept (rather than a definitive one) relevant to public policy determination; evaluation of services; and development of innovative local, national, and international programs. (Schalock et al 2002: p458)

The beginnings of a similar shift can be seen in recent work on quality of life in relation to dementia, for example in the work of Banerjee et al (2004; 2006). Measuring quality in relation to the lives of individual people with learning disability involves both the objective, commonly understood meaning of quality of life and also the subjective meaning of quality in terms of that which has become valued by individuals as they live their lives within their unique environments (Schalock et al 2002: p461). Although objective components are included, quality of life is regarded as being rooted in the subjective experiences of individuals. In the conceptualisation of quality of life in learning disability, the article describes nine core ideas that have been identified: inter- and intra-personal variability, personal context, a life-span perspective, holism, values, choices and personal control, perception, self-image, and empowerment.

In contrast with some approaches to the measurement of quality of life, where the assumption is that there is a reliable and valid 'true' measure of it, there is acknowledgment that the perceptions of carers, professionals and people with learning disabilities may be very different and perceptions may not be stable over time. The importance of identifying multiple perceptions when assessing quality of life is emphasised, as is the necessity of adapting assessment processes to the needs of the individual, such as by using nonverbal communication where language is limited (Schalock et al 2002).

# Conclusions and key recommendations

The focus of this review has been the development of quality of life indicators in relation to dementia. What has become clear in the process of reviewing the relevant literature is that we still know very little about quality of life in this area. The review has identified from the literature two broad approaches to measuring, or assessing quality of life: one reflects a more traditional, biomedical approach, where the emphasis is on objective measurement of quality of life; the other focuses on getting inside the subjective experience of dementia. There are approaches that seek to combine these, and few approaches to quality of life would completely discount the relevance of a subjective account in some form. However, the difference in emphasis is important. Most importantly, these approaches are characterised by contrasting ways of conceptualising quality of life.

From the evidence reviewed it is clear that the perspective of the person with dementia has for too long been omitted or ignored compared to other perspectives on quality of life, particularly formal, theoretical or medical perspectives. The traditional biomedical approach to assessing quality of life has been shown to be particularly problematic because it assumes a linear correlation between poor health and poor quality of life. In the case of dementia, significant amounts of work on quality of life have been based on the premise that deteriorating cognitive capacity will have a correspondingly adverse effect on quality of life. Whilst we do not want to caricature this body of work, and it offers much that is of value, there is clear evidence that the disease-oriented measures that have been dominant are not as helpful as once thought. In simple terms, the assumption that dementia inevitably results in poor quality of life from the perspective of the person with dementia is faulty.

Quality of life has traditionally been understood as a unitary 'true' measure that needs to be uncovered. Differences between ratings of quality of life, say between carers and people with dementia, have thereby been assumed to mean that one or the other is unreliable. The implication that there is one true quality of life measure is problematic, not least because it underestimates the complexity of human experience. The notion of a true reflection of quality of life is, we believe, a central one in that it helps to demarcate between the different approaches to how quality of life is conceptualised and, consequently, which indicators are considered important for assessing or measuring it. From the evidence reviewed, we would emphasise that quality of life is not

just multi-dimensional, it is multiperspectival. In other words, how quality of life is understood depends on where you are looking from. As Higgs et al (2005) put it so succinctly:

...quality of life needs to be seen as an expanding concept rather than a restricted one. (p29)

It is clear that a good deal of work has already been done to reconceptualise quality of life from the perspective of the person with dementia.

The idea that a single instrument could be used to assess quality of life at each stage of development of an illness such as dementia is almost certainly redundant and much more dynamic approaches to the task are required. Whilst we are satisfied with the evidence that people with severe dementia can communicate in meaningful ways about their quality of life, we are equally persuaded that the process for gathering this information is complex and calls for great sensitivity. The development of methodologies to enable the assessment of quality of life from the perspective of someone with severe dementia is of central importance. Any steps to make further progress in developing this work should be welcomed.

Evidence based on assessing quality of life from the perspective of the person with dementia suggests that what is important for quality of life for someone with dementia is, in many respects, the same as that for someone who does not have dementia. Positive social relationships, psychological well-being, independence and financial security are things that most of us need in order to feel we have a good quality of life. However, some research highlights some areas that appear to have greater significance for someone with dementia. These areas include being of use and giving meaning to life, security and privacy, and self-determination. The domain of self-concept in one study is of great interest and work in this area could be developed further. It is believed to be unique to dementia and, as it incorporates stigma-related concepts such as embarrassment and self-esteem, it addresses issues that are of central importance for people with dementia.

Stigma and discrimination have a serious and detrimental effect on the quality of life of people with dementia and there are important links between these experiences and other problems such as social isolation (Katsuno 2005). The impact of the notion of personhood in dementia has led to a paradigm shift in the way the perspectives of people with dementia are understood and their voices are increasingly incorporated into research and practice (Bartlett and O'Connor 2007). However, it has been argued that a further shift towards incorporating notions of citizenship for people with dementia would help address stigma and discrimination:

Promoting citizenship, rather than personhood, would facilitate a shift into the realm of rights and responsibilities and experiences as common/shared – quite different than the focus on experiences as unique/individual and needs-based entitlements that are most often associated with the concept of personhood (Bartlett and O'Connor 2007). (Hulko 2009: p142)

Some of the most significant studies emphasise the importance of considering inequality between groups in understanding quality of life and how it should be assessed. More specifically, it is the consequences of inequality that are of concern; in particular, the capacity of inequality to constrain and limit quality of life. The orientation of the research reviewed from mental health comes from a different evidence base compared to that from people with dementia and older people, and has as its focus patient outcome measures rather than quality of life. However, its specific contribution is an important one as it serves to highlight the importance of user perspectives and participatory approaches.

The population of people with dementia, like any other population, is heterogeneous in terms of individual biography, life course factors, 'race', social class, gender and sexualities. There is strong evidence that such factors mediate in significant ways in terms of the individual experience of quality of life. The future development of approaches to assessing quality of life must engage with and reflect this diversity if they are to be effective and experienced as authentic and meaningful by people with dementia.

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