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Defining the outcomes of community care: the perspectives of older people with dementia and their carers

CLAIRE BAMFORD* and ERROLLYN BRUCE†

ABSTRACT

There is growing recognition of the need for outcome measures which reflect the aims of services for people with dementia. The development and application of existing outcome measures has often marginalised people with dementia. 'Experts' and carers have been viewed as primary sources when identifying relevant outcomes or domains of quality of life, and proxy respondents have often been responsible for rating outcomes on the resulting measures. This paper reports a small consultation with people with dementia and their carers to identify the desired outcomes of community care. While there was considerable overlap in the outcomes identified by people with dementia and their carers, a number of limitations of relying solely on carers as proxy respondents were identified. A key outcome, which has been relatively neglected in previous work, was maximising a sense of autonomy. A range of outcomes related to the ways in which services are delivered were also identified. Future evaluative studies should encompass both quality-of-life outcomes and service-process outcomes (the impacts of the ways in which services are delivered) in addition to other outcome measures relevant to the aims and objectives of the service.

KEY WORDS – dementia, outcomes, quality of life, proxy respondents.

Introduction

Within the field of dementia care there is growing interest in the topic of outcomes, or impacts of care, both in the UK and internationally. For example, recent conferences and journal issues have focused on defining and measuring outcomes and quality of life of people with dementia[1]. This interest reflects growing demands for evidence-based practice, cost-effectiveness and, within the UK, the emphasis of central

* Social Policy Research Unit, University of York, UK.
† Bradford Dementia Group, University of Bradford, UK.

government on information about the outcomes of care rather than inputs and activities (Department of Health 1998; NHS Executive 1998). Many studies of community services for people with dementia have shown only limited effects (*e.g.* Askham and Thompson 1990; Wimo *et al.* 1994; Levin *et al.* 1994). This has also stimulated interest in new approaches to assessing outcomes for people with dementia since existing measures may not detect outcomes that are meaningful and significant to service users.

Outcome measures used to evaluate services for people with dementia include: cognition; behavioural, mood and psychiatric symptoms; physical health status; functional and self-care abilities; family and staff caregiver outcomes; service use and costs; and quality of life (Nocon and Qureshi 1996; Downs 1997; Smyth *et al.* 1997; Whitehouse and Maslow 1997). A detailed discussion of conceptual and methodological issues and a review of the major instruments available for assessing outcomes in each of these areas, is provided in the special issue of Alzheimer Disease and Associated Disorders (1997). With the exception of quality of life measures, the appropriateness of these measures has been questioned, since they are not necessarily related to the aims of services (Ramsay *et al.* 1995; Downs 1997; Zarit *et al.* 1999).

Quality of life is an increasingly important component of evaluative studies within medical research generally (Bowling 1997), and in the last few years there has been considerable progress in developing disease-specific measures of quality of life for people with dementia. A distinction can be made between uni- and multi-dimensional approaches. The former focus on a single dimension, or domain, of quality of life, for example, psychological wellbeing (Volicer *et al.* 1999) or affect (Lawton *et al.* 1999). In contrast, multi-dimensional approaches seek to include the range of domains of quality of life important to people with dementia. Three multi-dimensional measures of quality of life for people with dementia are described in a recent issue of the *Journal of Mental Health and Aging* (1999). All three measures include domains or items relating to: social interaction or sense of belonging; mood; enjoyment (of activities or aesthetics); and sense of self (Brod *et al.* 1999; Logsdon *et al.* 1999; Rabins *et al.* 1999).

A key limitation of many existing outcome and quality-of-life measures for people with dementia is their marginalisation of the perspectives of people with dementia themselves. People with dementia have often had a limited role in identifying relevant outcomes or domains of quality of life; furthermore, information about outcomes or quality of life is often collected from proxy respondents, usually family or staff caregivers, or through observation.

The views of users

Although UK policy has emphasised the need to involve service users in planning and developing services (Department of Health 1989), few studies have successfully explored the views of people with dementia about their needs or the desired outcomes of services. Although the National Consumer Council (1990) interviewed people with dementia and their carers, to identify what they wanted from services, the resulting instrumentation for evaluating services focused exclusively on carers. Another pilot study to determine the key objectives for dementia services and the needs and expectations of service users included the views of general practitioners, community nurses, specialist service professionals, carers and ex-carers, but not those of people with dementia (Ramsay *et al*. 1994). Similarly, only the views of professionals and representatives of voluntary agencies were included in a series of workshops to identify indicators of quality of life for people with dementia using home health care services (Albert *et al*. 1997). Cox *et al*. (1998) suggest that desired outcomes should reflect underlying values as well as the explicit aims and objectives of services. On the basis of a literature review, expert opinion and subsequent consultation with a range of professionals, family carers and people with dementia, they identify five core values: maximising personal control; enabling choice; respecting dignity; preserving continuity; and promoting equity (Cox *et al*. 1998).

Recent studies of user-defined outcomes of UK community care suggest that some of the outcomes sought from services relate to stages in the life cycle and type of impairment. For example, outcomes sought by younger disabled people included access to paid work and support with parenting roles (Bamford *et al*. 1999), whereas older people emphasised keeping alert and active (Qureshi *et al*. 1998). A key outcome for deaf people was being able to communicate with the hearing world (Bamford *et al*. 1999), whereas people with functional mental illness valued changes in symptoms and behaviours, for example, feeling less anxious or depressed, being more active and interested in life and relating better to family members (Qureshi *et al*. 1998). In both of these studies maximising choice and control over one's life emerged as key themes which underpinned these more specific outcomes. While the outcomes sought by people with dementia probably overlap considerably with those identified by other service users, there may be important differences in emphasis or additional outcomes which relate to the nature of dementia. The importance of the ways in which services are delivered was also stressed by users

consulted about desired outcomes of community care (Turner 1997; Qureshi *et al.* 1998; Bamford *et al.* 1999).

Drawing on published accounts of living with dementia and transcripts of interviews with people with dementia, Gwyther (1997) has identified a range of outcomes relevant to people with dementia. These include: a sense of control; inclusion; reciprocity; meaningful activities; feeling safe and secure; maintaining self-esteem; and maximising physical wellbeing through effective health care. She also emphasises the importance of the process of service delivery, in particular being treated 'normally' and having services which match perceived needs. Finally, Gwyther (1997) suggests that aspects of health care, such as having one's symptoms recognised, being given a diagnosis and participating in research programmes, may be viewed as valued outcomes in themselves.

It is generally accepted practice to include people with the condition in the development of disease-specific quality-of-life measures, and the importance of involving people with dementia in identifying relevant domains of quality of life has been stressed (Howard and Rockwood 1995; Gwyther 1997; Bond 1999). However, the extent to which people with dementia have been involved in development work on disease-specific measures of quality of life has varied. Some measures have relied only on input from family caregivers, professionals and experts in their development (Rabins *et al.* 1999). While the work carried out by Logsdon and her colleagues included people with dementia, they were asked to review draft items, selected on the basis of a review of the relevant literature on quality of life in older adults and other chronically ill populations, rather than identify relevant domains from their own experience (Logsdon *et al.* 1999). In contrast, other development work included expert panels of people with dementia, caregivers and care providers (Brod *et al.* 1999). The resulting quality-of-life instruments also vary in their method of administration. While one measure focuses on observable behaviour and relies solely on proxy respondents (Rabins *et al.* 1999), the other measures include subjective assessments of quality of life by people with dementia (Brod *et al.* 1999; Logsdon *et al.* 1999), with one measure also including a rating of quality of life by the caregiver (Logsdon *et al.* 1999).

There are a number of reasons for the reliance on proxy reports or observation in evaluating outcomes or quality of life of people with dementia. Carers have often been identified as the main beneficiaries of services rather than the people they care for (Goldsmith 1996; Downs 1997). It has been suggested that therapeutic nihilism, or the failure to

recognise that people with dementia can experience at least relative wellbeing, has led to a neglect of their experiences of care (Kitwood and Bredin 1992*a*; Marshall 1997). It is often assumed that people with dementia are inherently unreliable, too confused or too out of touch with reality to be considered as valid respondents (Goldsmith 1996; Cotrell and Schulz 1993; Sutton and Fincham 1990). In particular, they may have difficulties in making cumulative value judgements (Kitwood and Bredin 1994). The exclusion of people with dementia, however, ignores variability in their communicative abilities and fails to recognise their ability to provide accurate reports of their current situation (Cotrell and Schulz 1993).

These assumptions about the (lack of) competence of the person with dementia have often led to the use of carers as proxy respondents. However, there is growing recognition that this is not unproblematic. It has been argued, for example, that people with dementia and their carers have different needs, the strains of the relationship are likely to affect perceptions, and that carers are often too grateful for the help they receive to voice any criticisms (Cotrell and Schulz 1993; Barnett 1997; Bender 1998). Research on the accuracy of proxy data has been inconclusive. While some authors report greater reliability for observable behaviour, activities and symptoms (Cotrell and Schulz 1993; Magaziner 1997), others suggest that even proxy data on functional abilities may be unreliable (Ostbye *et al.* 1997).

Observational approaches to evaluating services for people with dementia also have important limitations. Dementia care mapping is one well-known observational technique which examines the extent to which care either contributes to or detracts from relative wellbeing (*e.g.* Kitwood and Bredin 1992*b*, 1994; Fox 1995). Although this technique attempts to focus on the experience of the person with dementia, it has a number of shortcomings. First, it can only be used to evaluate services provided in communal settings. Secondly, the underlying assumptions, for example, that it is better to be engaged than disengaged, that interacting with people promotes wellbeing, may not be equally applicable to all individuals. Thirdly, it has been argued that the empirical basis for these assumptions is weak (Adams 1996; Harding and Palfrey 1998). Finally, although described as 'a form of user feedback' (Brooker *et al.* 1998) the technique relies on interpretation (Gilleard and Higgs 1998) and has no systematic recording frame for allowing people with dementia to express their views directly.

There is now growing recognition that people with dementia are able to provide accurate and valid reports of their experience of services. A number of studies have successfully used informal interviews

to explore the subjective views of people with dementia (Lam and Beech 1994; Sperlinger and McAuslane 1993; Sutton and Fincham 1990; Murphy *et al.* 1996; Webb *et al.* 1998). These studies have generally been concerned with day or respite care and have included people at a less severe stage of dementia. More recently, several authors have reported the feasibility of using more structured approaches with people with dementia to collect information on their quality of life (Brod *et al.* 1999; Logsdon *et al.* 1999; Mozeley *et al.* 1999).

We report here on a small study to explore the feasibility of consulting people with dementia about the types of outcomes they seek from community care services. This work was conducted as part of the consultations with older service users, reported by Qureshi *et al.* (1998). Following a description of the participants and methods, we discuss the outcomes identified by people with dementia and their carers. We explore the extent to which the user-defined outcomes in our study are consistent with: outcome measures commonly used in service evaluation; domains identified in research on the quality of life of people with dementia; themes highlighted in previous consultations with people with dementia; and outcomes identified by other service users. We then examine the extent to which the views of people with dementia and their carers coincide, and consider the implications of our findings for the use of carers as proxy respondents. In conclusion, we identify further development work needed before the outcomes we have identified can be applied in practice. Throughout the remainder of this paper, we use the term 'service user' to describe the people with dementia who took part in our study, and the term 'carer' to refer to their main informal (unpaid) carer.

Methods and participants

Approaches to data collection

Therapeutic group work has demonstrated the ability of people with dementia to participate successfully in groups (Yale 1991; Gibson 1993; Feil 1993; Cheston 1996). We considered group discussions to have a number of potential advantages over individual interviews including:

- enhanced quantity and quality of interaction (Bleathman and Morton 1992),
- reduced pressure on individuals to respond to every question, thereby lessening threats to self-esteem if they did not understand or could not answer specific questions,

- increased access to memories outside the current context, since sharing experiences might trigger recall of similar events or feelings,
- opportunities for mutual support.

We planned to conduct a series of six formal group discussions, since we anticipated that talking to service users on more than one occasion would help to identify key themes. Additionally, we thought a number of meetings would allow participants to give different views according to how they were feeling at the time, which could compensate for their difficulties in making cumulative value judgements (Sperlinger and McAuslane 1993).

Once the discussions began, however, we realised that a more flexible approach, drawing data from a variety of sources, would increase our understanding of the outcomes users sought from services. The methods of data collection used, and participants involved in each approach, are summarised in Table 1. Five formal group discussions went ahead as planned over a four-week period. We replaced one of the scheduled formal discussions with two parallel informal discussions in the day room to explore the impact of context. This was in response to our observation that participants sometimes expressed different views of services during informal conversations from those in the formal discussions. Individual interviews were conducted with two participants to explore themes and issues raised during discussions which they did not attend. Data from each of these approaches were tape-recorded and transcribed for analysis.

Finally, useful data emerged from our informal conversations with participants. These took place in the day room before and after the group discussions, and during the process of convening the group. These informal conversations were not tape recorded, but were selectively written up in field notes. The participants involved in four key conversations in which their feelings or views about services contrasted with those previously expressed in a group discussion or individual interview are shown in Table 1. An overview of the advantages and disadvantages of different methods of data collection is the subject of a separate publication (Bamford forthcoming).

Recruitment and characteristics of service users

We recruited service users from a resource centre for older people with mental health problems. The centre provides long-stay accommodation, day care, respite care, support for carers and an outreach team. Senior members of staff identified service users who, in their opinion, would be able to follow and contribute to group discussions and who

T A B L E 1. *Approaches to and participation in data collection*

Participant	Formal group discussions attended	Involvement in informal group discussions	Individual interview	Informal conversation
1	1, 2, 3, 4, 5	group a		yes
2	1, 2, 3, 4, 5	group a		
3	1, 2, 3, 4			
4	1, 3, 5	group b		yes
5	1, 3, 4		yes	yes
6	1, 3, 4			
7	1, 2			
8	1, 4			
9	5	group a		
10	3	group a		
11	1		yes	
12	5			
13	5			
14	5	group b		
15*	none	group b		yes

* This participant left the first meeting before it started and chose not to attend subsequent meetings, although she contributed to informal discussions and conversations.

would be attending for day or respite care during the period of data collection. Staff excluded people with severe cognitive impairments, those with communication difficulties and those who disliked being sedentary. The degree of control this procedure gave staff over participation was offset to some extent by allowing other interested service users to join the discussions. This enabled us to include people who had not been nominated because, for example, staff thought they might be disruptive.

There is increasing recognition that obtaining informed consent is a complex and difficult process in any qualitative research (Mason 1996). Our aim in seeking consent was to ensure that potential participants had a genuine choice over whether or not to take part which was based on some understanding of the purpose of the study and how what they said would be used. We therefore approached potential participants individually to describe the study and invite them to participate. We chose not to seek written consent since we were concerned that it might create unwarranted anxiety, for example where people with dementia could recall signing an 'official' form, but were unable to remember why. Instead, we relied on verbal and behavioural consent, and stressed that each participant was free to withdraw at any point during the discussions. The refusal of some participants to attend some meetings and the withdrawal of others from on-going discussions, suggests that we succeeded in ensuring a degree

TABLE 2. *Characteristics of people with dementia*

Gender	
Male	1
Female	14
Age	
60–69	1
70–79	2
80–89	9
90+	3
Living arrangements[1]	
Alone	8
With adult children	4
With spouse and adult children	2
Service use[2]	
Day care	14
Regular respite care	5
Home care	7
Total	15

[1] One participant lived in long-stay accommodation at the centre, but continued to use the day care facilities. She attended one discussion at the request of another participant.
[2] Since more than one service could be received, the sum of this column is more than 15.

of choice over participation. We asked permission to tape-record discussions and individual interviews. To illustrate how the data had been used, we fed back a preliminary analysis of the outcomes identified to participants present at the penultimate group discussion.

Although we included service users of different ages, with varied living arrangements and experience of a range of services, staff were only able to identify one male service user whom they felt would be able to participate (Table 2). Half the participants were described by staff as having 'moderate' dementia (*i.e.* they were able to carry out activities of daily living with assistance, though not on their own), and half as having 'mild' dementia (Jacques 1992). One participant was visually impaired, one had a severe hearing impairment and four had mobility difficulties.

Management and content of discussions and interviews

Meetings generally lasted for an hour and followed a similar format each time. There were three facilitators at most meetings (the authors and a Community Psychiatric Nurse), and a member of the day care staff also attended the first two meetings as a familiar face. A total of 15 older people with dementia took part, two of whom attended all five formal group discussions. The number of service users attending formal discussions ranged from four to nine.

Themes:
- Coming to day care and respite care
- Types of help received at home
- The experience of being helped
- Help that might be needed in the future
- Letting people know how you feel about help

Vignette:

Jack is 80 and lives alone. He's not keeping on top of the cooking and cleaning these days and doesn't see much of other people. When he had a fall recently, he was alone for hours without any help.

- What do you think should be done about Jack?
- How might Jack feel about getting help?
- How could we find out how Jack is getting on?
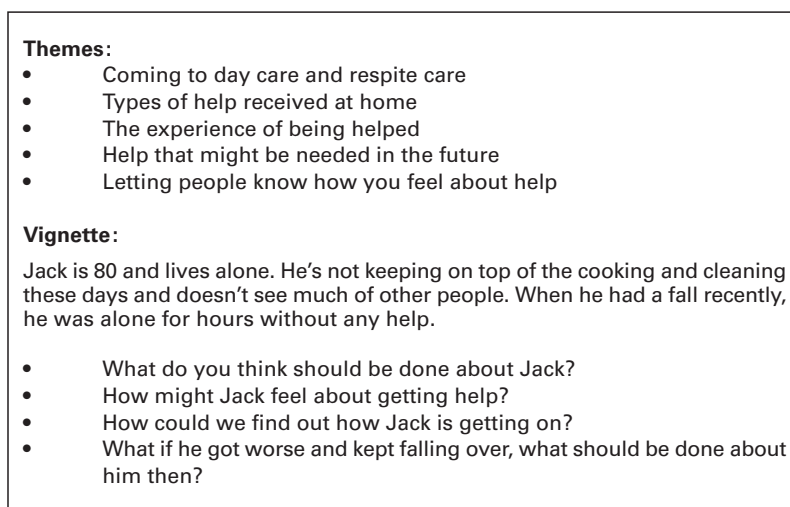- What if he got worse and kept falling over, what should be done about him then?

Figure 1. Themes and vignette used in discussion groups.

We used simplified versions of a topic guide and vignette which had been developed for discussion groups with older people (Bagshaw and Unell 1997). The main themes covered in the discussions and the vignette are shown in Figure 1. We also used photographs of older people receiving assistance with everyday tasks to prompt discussion.

Analysis

In analysing the data we were not so much concerned with the 'truth' or otherwise of what was said, but rather in understanding what was being communicated. In common with previous studies, we treated everything that service users said as an attempt to tell us something about their experience (Kitwood 1990; Sperlinger and McAuslane 1993). We remained cautious, however, about the use of metaphors and have made no attempt to interpret comments which did not clearly relate to people's experiences of services. The tape recordings of group discussions and individual interviews were transcribed and subsequently analysed, using dedicated software for the analysis of qualitative data[2]. The data were coded, then search and retrieval procedures were used to explore emerging themes in more detail.

Carers

Where possible we informed the carers of the nominated people with dementia about the group discussions and invited them to take part in

an individual interview. Of the seven carers contacted, one was unavailable and the rest were interviewed in their own homes. The carers interviewed comprised three daughters, one son (who chose to be interviewed with his spouse), one granddaughter and one spouse. Four of the carers lived with the person they supported; in three cases the older person with dementia had moved in as a result of their increasing frailty. Four carers were in employment and two were over retirement age. All the carers lived locally and all but one had at least daily contact with the person they supported. The carers of four service users who subsequently joined at least one group discussion were not contacted.

The interviews were conducted by members of the research team who were not involved in data collection with service users. A topic guide was used, focusing on four main themes: the range of services used by the person with dementia; the outcomes of these services for the person with dementia; the strategies the carer used to evaluate these outcomes; and finally the outcomes that carers desired from services for themselves (these are not reported here). The interviews were tape recorded, transcribed, then coded and analysed using qualitative analysis software.

Desired outcomes of community care for older people with dementia

We have made a conceptual distinction between two types of outcome: quality-of-life outcomes and service-process outcomes. The specific desired outcomes included in each of these categories, and the relationship between them, are shown in Figure 2.

Quality-of-life outcomes relate to a key theme of being able to access normal activities and patterns of life in ways that maximise choice and control. Activities do not simply centre on personal care and domestic tasks but include opportunities to socialise, to engage in activities and to achieve a sense of social integration.

Service-process outcomes are concerned with the desired impacts of service delivery. Service-process outcomes are important, either because of their close relationship with the achievement of desired quality of life outcomes, or because of their emotional impact on service users.

The following sections describe quality-of-life and service-process outcomes in more detail. We highlight discrepancies between service

Overall aims	Service inputs	Service-process outcomes	Specific quality-of-life outcomes
Overall desired outcomes	What is done	How it is done Desired impacts of service delivery	Desired impacts, or end results

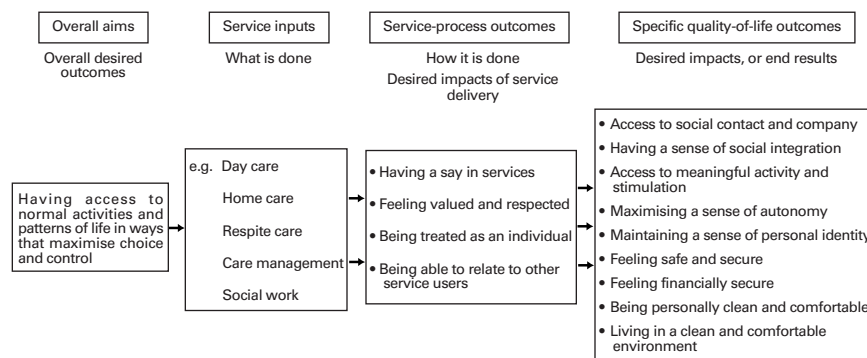| Having access to normal activities and patterns of life in ways that maximise choice and control | e.g. Day care

Home care

Respite care

Care management

Social work | • Having a say in services

• Feeling valued and respected

• Being treated as an individual

• Being able to relate to other service users | • Access to social contact and company
• Having a sense of social integration
• Access to meaningful activity and stimulation
• Maximising a sense of autonomy
• Maintaining a sense of personal identity
• Feeling safe and secure
• Feeling financially secure
• Being personally clean and comfortable
• Living in a clean and comfortable environment |

Figure 2. Framework for understanding outcomes for older people with dementia.

users and carers, and draw attention to any findings that are likely to be an artefact of the methodologies used.

Access to social contact and company

Companionship and opportunities to socialise were recurrent themes in our discussions with service users and our interviews with carers. Service users described three factors which decreased their social contacts: the deaths of their spouse, other family members or friends; moving to live with relatives; and their memory problems. While service users and their carers recognised that those who lived alone were particularly vulnerable to isolation, social contact was thought to be an important outcome regardless of living arrangements. Even service users who lived with others could have extended periods on their own, and they often valued the opportunity to talk to somebody different:

I have a break from the men when you come here, you talk to ladies, that's what I like about it. (Service user)

Carers and, to a lesser extent, service users not only valued company as an end in itself, but also highlighted the negative consequences that could result from a lack of social contact:

She strives for company and companionship, and if she doesn't get that every day she gets quite depressed and starts to wander a bit, which used to worry me … she's quite a chatty person and yes, I think that's what she enjoys, the companionship. (Carer)

I've gained company for a start and I think that's a big thing. I think you can get morbid when you're on your own so long. Especially if it's bad weather, you can't get out. (Service user)

Having a sense of social integration

Several service users commented on the importance of feeling integrated into the local community. This sense of integration could be disrupted when service users left a familiar neighbourhood to move in with relatives:

I've lived by myself, but you see I went out a lot more. You lose your friends when you move. (Service user)

Although some carers talked briefly about social integration, their perspective was often different from that of service users. For example, one carer talked about relationships with other local residents in terms of the role of neighbours in monitoring the activities of the person with dementia such as wandering outside the home. Carers valued locally-based facilities and staff, but otherwise did not comment on the role of services in achieving social integration:

One of the good things, with it being in this area … there's been an odd lady or gentleman that she went to school with … and there's people there that used to be at the chapel. (Carer)

Access to meaningful activity and stimulation

Having something to do and somewhere to go were recurrent themes both for service users and carers. The change of scenery and opportunity to get out of the house provided by day care were valued. The benefits of day care extended beyond the time spent at the day centre, as indicated in this exchange between two service users:

When you've been here and you go home, you feel good don't you? (Service user)

Well you've something to think about when you go back home haven't you? (Service user)

The importance of selecting meaningful and relevant activities which provide service users with a sense of achievement was highlighted. While carers were positive about the activities and stimulation provided at the day centre, these were often criticised by service users:

There's nowt wrong about the place don't get me wrong, but … you get a bit bored. (Service user)

The importance of daily routines and activities in providing meaningful occupation was highlighted by one service user when we asked whether the home care service was good:

I do in some cases, but if you can do it, I don't think it is. Because it takes your jobs away from you that you'd occupy your time with … But if you're not feeling well or anything like that, well then it's a godsend really. (Service user)

Maximising a sense of autonomy

Service users frequently mentioned issues relating to being 'in control'. Many participants enjoyed recounting and listening to anecdotes that showed their ability to gain the upper hand, particularly in situations involving professionals. Maintaining a sense of autonomy in the face of unwelcome and increasing dependency was an important outcome identified by service users and carers. It was clear that remaining at home was often an important symbol of control. Although one person with dementia reported that she would consider long-term care if necessary, generally there were strong feelings against long-term care, which was seen as inevitably leading to a loss of autonomy:

There's a lot isn't there to be said to come home and to lock your door and it's your own place ... and do what you like. (Service user)

For many participants, accepting help from others could undermine their sense of autonomy and one service user spoke of feeling 'redundant'. This highlights the importance of providing services in ways that enable users to retain a sense of being in control.

While carers also identified maintaining a sense of control as an important outcome, this could be an area of tension between users and carers. For example, carers sometimes tried to exert control over the person with dementia, particularly where safety or personal hygiene was being compromised. Such attempts were by no means always successful, since the person with dementia did not necessarily co-operate. Carers generally shared the view of service users that a sense of choice and control could best be achieved by living in their own homes.

Maintaining a sense of personal identity

Retaining personal identity and a sense of oneself as a competent and valued person was another key outcome identified by people with dementia. Many of the women who took part had previously looked after their husbands and families. Their sense of personal identity was therefore strongly bound up with their ability to fulfil traditional roles such as cooking and cleaning. Accepting help from services could threaten their personal identity and have a negative impact on self-esteem:

I thought I was going to die myself, because I felt that way. Giving in. I were sick of being like I were. I felt as though I were putting on everybody and I can't stand that. I'd rather give than take off anybody. (Service user)

Carers rarely identified maintaining a sense of personal identity as an important outcome and made few comments about the potentially negative impacts of services on the person they supported.

Feeling safe and secure

The sense of being safe and secure may be particularly elusive for these service users because of their problems with memory and orientation. Regular morning and evening calls from the home-care service were generally viewed positively and gave service users confidence that help was available if needed:

Well I think it makes you feel safe, you know. You're doing your own thing, someone coming in and if anything has happened they're there to see to it. So I think myself that's the best way to do it. (Service user)

One significant barrier to feeling safe and secure was fear of crime. Faced with growing confusion over, for example, where valuables had been safely put away, it is not surprising that service users felt vulnerable and anxious about crime. Providing reassurance about time and place also contributed to a sense of security for people with dementia.

In relation to this outcome, carers tended to focus on reducing levels of anxiety and agitation rather than maximising a sense of safety and security.

Feeling financially secure

Assistance with managing personal finances was valued by some service users. Although some participants appeared to retain responsibility for managing all aspects of their finances, the majority received some help with paying bills, either from relatives or home-care staff. It was not always clear to the person with dementia how financial arrangements were made, but the main emphasis seemed to be on ensuring that bills were paid promptly:

Well my rent lady gets her rent. I don't know where she gets it from but I don't pay rent but she gets it from somebody. (Service user)

More substantial help with finances was received by some service users, particularly those who had moved in with relatives. The resulting freedom from managing household expenses was highly valued by service users.

This outcome did not emerge during our interviews with carers. Since help with financial matters is usually taken on by relatives, it is not surprising that carers did not identify this as an outcome of services.

Being personally clean and comfortable

Several service users who took part received help with bathing and/or used the hairdressing service at the day centre. One result of this personal care was the subjective feeling of being clean, another was the feeling of being presentable:

Well it keeps you looking tidy doesn't it really? … You don't feel ashamed of yourself. (Service user)

Carers also identified being clean as an important outcome for service users, although it was clear that the priority given to this outcome and standards of personal cleanliness could be a source of tension between service users and their carers. The care taken over the personal appearance of one person with dementia during respite care was a source of considerable satisfaction:

One day she came home, she had all her nails painted, I says 'oh aren't you glamorous' … and so she were dead chuffed you know, and she'd had her hair done. (Carer)

Service users and carers identified regular and nutritious meals as an important outcome in view of the difficulties and effort of preparing meals, particularly for those who lived alone.

Living in a clean and comfortable environment

While it was clear that many participants placed a high value on housework, service users said little about the role of services in achieving this outcome. Discussion of the fictitious case study generated some discussion about the importance of providing domestic help and not allowing 'Jack' to live in a mess.

Our interviews with carers focused on the differences that services made to the person with dementia whom they supported. Since many of the carers, particularly those who shared a house with the person with dementia, were themselves responsible for cleaning, they did not identify this as an outcome of services.

Service process outcomes

Having a say in services

Ensuring that service users had some influence over what help was provided, when and by whom was an important outcome for service users and carers. In describing home-care staff, one service user commented:

They let you do your own thing. And if you want to chat, they'll chat with you. If there's anything in particular you want doing, they'll do it. There's no interference. (Service user)

The degree of choice and control experienced by service users appeared to be more limited in relation to personal care. For example, one service user who preferred to bathe at home under the supervision of her home-care assistant was nevertheless usually bathed at the day centre. Similarly, a lack of control over hair styling was reported:

They're always wanting to do your hair. Now I can't help it but I cannot do with my hair taken that way … I know it sounds silly but it annoys me. (Service user)

Carers highlighted the importance of services fitting in with the daily routine of service users, but the extent to which this was achieved varied. While respite care avoided imposing a structured routine on service users, the timing of evening visits by home-care staff was not sufficiently flexible. Carers also thought that continuity was important, since it facilitated the development of trusting relationships and minimised confusion and anxiety. Although the issue of continuity was discussed with service users, it did not emerge as an important aspect of care. Some participants appeared to accept the difficulties of providing the same members of staff given the high levels of care they received. Others could only remember receiving help from one person and therefore found it difficult to comment on the benefits of continuity. The importance of continuity to service users may therefore have been underestimated.

Feeling valued and respected

For service users, being treated as a normal person despite their difficulties was an important aspect of service delivery:

You like to feel you're just treated like anybody else. They realise your capabilities, you know. (Service user)

Carers emphasised the importance of the relationship between service providers and the person they supported, and particularly valued staff who were genuinely caring:

I don't care whether they don't dust or anything, but they care for her … they're kind to her and I think that's the main thing. (Carer)

Being treated as an individual

Providing help in ways that enabled service users to be as independent as possible and avoided over-dependency and loss of skills was valued by service users and carers. In view of the ambivalence of service users

towards accepting help it is not surprising that a low-key approach by staff was appreciated:

They don't make you feel as though they're doing a great favour for you, they just do it. (Service user)

Sensitivity to individual feelings and preferences was especially important in relation to intimate personal care, such as bathing. Attention was also needed to apparently trivial issues which could have a significant impact on service users, for example, when their usual chair at day care was taken by someone else.

In order to meet individual needs, carers highlighted the importance of flexibility and equality of opportunity, in particular ensuring that services were accessible for service users with physical or sensory impairments.

Being able to relate to other service users

There was little explicit discussion of relationships with other service users in the group discussions, although non-verbal behaviour indicated some tensions between group members. It was clear that the majority of participants had formed friendships with other service users. Comments about other service users invariably focused on people with more severe impairments, who tended to be marginalised and seen as 'different':

He's a raving idiot the way he talks. I won't say owt to him. I can't afford to 'cos he's barmy. (Service user)

In contrast, carers focused on the degree to which the person they supported was accepted by other service users, and stressed the importance of facilities for people with similar levels of cognitive impairment and common interests.

The role of carers as proxy respondents

Carers experienced some difficulties in identifying the outcomes of services for the person they supported, some of which were articulated; others were unexpressed but implicit in their responses. One problem frequently mentioned by carers was that they received little feedback about services from the person they supported:

By the time she's come home and she's had her tea, you wouldn't think she's been, because she's forgotten where she's been. Because I'll say 'Have you had a nice day?' 'Well, where have I been?' So you see she doesn't really know where she has been. (Carer)

Limited contact with services, especially those provided outside the home, added to carers' difficulties in assessing outcomes. Even where services came into the home, carers did not necessarily observe all of the support provided:

They [home-care staff] were all lovely. And if they weren't she never said. Anyhow, you know, by the time they'd gone downstairs and gone home, even if she didn't like them she'd probably have forgotten anyhow. (Carer)

Although not explicitly acknowledged by carers, their own dependence on and gratitude for services could lead to the discounting of any negative impacts, as suggested in the above quote. It was clear from the interviews that carers had difficulties in criticising services and sometimes accepted unsatisfactory arrangements.

Finally, carers sometimes had difficulties in disentangling the outcomes they desired from those valued by the person they supported:

We bought her new clothes to go in because you want them to look nice and she looked a little picture. She was sat in the chair. They had done her hair and she was spotless. She had a cup of tea by her side. She looked a little old lady just content. (Carer)

Discussion

Based on discussions, interviews and informal conversations with older people with dementia and interviews with their carers, we have identified two types of outcomes: quality-of-life outcomes and service-process outcomes (Figure 2). Quality-of-life outcomes centre on having access to normal activities and patterns of life in ways that maximise feelings of choice and control and encompass social, physical and emotional needs. Service-process outcomes are concerned with the desired impacts of service delivery.

Our quality-of-life outcomes reflect the principles underlying community care, recently confirmed as promoting independence and enabling people to live fuller and more active lives (Department of Health 1998). The emphasis on service-process outcomes is consistent with the demand for more 'user-centred' services in the UK (Department of Health 1998), and the principle of enabling service users to retain as much control as possible over support received, which informs policy in all European Union member states (Marshall 1999).

Although the outcomes identified in our study are consistent with the explicit aims of community care policy, they have little in common with measures typically used to evaluate community services (Nocon and Qureshi 1996; Downs 1997; Smyth *et al.* 1997; Whitehouse and

Maslow 1997). Service users did not identify changes in cognitive functioning or the frequency of 'problem' behaviours as desired outcomes of services. Furthermore, it was clear from our discussions with people with dementia that measures such as admission to long-term care or level of service provision were problematic, since they were not unambiguously linked to desired outcomes. For example, while remaining at home may maximise a sense of control and help to retain identity and self-esteem for some people with dementia; others may be immobilised by the insecurity of being alone in an increasingly unfamiliar environment.

While service users emphasised a sense of autonomy, this has rarely been included in service evaluations. Where levels of independence have been assessed, the emphasis has generally been on functional abilities, such as self-care, mobility and continence. Such measures do not address the 'extent of perceived control, which allows a sense of independence, despite the fundamental and wide-ranging dependence on others that is the reality for most people' (Woods 1999:101–2). Being able to make choices and to exercise control have been identified as important components in assessing quality of life and evaluating services (Cox *et al.* 1998; Bond 1999). While maintaining independence and choice are well-established policy aims, relatively little attention has been given to operationalising this principle in practice, or to how to evaluate the extent to which services are successful in maximising autonomy (Marshall 1999).

Despite the mismatch between the outcomes identified in our study and measures often used to evaluate services, our findings are generally consistent with the domains included in disease-specific measures of quality of life and themes identified in previous consultations and therapeutic work with people with dementia. In particular, companionship, social integration and meaningful activity have been recurrent themes in previous consultations with people with dementia (Sutton and Fincham 1990; Sperlinger and McAuslane 1993; Lam and Beech 1994; Murphy *et al.* 1996) and domains related to these desired outcomes are included in existing quality of life measures (Brod *et al.* 1999; Logsdon *et al.* 1999; Rabins *et al.* 1999). Maintaining a sense of personal identity is also included in these quality-of-life measures and, together with promoting emotional security, has been identified as a major goal of therapeutic work with people with dementia (Cheston and Bender 1999).

While many of the outcomes identified in our study were consistent with previous work, there were important discrepancies. Existing quality of life instruments include domains related to affect and mood,

and previous consultations with people with dementia have drawn attention to the value placed on psychological wellbeing (Sutton and Fincham 1990; Murphy *et al.* 1996). With the exception of feeling safe and secure, participants in our study did not generally identify changes in affect or mood as an outcome of services. This may be due to the methodology used: participants may be more likely to discuss their emotional state or psychological wellbeing in individual interviews or therapeutic groups; also our discussions focused on outcomes of current services, and none of the participants were in receipt of any therapeutic services which aimed to enhance mood or psychological wellbeing.

The value placed on independence and the ambivalence that may be experienced over accepting assistance from others has been highlighted in therapeutic groups with people with dementia (Lamers *et al.* 1996; Cheston 1996). A sense of autonomy or control, however, is a domain which seems to be relatively neglected in existing quality-of-life measures. Although one measure includes an item on 'being able to make one's own decisions' (Brod *et al.* 1999), other measures have not identified a sense of control as an important domain (Logsdon *et al.* 1999; Rabins *et al.* 1999).

Our discussions with people with dementia also highlight the value of practical outcomes such as being able to manage money, being physically clean and comfortable, and living in a clean and comfortable environment. Only one quality-of-life measure directly includes items related to these practical outcomes (Logsdon *et al.* 1999). There has been little emphasis on these practical outcomes in previous consultations with people with dementia, perhaps reflecting their focus on day and respite care.

The desired outcomes identified in our study relate closely to the four dimensions of wellbeing which form the theoretical basis of dementia care mapping (Kitwood and Bredin 1992*a*). A *sense of social confidence* is reflected in our desired outcomes of companionship, social integration and being able to relate to other service users. A *sense of personal worth* relates to maintaining a sense of personal identity and feeling valued and respected. A *sense of agency* reflects the desired outcomes of maximising a sense of autonomy, having a say in services and access to appropriate activities. Finally, a *sense of hope* overlaps with feeling safe and secure. Our findings therefore give some empirical support to the theoretical basis of dementia care mapping and confirm that it reflects, at least partly, the perspectives of people with dementia.

The validity of our findings can also be assessed by comparing them with previous work on desired outcomes of community care. While the quality-of-life outcomes identified by people with dementia and other

older people were generally consistent, there were some significant differences. A minority of cognitively intact older people identified outcomes related to improving their physical and/or mental state. These outcomes, however, were particularly relevant to older people receiving rehabilitation and those with functional mental illness (Qureshi *et al.* 1998), which may explain why they were not identified as important outcomes in our study.

Three desired quality-of-life outcomes – a sense of social integration, maintaining a sense of personal identity and being able to manage personal finances – were given more emphasis by people with dementia. The emphasis on social integration may reflect the more restricted social networks of people with dementia (Wenger 1994). The ways in which a sense of personal identity and self-worth can be undermined in people with dementia have already been described (Gwyther 1997). Previous studies have drawn attention to the benefits and disadvantages of ceding control over aspects of life such as finances, medication and appointments to a surrogate decision-maker (Gwyther 1997; Langan and Means 1995). Within the context of UK community care, the need for independent advocacy to protect older people with dementia from financial abuse, and for clearer guidelines and procedures for social care staff in relation to financial assessments and day-to-day money handling has been highlighted (Langan and Means 1995).

Service-process outcomes have often been neglected in evaluating community services and other interventions. Although earlier studies have drawn attention to the importance of the ways in which services are delivered (Harding and Beresford 1996), consideration of service process has often focused on whether or not services have certain characteristics known to be valued by users (for example, reliability and continuity). Such characteristics are not necessarily linked to desired service-process outcomes. Continuity, for example, will only enhance the extent to which a service user 'has a say in services' if the regular provider is well-briefed and able to respond to changing needs and priorities.

Themes related to each of the service-process outcomes identified in our study have arisen in previous consultations with people with dementia (Sutton and Fincham 1990; Lam and Beech 1994; Murphy *et al.* 1996; Sperlinger and McAuslane 1993) and other service users (Turner 1997; Qureshi *et al.* 1998). Three service-process outcomes identified by other service users were not raised by people with dementia: value for money; the need for services to fit in with patterns of care giving and receiving within the family; and the need for services to be culturally sensitive (Turner 1997; Qureshi *et al.* 1998). Since

many of the people with dementia who took part were not aware of the financial costs of services, the lack of emphasis on value for money is to be expected. It is likely that our focus on the impacts of services, and the context in which data collection took place, minimised any discussion of informal care giving and how this fitted in with services. Finally, cultural sensitivity was usually identified as a desired service-process outcome by service users from minority ethnic groups; since all of the people with dementia who took part were from a white, European background it is not surprising that this issue did not arise. Being able to relate to other service users was an important service-process outcome for people with dementia but not other older people. This may reflect the specific difficulties experienced by people with dementia in relating to other service users, but at the same time differentiating themselves from those with more severe cognitive impairments (Sperlinger and McAuslane 1993).

Since carers express their views more fluently and quickly than people with dementia, it is tempting to rely on them as proxy respondents. Previous studies have observed that people with dementia and their carers do not necessarily have consistent views on services (Webb *et al.* 1998). Similarly, we found important differences in emphasis, particularly in relation to maintaining a sense of personal identity, social integration and feeling safe and secure. Carers were often more concerned with the negative consequences of failing to achieve outcomes than with the positive benefits of desired outcomes. Carers sometimes had difficulty in disentangling outcomes they wanted for themselves from those of relevance to the person with dementia. Their limited knowledge of services and lack of feedback provided by service users added to their difficulties in identifying outcomes.

The findings reported here are from a small exploratory study. Additional work is needed to explore the extent to which the same or similar outcomes are sought from different services, particularly those provided in the home, and by people with dementia who were either under-represented or not represented in our study, for example, minority ethnic groups, men, and younger people with dementia. Further work is also needed to examine whether desired outcomes change with increasing cognitive impairment, particularly since it has been suggested that there may be a greater emphasis on comfort and dignity in the end stages of dementia (Teno *et al.* 1997). While the ability of people with mild and moderate cognitive impairments to give their views through interviews and discussions is now well established, alternative approaches which will enable the inclusion of people with severe dementia need to be explored.

Conclusion

The desired outcomes identified in our study bear little resemblance to outcome measures commonly used to evaluate community care services. They are, however, largely consistent with: domains included in disease-specific quality-of-life measures; the views expressed in previous consultations with people with dementia; the theoretical basis of dementia care mapping; and outcomes identified by other service users, suggesting that our findings have some validity. A key outcome for people with dementia was maximising a sense of autonomy. This outcome has been relatively neglected in previous work. However, with growing recognition of the need for advocacy to enable people with dementia to participate meaningfully in decision-making, enhancing autonomy is becoming an important issue for service providers (Burton 1997). Our work also highlights the importance of service-process outcomes. The impacts, or outcomes, of the ways in which services are delivered have rarely been evaluated. This is problematic since such outcomes are not only highly valued by service users and carers but are strongly linked to the achievement of desired quality-of-life outcomes.

The differing perspectives and priorities of people with dementia and their carers suggest that caution is needed in relying only on carers as proxy respondents. Other studies have also challenged the implicit view of carers as dispassionate, disinterested and objective informants (Cotrell and Schulz 1993; Barnett 1997; Bender 1998). Further work is needed to explore how carers can most usefully contribute to evaluating outcomes for people with dementia.

The outcomes identified in our study could potentially offer a new approach to evaluating community services, based on the perspectives of service users. Further development work is needed to identify ways of collecting information on these outcomes. Before more user-focused outcome measures can be used in practice, however, a fundamental shift in perspective is required. The reliance on measures drawn exclusively from a medical perspective to evaluate community services needs to be replaced by approaches which are more consonant with the underlying aims of community care, and which acknowledge the validity of the perspective of people with dementia.

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NOTES

1 'Defining and measuring outcomes in Alzheimer disease research: Do we agree?' Conference held in Washington, DC, U.S.A., 11–12 September 1996. 'Exploring outcomes in dementia', Conference held in Stirling, U.K., 27 August 1998. Alzheimer Disease and Associated Disorders, 1997, **11**, Supplement 6. Journal of Mental Health and Aging, 1999, **5** (1).
2 *Text Detective*, written by David Reeves at Hester Adrian Research Centre, University of Manchester, Manchester.

References

Adams, T. 1996. Kitwood's approach to dementia and dementia care: a critical but appreciative review. *Journal of Advanced Nursing*, **23**, 948–53.

Albert, S., Marks, J., Barrett, V. and Gurland, B. 1997. Home health care and quality of life for patients with Alzheimer's disease. *American Journal of Preventive Medicine*, **13**, 6, 63–8.

Alzheimer Disease and Associated Disorders 1997. **11**, Supplement 6.

Askham, J. and Thompson, C. 1990. *Dementia and Home Care: a Research Report on a Home Support Scheme for Dementia Sufferers*. Age Concern England, Mitcham, Surrey.

Bagshaw, H. and Unell, J. 1997. *Examining Outcomes in Community Care*. Social Policy Research Unit Working Paper Number 1613. University of York, York.

Bamford, C., Vernon, A., Nicholas, E. and Qureshi, H. 1999. *Outcomes for Younger Disabled People and their Carers: Overview*, Outcomes in Community Care Practice, Number Six, Social Policy Research Unit, University of York, York.

Bamford, C. Forthcoming. Consulting older people with dementia: the value of different approaches. In Murphy, C., Killick, J. and Allan, K. (eds), *The User's Voice: Involving People with Dementia in Improving Services*. Dementia Services Development Centre, University of Stirling, Stirling.

Barnett, E. 1997. Collaboration and interdependence: care as a two-way street. In Marshall, M. (ed), *State of the Art in Dementia Care*. Centre for Policy on Ageing, London.

Bender, M. 1998. Shifting our focus from brain to mind. *Journal of Dementia Care*, January/February, 20–22.

Bleathman, C. and Morton, I. 1992. Validation therapy: extracts from 20 groups with dementia sufferers. *Journal of Advanced Nursing*, **17**, 658–66.

Bond, J. 1999. Quality of life for people with dementia. Approaches to the challenge of measurement. *Ageing and Society*, **19**, 561–79.

Bowling, A. 1997. *Measuring Health: a Review of Quality of Life Measurement Scales*. 2nd Edition. Open University Press, Buckingham.

Brod, M., Stewart, A. L. and Sands, L. 1999. Conceptualization of quality of life in dementia. *Journal of Mental Health and Aging*, **5**, 1, 7–19.

Brooker, D., Foster, N., Banner, A., Payne, M. and Jackson, L. 1998. The efficacy of

dementia care mapping as an audit tool: report of a 3-year British NHS evaluation. *Ageing and Mental Health*, **2**, 1, 60–70.

Burton, A. 1997. Dementia: a case for advocacy? In Hunter, S. (ed), *Dementia: Challenges and New Directions*. Jessica Kingsley Publishers, London.

Cheston, R. 1996. Stories and metaphors: talking about the past in a psychotherapy group for people with dementia. *Ageing and Society*, **16**, 579–602.

Cheston, R. and Bender, M. 1999. *Understanding Dementia*. Jessica Kingsley Publishers, London.

Cotrell, V. and Schulz, R. 1993. The perspective of the patient with Alzheimer's Disease: a neglected dimension of dementia research. *The Gerontologist*, **33**, 2, 205–11.

Cox, S., Anderson, I., Dick, S. and Elgar, J. 1998. *The Person, the Community and Dementia: developing a value framework*. Dementia Services Development Centre, Department of Applied Social Science, University of Stirling.

Department of Health. 1989. *Caring for People: Community Care in the Next Decade and Beyond*, Cm 849. HMSO, London.

Department of Health. 1998. *Modernising Social Services*. Department of Health, London.

Downs, M. 1997. Evaluating dementia services. In Marshall, M. (ed), *State of the Art in Dementia Care*. Centre for Policy on Ageing, London.

Feil, N. 1993. *The Validation Breakthrough. Simple Techniques for Communicating with People with Alzheimer's-type Dementia*. Health Professions Press, London.

Fox, L. 1995. Mapping the advance of the new culture in dementia care. In Kitwood, T. and Benson, S. (eds), *The New Culture of Dementia Care*. Hawker Publications Ltd, London.

Gibson, F. 1993. What can reminiscence contribute to people with dementia? In Bornat, J. (ed), *Reminiscence Reviewed: Evaluations, Achievements, Perspectives*. Open University Press, Buckingham.

Gilleard, C. and Higgs, P. 1998. Old people as users and consumers of healthcare: a third age rhetoric for a fourth age reality? *Ageing and Society*, **18**, 2, 233–48.

Goldsmith, M. 1996. *Hearing the Voice of People with Dementia: Opportunities and Obstacles*. Jessica Kingsley, London.

Gwyther, L. 1997. The perspective of the person with Alzheimer disease: which outcomes matter in early to middle stage of dementia? *Alzheimer Disease and Related Disorders*, **11**, Supplement 6, 18–24.

Harding, N. and Palfrey, C. 1998. *The Social Construction of Dementia: Confused Professionals?* Jessica Kingsley Publishers, London.

Harding, T. and Beresford, P. 1996. *The Standards we Expect*. National Institute for Social Work, London.

Howard, K. and Rockwood, K. 1995. Quality of life in Alzheimer's Disease. *Dementia*, **6**, 113–16.

Jacques, A. 1992. *Understanding Dementia*. Churchill Livingstone, Edinburgh.

Journal of Mental Health and Aging 1999, **5**, 1.

Kitwood, T. 1990. Psychotherapy and dementia. *BPS Psychotherapy Section Newsletter*, **8**, 40–56.

Kitwood, T. and Bredin, K. 1992*a*. Towards a theory of dementia care: personhood and well-being. *Ageing and Society*, **12**, 269–87.

Kitwood, T. and Bredin, K. 1992*b*. A new approach to the evaluation of dementia care. *Journal of Advances in Health and Nursing Care*, **1**, 5, 41–60.

Kitwood, T. and Bredin, K. 1994. Charting the course of quality care. *Journal of Dementia Care*, May/June 22–3.

Lam, J. and Beech, L. 1994. "I'm sorry to go home". The weekend break project: Consultation with users and their carers. Unpublished paper. Department of Psychology, St Helier NHS Trust, Sutton Hospital, Surrey.

Lamers, C., Culpan, S. and Lewins, J. 1996. Listening to the experience of forgetting: a therapy and coping group for people suffering from a dementia syndrome. A pilot study. Unpublished paper. Sevenairs Day Hospital, Sheffield.

Langan, J. and Means, R. 1995. *Personal Finances, Elderly People with Dementia and the 'New' Community Care*. Anchor Housing Association, Kidlington.

Lawton, M. P., van Haitsma, K., Perkinson, M. and Ruckdeschel, K. 1999. Observed affect and quality of life in dementia: further affirmations and problems. *Journal of Mental Health and Aging*, **5**, 1, 69–81.

Levin, E., Moriarty, J. and Gorbach, P. 1994. *Better for the Break*. HMSO, London.

Logsdon, R. G., Gibbons, L. E., McCurry, S. M. and Teri, L. 1999. Quality of life in Alzheimer's Disease: patient and caregiver reports. *Journal of Mental Health and Aging*, **5**, 1, 21–32.

Magaziner, J. 1997. Use of proxies to measure health and functional outcomes in effectiveness research in persons with Alzheimer's disease and related disorders. *Alzheimer Disease and Associated Disorders*, **11**, Supplement 6, 168–74.

Marshall, M. 1997. Introduction: state of the art in dementia care. In Marshall, M. (ed), *State of the Art in Dementia Care*. Centre for Policy on Ageing, London.

Marshall, M. 1999. What do service planners and policy-makers need from research?. *International Journal of Geriatric Psychiatry*, **14**, 86–96.

Mason, J. 1996. *Qualitative Researching*. Sage Publications, London.

Mozeley, C. G., Huxley, P., Sutcliffe, C., Bagley, H., Burns, A., Challis, D. and Cordingley, L. 1999. 'Not knowing where I am doesn't mean I don't know what I like': cognitive impairment and quality of life responses in elderly people. *International Journal of Geriatric Psychiatry*, **14**, 776–83.

Murphy, C., Glover, M. and Davis, K. 1996. *An Evaluation of Stirling Town Break*. Dementia Services Development Centre, Department of Applied Social Science, University of Stirling.

National Consumer Council 1990. *Consulting Consumers in the NHS: a Guideline Study. Services for Elderly People with Dementia Living at Home*. National Consumer Council, London.

National Health Service Executive 1998. *The New NHS Modern and Dependable: a National Framework for Assessing Performance*. Department of Health, London.

Nocon, A. and Qureshi, H. 1996. *Outcomes of Community Care for Users and Carers*. Open University Press, Buckingham.

Ostbye, T., Tyas, S., McDowell, I. and Koval, J. 1997. Reported activities of daily living: Agreement between elderly subjects with and without dementia and their carers. *Age and Ageing*, **26**, 99–106.

Qureshi, H., Patmore, C., Nicholas, E. and Bamford, C. 1998. *Overview: Outcomes of Social Care for Older People and Carers*. Outcomes in Community Care Practice, Number Five, Social Policy Research Unit, University of York, York.

Rabins, P., Kasper, J. D., Kleinman, L., Black, B. S. and Patrick, D. L. 1999. Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's disease. *Journal of Mental Health and Aging*, **5**, 1, 33–48.

Ramsay, M., Winget, C. and Higginson, I. 1994. *Outcomes of Dementia Care: Views of General Practitioners, District Nurses, Informal Carers and Specialist Teams*. Internal report. Kensington, Chelsea and Westminster Health Authority, London.

Ramsay, M., Winget, C. and Higginson, I. 1995. Review: measures to determine the outcome of community services for people with dementia. *Age and Ageing*, **24**, 73–83.

Smyth, K. A., Ferris, S. H., Fox, P., Heyman, A., Holmes, D., Morris, J. N., Phillips, C. D., Schulz, R., Teresi, J. and Whitehouse, P. J. 1997. Measurement choices in multi-site studies of outcomes in dementia. *Alzheimer Disease and Associated Disorders*, **11**, Supplement 6, 30–44.

Sperlinger, D. and McAuslane, L. 1993. 'I don't want you to think I'm ungrateful … but it doesn't satisfy what I want'. A pilot study of the views of users of services for people with dementia in the London Borough of Sutton. Unpublished paper. Department of Psychology, St Helier NHS Trust, Sutton Hospital, Surrey.

Sutton, L. and Fincham, F. 1990. Respite care from the point of view of the person with a dementia. Unpublished paper. Moorgreen Hospital, Southampton.

Teno, J., Landrum, K. and Lynn, J. 1997. Defining and measuring outcomes in end-stage dementia. *Alzheimer Disease and Associated Disorders*, **11**, Supplement 6, 25–9.

Turner, M. 1997. Reshaping our lives. *Research Policy and Planning*, **15**, 2, 23–5.

Volicer, L., Hurley, A. C. and Camberg, L. 1999. A model of psychological well-being in advanced dementia. *Journal of Mental Health and Aging*, **5**, 1, 83–94.

Webb, S., Moriarty, J. and Levin, E. 1998. *Social Work and Community Care and Community Care Arrangements for Older People with Dementia*. National Institute for Social Work, London.

Wenger, G. C. 1994. Support networks and dementia. *International Journal of Geriatric Psychiatry*, **9**, 181–94.

Whitehouse, P. and Maslow, K. 1997. Defining and measuring outcomes in Alzheimer Disease research: Introduction and overview. *Alzheimer Disease and Associated Disorders*, **11**, Supplement 6, 1–4.

Wimo, A., Mattsson, B., Krakau, I., Eriksson, T. and Nelvig, A. 1994. Cost-effectiveness analysis of day care for patients with dementia disorders. *Health Economics*, **3**, 395–404.

Woods, B. 1999. Promoting well-being and independence for people with dementia. *International Journal of Geriatric Psychiatry*, **14**, 97–109.

Yale, R. 1991. *A guide to Facilitating Support Groups for Newly Diagnosed Alzheimer's Patients*. Alzheimer's Association, Palo Alto, CA.

Zarit, S. H., Gaugler, J. E. and Jarrot, S. E. 1999. Useful services for families: research findings and directions. *International Journal of Geriatric Psychiatry*, **14**, 165–81.

Address for correspondence:
Claire Bamford, Social Policy Research Unit, University of York, Heslington, York, YO10 5DD