

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

# Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

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*Report for the National Institute for Health Research Service Delivery and Organisation programme*

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prepared by

Ms Claire Bamford

- Institute of Health and Society, Newcastle University

Dr Hilary Arksey

- Social Policy Research Unit, York University

Mrs Marie Poole

- Institute of Health and Society, Newcastle University

Dr Catherine Kirkley

- Institute of Health and Society, Newcastle University

Dr Julian Hughes

- Northumbria Healthcare NHS Foundation Trust

Dr Lynne Corner

- Institute for Ageing & Health, Newcastle University

Professor John Bond

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Institute of Health and Society, Newcastle University

Address for correspondence

John Bond

Institute of Health and Society, Newcastle University, 21 Claremont Place,  
Newcastle upon Tyne, NE2 4AA

E-mail: [john.bond@ncl.ac.uk](mailto:john.bond@ncl.ac.uk)

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## Identity of study participants and case study sites

In order to protect the identity of individuals we have provided a code for each of the participants and indicate whether they are a person with dementia, carer or member of staff. In Appendix 1 we provide a description of each of the six services which participated in the case studies. The services have not been named but are referred to by a number, usually accompanied with a brief description of the type of respite care or short break provided. Participants in the case studies have been allocated a unique identifying code indicating the type of participant (p for person with dementia; c for carers; s for staff); the service id number and the participant number. Thus p405 is a person with dementia at service 4 with the id '05'.

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## Ethical and research governance approval

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- Northumberland, Tyne and Wear NHS Trust (objectives 1,2 and 3) (Reference: 2006NEPCMH002)
- Sheffield Social Care Trust (objectives 1 & 2) (Reference ZG91)
- Newcastle City Council (objectives 1 & 2)
- NHS Borders (objective 1)
- Cambridgeshire & Peterborough Mental Health Partnership Trust (objective 1)
- Staffordshire County Council (objective 1)
- Newcastle City Council (objective 3) (Reference: RGA0707)
- Bracknell Council (objective 3)
- Sheffield Care Trust (objective 3) (Reference: ZJ58)

## *The Report*

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# 1 Introduction

## 1.1 Background and policy context

Dementia represents a significant challenge to health and social care services in terms of the numbers of people affected, the impacts on people with dementia and their families, and the financial costs to the economy (Figure 1).

**Figure 1. Dementia in the UK<sup>1</sup>**

*Numbers of people with dementia:*

- 1.1% of the population
- 700,000 people with dementia currently
- More than 1 million people will be affected by 2025
- Two-thirds of people with dementia live at home, most supported by informal carers

*Informal carers:*

- 476,000 informal carers of people with dementia in England (equivalent to some 574,000 in UK)
- Informal carers bear one-third of the financial costs (through lost earnings, provision of care etc).

*Financial costs of dementia:*

- Annual cost of £17 billion
- Cost to health and social care economy is more than cancer, heart disease and stroke combined.

<sup>1</sup> Knapp *et al.* (2007) ; National Audit Office (2007)

These statistics, however, provide little insight into the biopsychosocial heterogeneity of people with dementia and their carers or the diversity of experience of living with dementia. The biomedical approach to dementia, which focused on enumerating cognitive function, activities of daily living and behavioural and perceptual symptoms (Bond, 1992), has been challenged by a growing emphasis on person-centred care (Brooker, 2004;

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Kitwood, 1997; Kitwood and Benson, 1995). This recognises the continuing personhood of the person with dementia and the need to find ways of supporting and enhancing well-being and quality of life. This reconceptualisation of people with dementia has significant implications for service delivery. While respite care and short breaks have historically been perceived as a service for carers (Nolan and Grant, 1992), there is a growing recognition that they need to provide a positive and enriching experience for service users (Weightman, 1999). This aspiration is reflected in a change in terminology from 'respite care' to 'short-term breaks' (Weightman, 1999). This emphasis has recently been reiterated in recent documents specifically relating to dementia, including the National Dementia Strategy (Department of Health, 2008b) and the SCIE/NICE guideline on supporting people with dementia and carers (Social Care Institute for Excellence and National Institute for Health and Clinical Excellence, 2007).

At the same time, there is continuing emphasis on the need for carers to have access to respite care or short breaks. Family members and friends provide much of the support to people with dementia living at home (RIS MRC CFAS Resource Implications Study Group of the Medical Research Council Cognitive Function and Ageing Study, 1999). Although many carers identify positive aspects to their role, there is also evidence of a range of negative impacts, including stress and depression (Brodaty, 2007; Moise *et al.*, 2004; Morris *et al.*, 1988; Pickard, 2004; RIS MRC CFAS, 2000; RIS MRC CFAS Resource Implications Study Group of the Medical Research Council Cognitive Function and Ageing Study, 1997; Schneider *et al.*, 1999; Sørensen *et al.*, 2002). A break from caring is thought to enhance carers' psychological and physical well-being, thus enabling them to continue to support the person with dementia in the community and delay admission to long-term care (Rudin, 1994; Strang and Haughey, 1998). Respite services have therefore been seen as central to achieving care in the community and containing the costs of long-term care (Department of Health, 2006; Donaldson and Gregson, 1989; Levin *et al.*, 1994; Moriarty and Levin, 1993; Social Care Institute for Excellence and National Institute for Health and Clinical Excellence, 2007). More recent policy initiatives, focused on improving support for carers, have continued to emphasise the importance of respite care and short breaks (the Carers and Disabled Children Act (Department of Health and Department of Education and Skills, 2005), National Service Framework for Older People (Department of Health, 2001a), National Service Framework for Long-term Conditions (Department of Health, 2005b), Carers Strategy (HM Government, 2008)). These initiatives sought to improve service utilisation by addressing the criticisms levelled by carers at existing respite services, for example, the lack of choice, quality and appropriateness of respite services (Ashworth and Baker, 2000; Briggs and Askham, 1998; Frost, 1990; Jewson *et al.*, 2003; Katbamna *et al.*, 1998; Social Services Inspectorate, 2000).

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Increasing the diversity of respite care and short breaks is seen as a key strategy to enhance services. To stimulate more flexible and innovative models of respite care and short breaks, £1 billion was made available through the Carers' Special Grant (Department of Health, 1999; Department of Health, 2005c; HM Government, 2008) with a further £150 million planned as part of the new Carers Strategy (HM Government, 2008). Direct payments, extended to older people in 2000 provide an alternative route to increasing choice and control of services aimed at providing a break from caring (Department of Health, 2000; Department of Health, 2005c; Department of Health, 2005a). Traditional models of respite care such as day care and institutional respite care have been supplemented with more innovative models including in-home respite (Parahoo *et al.*, 2002; Ryan *et al.*, 2002), host-family respite (Robertson, 2002), home day care (Mitchell, 1999) and outward bound breaks (Calvert Trust, 2004). While many services continue to focus on separating the person with dementia and carer, there has been interest in services for couples which enable the person with dementia and their carer to do joint activities or go on a short break together (Searson *et al.*, 2008; Sheard, 2004; Weightman, 1999). Holiday services may provide additional support so that the carer can choose to reduce their involvement in caring during the break (Vitalise, 2008). While traditional forms of respite care, such as overnight stays and day care, are widely available, more innovative services are less well dispersed, limiting choice for many people with dementia and their carers. Despite a 15 percent increase in the number of carers accessing such services (Commission for Social Care Inspection, 2008), community mental health teams recently identified the lack of respite care and short breaks as the second most important barrier to delivering effective care for people with dementia (National Audit Office, 2007). The need for more respite care and short breaks has also been highlighted by carers (HM Government, 2008) and a survey of services in Scotland indicated significant under-provision (Murphy and Archibald, 2004).

Despite the prominent emphasis on respite care and short breaks in policy and other initiatives to improve services for people with dementia, there is surprisingly little evidence regarding the effectiveness of such services. Reviews of respite care and short breaks for people with dementia concluded that existing evidence regarding the effectiveness of these services is inconsistent and inconclusive (Arksey *et al.*, 2004; Lee and Cameron, 2004). A more recent review, including services for all frail older people, suggested that respite care and short breaks have:

- neither a positive nor negative impact on frail older people
- a small beneficial impact on carers
- no impact on admission to long-term care (Mason *et al.*, 2007).

The absence of evidence that services are effective, however, is not the same as evidence that services are ineffective (Arksey *et al.*, 2004). There are significant conceptual and methodological challenges in evaluating

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respite care and short breaks (Arksey *et al.*, 2004; Lee and Cameron, 2004; McNally *et al.*, 1999). Service objectives are not always explicit and vary between, and even within, services. For example, whilst some services aim to prevent institutional admission, others focus on facilitating the move from community to long-term care. Indeed, a single service may at times focus on both of these objectives, either with different people with dementia, or with the same individual at different points in the illness trajectory.

Outcome measures have not necessarily included the outcomes valued by people with dementia (Bamford and Bruce, 2000) and their carers (Department of Health, 2001b), consequently the subjective levels of satisfaction reported by carers have not consistently been captured in evaluative studies (Arksey *et al.*, 2004; Ashworth and Baker, 2000). There is a considerable body of work documenting the psychological needs (Kitwood, 1997), outcomes (Bamford and Bruce, 2000; Nicholas and Patmore, 1999) and components of quality of life (Brod *et al.*, 2002; Corner, 2003; DeJong *et al.*, 1989; Logsdon *et al.*, 1999; Parse, 1996; Rabins *et al.*, 1999; Selai *et al.*, 2000; Smith *et al.*, 2005) valued by people with dementia and carers. Although concepts such as making a contribution, integration and identity have consistently been identified as important by people with dementia, these have rarely been addressed in studies of respite care and short breaks and are not necessarily reflected in existing measures of quality of life for people with dementia (Albert *et al.*, 1996; Bond, 1999; Corner, 2003; DeJong *et al.*, 1989; Smith *et al.*, 2005).

With growing diversity of respite care and short breaks, there is a need for evaluative tools that can be used across different models to compare the impacts of services for people with dementia and carers (Arksey *et al.*, 2004; Jeon *et al.*, 2005). Research to explore whether particular groups of people with dementia and carers benefit more from certain types of respite care and short breaks has also been suggested (Arksey *et al.*, 2004). Currently little is known about the relative merits of different models of respite care and short breaks or whether the new terminologies of 'short breaks' and 'person-centred care' have resulted in significant changes in the day-to-day delivery of care. One difficulty in developing tools suitable for a range of models of respite care and short breaks concerns the different aims of services. The provision of person-centred care is an underlying theme common to all services. A focus on person-centred care would also ensure that evaluation was aligned to a key policy objective.

Although person-centred care is a central policy objective (Standard 2 of the National Service Framework for Older People, Department of Health, 2001a) the issue of how to operationalise and evaluate this concept is under-researched. This partly reflects the lack of consensus over the precise meaning of person-centred care (Brooker, 2004; Nolan *et al.*, 2004). Few measures are theoretically grounded in the concept of person-centred care. The most widely known tool based on the principles of person-centred care is Dementia Care Mapping (DCM, see Section 5.5)

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which was developed to evaluate services from the perspectives of people with dementia (Kitwood and Bredin, 1992). Although DCM has been widely used, it has a number of limitations. It was developed for communal settings (making it unsuitable for one-to-one services), the underlying assumptions do not allow for individual differences in the preferred extent of interaction with others (Bamford and Bruce, 2000), it has been argued that the empirical basis for these assumptions is weak (Adams, 1996; Harding and Palfrey, 1997) and it relies on interpretation by the observer (Gilleard and Higgs, 1998).

While DCM involves a detailed recording of the process of care, other indicators of person-centred care have tended to focus on the structure of care. For example, Reilly *et al.* (2006) included a policy of no uniforms for staff as one component of person-centred care. There is a tension between developing indicators that are workable in practice whilst being sufficiently detailed to capture the nuances of person-centred care. A series of benchmarking tools for person-centred care have been developed (Baker and Edwards, 2002) and the accompanying text includes a series of detailed questions which illustrate the rationale for the indicator and how it is linked to person-centred care. There is a danger, however, that the indicators may be completed at a simplistic and superficial level. The National Service Framework for Older People (Department of Health, 2001a) includes a range of components of person-centred care (see Table 5 in Chapter 3). However, in reviewing progress with implementation, the focus was on the single assessment process, integrated community arrangements and integrated provision of services (Healthcare Commission *et al.*, 2006). The report acknowledges that 'all older people are not yet genuinely treated as individuals' (Healthcare Commission *et al.*, 2006, page 96), but does not indicate how this conclusion was derived or address other aspects of person-centred care. The use of broad indicators to evaluate person-centred care, together with the reliance on professional perspectives may fail to reflect the reality of service delivery for people with dementia and carers (Abendstern *et al.*, 2006). There is therefore a need for reliable and valid instruments to measure person-centred care (Crandall *et al.*, 2007; Edvardsson *et al.*, 2008) from the perspectives of all stakeholders.

Focusing on the extent to which respite care and short breaks provide person-centred care provides an opportunity to address some of the methodological problems in evaluating such services by ensuring that outcomes valued by people with dementia and carers are included and that evaluation is aligned with a key policy objective. An emphasis on person-centred care additionally has the potential to address the diverse needs and preferences of people with dementia and their carers which are shaped by the identity categories, such as age, gender, race, ethnicity and class, to which they belong (Hulko, 2002; Iliffe and Manthorpe, 2004). Key findings from this brief review of the literature are summarised in Figure 2.

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### Figure 2. Key findings from existing literature

- There is little consensus over the meaning of person-centred care either in practice or policy documents
- As a result, there is limited research on how to operationalise and evaluate person-centred care. Although staff are aware that they 'ought' to deliver person-centred care, there is a lack of information on how to deliver such care and how to tell whether they are doing so successfully
- Existing evaluations of the outcomes of respite care and short breaks have been inconclusive, but a range of methodological issues have been highlighted

## 1.2 Aims and objectives

The overall aim of the study is to develop practical tools for evaluating person-centredness which can be used across a range of models of respite care and short breaks for people with dementia and their carers. The specific project objectives were:

- to identify the range of models of respite care and short breaks and describe how these are implemented in practice
- to develop an understanding of person-centred care and how it is operationalised in different models of respite care and short breaks from the perspectives of people with dementia, carers and service providers
- to iteratively develop and test practical tools for evaluating person-centred care.

## 1.3 Methods of research

We deviate from conventional practice in the presentation of our methods of research in a single chapter in order to give the reader greater understanding of the relationship between the different methods used and the objectives of the study. The study employed a mixed-methods design (Cresswell, 2003) that included quantitative and qualitative approaches throughout a number of phases of the research with a range of stakeholders (study participants). Specific methods used include structured literature reviews, telephone surveys, qualitative focus groups and focused interviews, instrument development, cognitive interviews and comparative case studies using ethnographic methods. Full details of the methods used are presented in Appendix 1. In this chapter we provide an overview of the methods used and link them to our specific research objectives. In subsequent chapters we provide a brief resumé of the methods used that are relevant to the data being presented.

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### **1.3.1 Overview of the study**

Table 1 provides an overview of the study and shows the relationship between specific objectives and the methods, stakeholders who participated in the study and outputs for each objective.

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**Table 1. Overview of study**

|                                   | Purpose  | Methods  | Participants   | Outputs   |
|-----------------------------------|--|--|--|---|
| Objective 1<br>(Chapter 2)        | To identify and describe models of respite care and short breaks   | Literature review of models of respite care and short breaks<br>Web search<br>Scoping telephone survey<br>Detailed telephone survey  | National organisations of and for people with dementia and carers<br>Service managers of selected models of respite care and short breaks  | Description of traditional and innovative models of respite care and short breaks; identification of potential participants for objectives 2 and 3  |
| Objective 2<br>(Chapters 3 and 4) | To clarify the meanings of person-centred care and how it is implemented in practice<br><br>To validate the framework of components of person-centred care | Literature review of person-centred care<br><br>Focused interviews<br>Focus groups<br><br>Observation conducted as part of the comparative case studies  | People with dementia, carers, front-line staff and managers<br>People with dementia, carers, front-line staff and managers<br>People with dementia, carers, front-line staff and managers in six services providing respite care or short breaks | Framework of components of person-centred care; identification of facilitators and barriers to person-centred care<br><br>Revised framework of components of person-centred care with examples of person-centred care in routine practice |
| Objective 3<br>(Chapters 5 and 6) | To identify and develop tools to evaluate person-centred care  | Review of measures used to evaluate respite care and short breaks<br>Mapping of content of existing measures to framework of components of person-centred care<br>Collation of existing items from literature review<br>Development of new items where necessary |  | Tools for evaluating person-centred care, comprising:<br>Interview with people with dementia<br>Carer questionnaire<br>Staff questionnaire<br>Vignettes for discussion by staff   |
| (Chapter 7)                       | To iteratively test and refine tools across a range of models of respite care and short breaks   | Comparative case studies including administration of tools, cognitive interviews, non-participant observation  | People with dementia, carers, front-line staff and managers in six services providing respite care or short breaks   | Revised tools   |

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### 1.3.2 Objective 1 – Models of respite care and short breaks

#### *Literature review*

The search strategy used in a previous structured review of respite care and short breaks for people with dementia (Arksey *et al.*, 2004) was rerun at intervals throughout the project to identify the range of service models. This was supplemented with hand searches of selected journals to identify models of respite care and short breaks which had not been rigorously evaluated. The Dementia Services Development Centre at Stirling also conducted a search to identify additional 'grey' literature.

#### *Web searches*

We focused on selected UK websites which were likely to include innovative practice, for example:

- local branches of the Alzheimer's Society
- the Older People's Mental Health Mapping exercise
- Commission for Social Care Inspection (CSCI)
- Social Care Institute for Excellence (SCIE).

#### *Scoping telephone survey*

Telephone interviews were conducted with representatives from Government agencies, statutory services in health and social care, voluntary agencies promoting or providing either dementia care or support services for carers and key individuals with an interest in respite and/or person-centred care for people with dementia. Participants were asked to identify the range of models of respite care and short breaks known to them and to provide contact details for providers of different models. We also explored their views on person-centred care.

#### *Detailed telephone survey*

We used the information obtained through the literature review, web search and scoping survey to identify and recruit managers of conventional and innovative respite provision in inner city, urban and rural locations, as well as services for specific groups of people with dementia such as younger people and people from black and minority ethnic groups. Focused interviews obtained a detailed description of the service provided by the participant's organisation. We also explored the meanings of person-centred care and how this was promoted within the service.

The results of these reviews and surveys are presented in Chapter 2.

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### **1.3.3 Objective 2 – The meanings of person-centred care**

#### ***Literature review***

Two team members (CB and JH) had recently completed a thematic analysis of different types of centredness (person-, patient-, family-, client- and relationship-centred care). This resulted in the identification of ten themes common to all types of centredness (Hughes *et al.*, 2008). These themes contributed to the development of the framework of components of person-centred care.

#### ***Focus groups and face-to-face focused interviews***

We used qualitative focus groups and face-to-face focused interviews to explore the meanings and components of person-centred care and to identify factors which facilitated or hindered the delivery of person-centred care. A range of stakeholders, with experience of different models of respite care and short breaks, were involved, including: people with dementia, carers, managers and front-line staff. Analysis of the data resulted in a draft framework of components of person-centred care (see Chapter 3), and the identification of barriers and facilitators to person-centred care (see Chapter 4).

#### ***Comparative case studies***

We used ethnographic methods in each of the six services participating in the comparative case studies (see also Objective 3) to 'validate' and refine the framework of components of person-centred care. The 'fit' of the data recorded in the field notes from non-participant observation was compared with the draft framework of components to identify any additional components that had not been articulated in the focus groups or face-to-face focused interviews. This ensured that the final framework was robust and inclusive.

### **1.3.4 Objective 3 – To identify, develop and test tools to evaluate person-centred care**

#### ***Review of measures used to evaluate respite care and short breaks***

Measures used to evaluate respite care and short breaks were identified through a structured review. We mapped the content of each measure onto the framework of components of person-centred care developed in Objective 2 and identified items which could potentially be included in the tools.

#### ***Development of tools***

Where there was a poor 'fit' between items in existing measures and our components of person-centred care, we used established principles of questionnaire design (Dillman, 1978; McColl *et al.*, 2001; Oppenheim, 1992) to develop new items.

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### ***Comparative case studies***

Services providing respite care and short breaks for the comparative case studies (Yin, 1984) were identified through the detailed telephone survey to provide a maximum variation sample (Patton, 2002). Within each service, we used cognitive interviews to assess the acceptability and feasibility of using the tools developed to evaluate person-centredness. Cognitive interviews are a form of semi-structured interview in which participants evaluate the question content and format of a structured instrument or interview schedule (Willis, 2005). This process highlighted any shortcomings of the tools and enabled them to be refined in readiness for psychometric testing (Oppenheim, 1992).

During fieldwork it became clear that the ethnographic data collected to validate the framework of components of person-centred care could also contribute to the validation of the tools, since it allowed us to compare responses to specific questions with what we observed in practice. It also provided supplementary information when participants seemed reluctant to criticise services. This observational data therefore also contributed to refining and validating the tools.

#### **1.3.5 Reference Group**

The research team was supported by a Reference Group which met four times during the project. The group comprised a range of stakeholders with knowledge of respite care and short breaks for people with dementia, including representatives of organisations of and for people with dementia, health and social care professionals, academics and 'key informant' carers (that is, carers who have both personal experience of caring and wider experience of carers' issues as a result of involvement in national or local organisations). The purpose of the Reference Group was to:

- identify different models of respite care and short breaks and select models for inclusion in the detailed telephone survey
- identify activities to help promote discussion of person-centred care in the focus groups and face-to-face interviews
- test and review the tools developed
- identify policy implications and inform the development of written materials for dissemination.

In addition to these formal meetings, the research team benefitted from informal communication with members of the Reference Group to obtain advice and feedback as and when required.

## **1.4 Terminology and definitions**

Person-centred care is an ambiguous and contested term. The relative neglect of social context and relationships in which people with dementia are situated has been criticised and led to the suggestion that 'relationship-centred' care may be a more appropriate term than person-centred care

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(Nolan *et al.*, 2004; Perks *et al.*, 2001). A recent review of the literature on 'centredness', including person-, client-, patient-, relationship- and family-centred care, indicated considerable overlap between the themes comprising different types of centredness (Hughes *et al.*, 2008).

Furthermore, the importance of the relational aspects of care was widely recognised, with many definitions of different types of centredness including an explicit focus on social context and relationships (Hughes *et al.*, 2008). It has been also been argued that person-centred care is a more inclusive term since personhood encompasses relationship (McCormack, 2004). In the context of social care in general, and dementia care in particular, the term person-centred care is the most familiar and widely used term; we have therefore used the term person-centred care.

In the original research proposal, we distinguished between person- and carer-centred care as a way of highlighting the different perspectives and needs of people with dementia and their carers. However, our work on the components of person-centred care (Chapter 3) indicated that the same components were relevant to people with dementia and carers.

Furthermore, since the term 'carer-centred care' is not in routine use, we have elected to use the term person-centred care for both the person with dementia and carer.

A change in terminology from 'respite care' to 'short-term breaks' has been proposed to reflect the aspiration towards delivering services that provide a positive experience for the person with dementia and their carer (Weightman, 1999). However, two concerns over the exclusive use of the term 'short-term breaks' were identified in discussions with members of the Reference Group: first, the term 'short-term breaks' does not adequately reflect the emphasis on relief from caring highlighted by carers; and second, while services may aspire to provide short breaks, the reality is that many services currently deliver respite. We will therefore use both terms 'respite care' and 'short breaks' interchangeably throughout the report.

In defining respite care and short breaks, we wanted to recognise that people with dementia without carers used such services (Scottish Executive, 2005). Where there was a carer, however, we wanted to capture the relief aspect. For people with dementia with carers, therefore, services providing respite care and short breaks had to meet two criteria:

- Relieving the carer of responsibility of care for the person with dementia
- and
- Providing a break from usual routine for the person with dementia and/or carer

For people with dementia with no carers, services providing respite care and short breaks were those that met the second element of this definition.

Services in which these aims were achieved incidentally, for example, through the provision of personal care, or social events (such as Dementia

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Cafés) were not included. Although video respite (Lund *et al.*, 1995) has been included in systematic reviews of respite care and short breaks (Arksey *et al.*, 2004; Mason *et al.*, 2007), this model was excluded from the present study since the carer remains responsible for the person with dementia.

### 1.5 Overview of report

This report describes the development and preliminary testing of tools to evaluate respite care and short breaks which focus on person-centred care and are suitable for use across a range of service models. The initial stages of the study involved identifying the range of models of respite care and short breaks (Chapter 2), developing and validating a framework of components of person-centred care (Chapter 3) and identifying factors that facilitated or hindered the delivery of person-centred care in routine practice (Chapter 4). The process of reviewing existing measures and mapping these to our framework of components of person-centred care is described in Chapter 5. Tools relevant to each of the key stakeholder groups (people with dementia, carers and staff) were then developed, building on existing measures where appropriate (Chapter 6). An iterative process of 'field' testing and tool refinement was then conducted in six different services providing respite care and short breaks (Chapter 7). We conclude by reviewing the main findings, discussing the strengths and limitations of the study, identifying further work required before the tools are used in routine practice, and discussing the implications for further research and policy in Chapter 8.

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## 2 Models of respite care and short breaks

### 2.1 Summary

This chapter reports on the models of respite care and short breaks identified through literature and web searches and telephone surveys. Services could be characterised on a number of dimensions including: duration, pattern of use, location, and the characteristics of service users and staff. We identified eight models of respite care and short breaks:

- day care
- home day care (in the home of a volunteer or care worker)
- clubs, interests or activity groups (day opportunities)
- home-based support (including sitting services)
- host-family respite (also known as adult placement schemes)
- overnight respite in specialist facilities
- overnight respite in non-specialist facilities (where one or two beds within a residential or nursing home or hospital ward are available for respite)
- holidays.

There is limited information about the availability of different models of respite care and short breaks. Existing data from Alzheimer Society websites and the Older People's Mental Health Mapping exercise suggests an emphasis on traditional models of respite care and short breaks which separate the person with dementia and carer. In order to maximise the benefits of the additional investment in respite care and short breaks as part of the new Carers Strategy (HM Government 2008), a comprehensive mapping exercise to identify service models and their availability is recommended. In addition, exploration of the preferences of people with dementia and carers is needed to ensure that investment is made appropriately. Although services providing respite care and short breaks had diverse aims, they all perceived person-centred care as being part of their remit, even when this was not an explicit aim. This confirms that person-centredness could potentially be used as a means of evaluating and comparing services.

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## 2.2 Introduction

This chapter discusses the range of models of respite care and short breaks which are consistent with the research team's working definition of respite:

- relieving the carer of responsibility of care for the person with dementia

and

- providing a break from usual routine for the person with dementia and/or carer.

Historically, the emphasis in many services was to provide a break for the carer to enable them to continue in their caring role (Care Services Improvement Partnership, 2008). Even though carers have identified respite care and short breaks as critical to their caring efforts (Cottrell and Engel, 1998), uptake of such services is often limited (Pickard, 1999). This discrepancy may reflect the fact that carers and service users often feel they have little choice in what is available (Social Services Inspectorate, 2000). Furthermore, many carers see traditional respite services as ill-suited to the needs of the person they are supporting (Archibald, 1996; Jewson et al., 2003; Perks et al., 2001).

The Carers Special Grant, introduced in 1999 as part of the National Strategy for Carers (Department of Health, 1999), represented a significant investment in respite care and short breaks. The overall intention was to address the problems of acceptability and availability of traditional respite services by encouraging innovation and the development of new models. The Carers Special Grant could be used to: review existing respite provision; consult with local residents to identify preferences regarding respite care and short breaks; and develop new services to address any gaps or shortfalls in provision. The intention of the Carers Special Grant was to benefit all users by extending the range of services and moving away from the provision of 'one size fits all' services. It was also proposed that the needs of specific groups of people with dementia and their carers, such as those from black and minority ethnic communities, younger people with dementia, and those living in rural areas, were addressed.

A further impetus to service development derives from the growing emphasis on the needs of service users. A good practice guide (Weightman, 1999), which accompanied the National Strategy for Carers (Department of Health, 1999) emphasised that respite care or short breaks should provide a positive, enriching experience for the service user, as well as a break for the carer. This emphasis has been reiterated in the National Dementia Strategy (Department of Health, 2008b) and the NICE/SCIE guideline on supporting people with dementia and their carers (Social Care Institute for Excellence and National Institute for Health and Clinical Excellence, 2007). The increasing emphasis on person-centred care for people with dementia, including appropriate activities and occupation, has also been influential in encouraging a joint focus on 'user and carer need' (Moriarty, 1999). Carers

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work hard to maintain the 'personhood' of an individual with dementia (Pickard, 1999), and not surprisingly want their relative to use services that do not undermine these endeavours.

A range of models of respite care and short breaks was identified in recent reviews (Arksey *et al.*, 2004; Mason *et al.*, 2007), including: day care outside the home; in-home services, host family respite; institutional/overnight respite; and video respite. In addition, respite programmes were available that offered service users and carers the choice of combining together different forms of respite care and short breaks, or provided such services as an integral part of a multi-dimensional carer support package.

There is some evidence that, contrary to conventional wisdom, a handful of 'innovative' services have been in existence for many years. For example, the first travelling day hospital was established in Hampshire in 1982 to address concerns about geographical isolation and poor transport (Moriarty, 2001). Homeshare, a home day care initiative in Ipswich, was set up by Suffolk Social Services department in 1985 (Moriarty, 2001). The absence of widespread adoption of innovative models of respite care and short breaks suggests that there may be barriers in replicating these services.

### 2.3 Resumé of method

The research methods used in this study are documented in Appendix 1. Here we summarise the methods used to identify the models of respite care and short breaks reported in this chapter.

#### ***Literature review***

We updated an existing literature review (Arksey *et al.*, 2004) that reported the effectiveness of respite care and short breaks for carers of people with dementia. We have used the same search strategy to identify papers published since the original review describing new models of respite care and short breaks. We supplemented the systematic search with a hand search of selected journals and a web search of selected UK websites.

#### ***Telephone surveys***

Scoping telephone interviews were conducted with representatives of a range of organisations in the public and independent sector that were responsible for dementia care or actively providing respite care and short breaks in order to identify the range of models of such services.

Detailed telephone interviews were subsequently conducted with managers of different models of respite care and short breaks identified in the scoping survey. Participants provided full details of their service and discussed the meaning of person-centred care.

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## 2.4 Models of respite care and short breaks

Through the literature review, web searches and telephone surveys a range of models of respite care and short breaks was identified. Respite care and short breaks are typically characterised by the setting in which the service is provided (Derence, 2005; Gilmour, 2002; Neville and Byrne, 2002) and the pattern or duration of service use (Derence, 2005; Neville and Byrne, 2002). In characterising the models of respite care and short breaks services we identified, we included both of these dimensions (Table 2). Four main providers of respite care and short breaks were identified: Social Services; NHS; voluntary organisations; and private providers. Since none of the models of respite care or short breaks was exclusively provided by any of these providers, details of service providers are not included in Table 2. While some models of respite care or short breaks, such as one-to-one support, were more frequently provided by Social Services or voluntary organisations, examples of similar services were identified which were provided by the NHS or private providers. The table highlights the diversity of respite care and short breaks which range from conventional services such as day care attendance outside of the home and overnight stays within long-term care settings to newer services delivered in the community such as home-based support, host-family respite (also known as adult placement schemes), home day care and short breaks and holidays. Some services providing day care and short breaks are activity or interest based (these are also known as day opportunities).

We also identified examples of innovative models of respite care and short breaks for people with dementia outside the UK. A study from the Netherlands described day care offered in a small dairy farm setting with a garden and animals (Schols and van der Schriek-van Meel, 2006). Another innovative service from the Netherlands was an integrated day care service that was offered to both the person with dementia and their carer, both separately and together (Dröes et al., 2004a; Dröes et al., 2004b). In Canada, an action research project involved a 'Balbucbonneuse' who provided a home-based service. This person would stay in the family home while the main carer went away for a rest or a break of, on average, ten-and-a-half days (Gendron and Adam, 2005). A Finnish model of home day care involved hosts who were recruited primarily among childminders, resulting in some mixed groups of children and older people which was felt to promote inter-generational solidarity (Seppänen, 1998). Although examples of similar services were not identified in the UK, we did not conduct a full mapping exercise, so the absence of such services may be an artefact of the methods used to identify services.

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**Table 2. Models of respite care and short breaks**

| <i>Model</i>  | <i>Key characteristics</i>   | <i>Typical settings</i>   |
|---|--|---|
| <b>Day care (outside the home)</b>                    | Emphasis on providing a range of activities in a stimulating environment. Services may be organised by severity, age or ethnic group. Day care provided in hospitals tends to emphasise assessment, therapeutic activities and monitoring (Lawley <i>et al.</i> , 2005; Wilson, 2008). | Specialist facilities; sheltered accommodation; residential homes; community buildings; hospitals; resource centres |
| <b>Specialist respite facility</b>                    | Provision of overnight respite, sometimes in conjunction with day care. Some facilities also provide residential/nursing care.   | Building based  |
| <b>Respite beds</b>                                   | Dedicated respite beds within a setting whose primary function is not the provision of respite care or short breaks.   | Specialist in-patient wards; residential or nursing homes   |
| <b>Home-based support (includes sitting services)</b> | One-to-one support is provided in the person with dementia's own home. The service user can choose whether to spend the time at home, use community facilities (e.g. go swimming) or visit friends.  | Person with dementia's home, range of community settings  |
| <b>Host-family respite</b>                            | The person with dementia stays overnight (or longer) with a paid or volunteer carer.   | Paid or volunteer carer's home  |
| <b>Home day care</b>                                  | Individuals or small groups of people with dementia spend the day with a host family.  | Paid or volunteer carer's home  |
| <b>Short breaks or holidays</b>                       | This may take the form of a traditional holiday or provide opportunities to try new experiences, e.g. outward bound activities.  | Hotels, bed and breakfast accommodation, specialist holiday centres with staff available to provide support         |
| <b>Clubs, interest or activity groups</b>             | Focus on a particular activity (e.g. computing, art) or a particular group of service users (e.g. younger people with dementia).   | Locations vary according to activity, e.g. computer club would typically use the same venue, unlike a walking group |

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Figure 3 illustrates three innovative services from within the UK: home day care, host-family respite and a holiday service.

### **Figure 3. Innovative models of respite care and short breaks**

#### **Home day care**

'Home from Home', developed in central Scotland, is a form of day care that involves a small group of people with dementia meeting in a domestic setting. Volunteers open their homes to three to six older people once or twice a week and, working in pairs, provide person-centred care, emphasising biography, individuality, choice and independence. The whole environment aims to promote togetherness and friendship. Transport and lunch is provided.

(Mitchell, 1999)

#### **Adult placement scheme**

In the 'Time to Share' service, again located in Scotland, the person with dementia (and their carer, if the carer wishes) lives with a family for a short break, or holiday, which generally lasts between 5 and 7 days, and can take place approximately every two months. The underlying principle is that the short break meets the varying needs of each individual person. The 'family providers' offer meals, a bed and companionship. They will take their guests for outings, play board games and generally try to do whatever the person with dementia wishes

(Archibald, 1996)

#### **Short breaks or holidays**

The Calvert Trust in Devon provides activity holidays for people with dementia. Daytime activities consist of canoeing, pony and trap riding, abseiling, the zip wire and swimming in the heated pool and jacuzzi. In addition, trips can be organised to a nearby working farm and to the coast. Residents are encouraged to take part in at least two activities per day. Participation is facilitated by having a nominated care worker for each person with dementia.

(Brooker, 2001)

The detailed telephone interviews with managers of selected services highlighted further diversity in terms of service aims, availability and characteristics of service users.

#### **2.4.1 Service aims**

We asked managers who took part in the telephone focused interviews about the aims of the respite care or short break they provided. Earlier reviews suggest that there is no consensus regarding the overall aim of

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respite care and short breaks (Arksey *et al.*, 2004). Traditionally such services served diverse purposes including to provide carers with a break from caring, to enable the person with dementia to continue living in the community for as long as possible and to prepare carers and/or the person with dementia for the latter's entry to long-term care. Telephone interviews with service managers confirmed the broad range of aims that respite care and short breaks seek to achieve. The majority of participants stated that the service they provided had a number of related aims. While some services prioritised the needs of people with dementia, others saw carers as the primary beneficiaries of services and yet others took a holistic approach, aspiring to meet the needs of the person with dementia and their carer.

The most common aim that participants identified, irrespective of the type of respite care or short break, was to provide the person with dementia with a positive experience (Table 3). This could include offering stimulation, social contact, and/or activities within a friendly, safe and caring environment. The second most frequently reported aim was to give the carer some free time and a break from their regular caring activities. A number of participants said that their organisation aimed to work with people with dementia in a person-centred way. Others focused on promoting the person with dementia's independence, and/or maintaining their skill levels. Other aims identified were enabling the person with dementia to continue to live at home for as long as possible and providing a sense of well-being and inclusion. Day units located within a hospital setting had slightly different aims which focussed on treatment and assessment (Lawley 2005; Wilson 2008).

**Table 3. Reported service aims**

| Aim  | Number of services (participants) reporting |
|--|---|
| Provide a break for the person with dementia that includes stimulating and meaningful activities                 | 12  |
| Provide a break for the carer  | 8   |
| Offer a person-centred service to people with dementia   | 5   |
| Maintain skills and independence of person with dementia   | 5   |
| Enable people with dementia to stay at home for as long as possible  | 4   |
| Take a holistic family approach, and try to meet/balance the needs of both people with dementia and their carers | 4   |
| Improve psychological well-being of person with dementia   | 3   |
| Provide advice and support to carers   | 3   |

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### 2.4.2 Service availability

Participants were asked to outline the opening hours of their service. Many day centres, for example, were open from 8.00 or 9.00 am until 5.00 or 6.00 pm, opening hours which in principle could have helped to meet the needs of carers who were also in paid work. The majority were open weekdays only, but a handful of services were available on a Saturday and/or Sunday. Some services offered shorter hours, for example 10 am until 3.00 or 4.00 pm and/or were only available one or two days each week. These included day care provided outside the home and also home day care.

Services offering the most flexibility were those that were available 24 hours a day, such as resource centres and wards providing continuing care. Resource centres often offered short overnight breaks alongside longer breaks and rolling programmes of respite care and short breaks, for example where the person with dementia spent four weeks at home and then two weeks at the resource centre. By reserving a bed for a person with dementia who lived in the community, wards providing continuing care were able to offer extremely flexible arrangements. This could range from day care with occasional evening or overnight stays to extensive care arrangements. For example, one such service provided day care which fitted around working hours to enable a carer to continue in paid employment. Another service had provided shared care for a younger person with dementia, whereby he stayed in the ward during the week whilst his wife was at work, but spent weekends with his family.

Few services participating in the detailed telephone survey routinely offered emergency respite service for people with dementia. One specialist resource centre had a number of dedicated beds for emergencies. Residential homes and wards providing continuing care were able to offer respite care or short breaks on an emergency basis, if they had spare capacity. One day centre that was situated adjacent to a residential home provided an SOS service on three nights each week, either in dedicated beds or, if these were all booked, using reclining chairs. This service could either be booked in advance (on a regular or occasional basis) or used in an emergency.

The annual entitlement to overnight stays tended to be variable. The minimum amount described in the interviews was four weeks per year. At the other extreme, shared care could result in the person with dementia spending more nights in the service than at home.

### 2.4.3 Service inclusion and exclusion criteria

Many services providing respite care and short breaks stipulated inclusion and exclusion criteria for potential service users. The most common inclusion criteria was having a diagnosis of dementia (or going through this process). This requirement is not always easy to achieve. It can take a long time for younger people with dementia, for example, to receive a dementia diagnosis (Daker-White *et al.*, 2002).

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The two most commonly cited exclusion criteria were: behaviour that challenges, particularly aggression which could have a negative impact on others in a group setting; and mobility problems, for example using a wheelchair, being unable to weight-bear and/or transfer from one chair to another. The level of personal care that an individual needed was an issue for some services, for example, there was no provision for people with incontinence that required bathing facilities at some services. Some services had age restrictions, for example accepting only service users aged 65 and over.

### 2.4.4 Availability of different models of respite care and short breaks

Having identified the range of models of respite care and short break services, we were interested in the extent to which these different models were widely available. It was beyond the scope of the study to collect primary data on the availability of the different models identified. We were, however, able to draw on two sources of data to provide some information on availability. Individual branches of the Alzheimer's Society include details of the services provided on the national website. Whilst not comprehensive (since not all branches have a website) we were able to summarise the models of respite care and short breaks available according to branch websites. A second source of information was the Older People's Mental Health Mapping Exercise (OPMH), conducted in 2006 (Barnes and Lombardo, 2006). Again, the information is not comprehensive, since not all providers of older people's mental health services took part in the mapping exercise. Further difficulties arose in identifying models of respite care and short breaks; the OPMH map included 34 service types, defined using Everybody's Business (Care Services Improvement Partnership, 2005). However, these service types did not readily relate to the models we identified and we relied on the description of each individual service provided by the staff inputting the data. The level of detail provided was variable, and this may have resulted in a small number of misclassifications. Day care outside the home and home day care were combined as it was not easy to distinguish reliably between these two service models. No structured information was available on whether day hospitals saw themselves as providing respite care or short breaks. Where the description of the service explicitly mentioned the provision of day care or respite, day hospitals were included in 'day care'. Otherwise, day hospitals were excluded since they often focus on diagnosis and rehabilitation rather than the provision of respite care or short breaks. In the OPMH mapping exercise, only residential homes with respite beds were included, whereas we had also identified a number of in-patient wards and continuing care wards with dedicated respite beds. It was not clear where such services were classified in the OPMH mapping exercise.

In view of the shortcomings of the data available, it is likely that information from both of these sources underestimates the range and number of services available. Nevertheless, the numbers of each service model available in England according to the Alzheimer Society websites and

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the OPMH mapping exercise are shown in Table 4. This shows marked variation in the availability of different service models and suggests a continued emphasis on traditional, communal forms of respite care and short breaks.

**Table 4. Models of respite care and short breaks available in England**

| Service model                        | Alzheimer Society websites | OPMH mapping |
|--------------------------------------|----------------------------|--------------|
| Day care (including home day care)   | 31                         | 122          |
| Specialist centres with respite beds | 0                          | 5            |
| Residential care with respite beds   | 0                          | 1            |
| Home-based support                   | 33                         | 36           |
| Host-family respite                  | 0                          | 1            |
| Short breaks or holidays             | 7                          | 0            |
| Clubs, interest or activity groups   | 15                         | 10           |

These findings are consistent with previous studies. Research on the impact of the Carers Special Grant indicated that the additional monies available did not result in a significant increase in the range and quality of respite care or short breaks provided (Arksey *et al.*, 2004; King's Fund, 2001; MacGregor, 2000). Variation in local implementation and a lack of attention to developing services for people from black and minority ethnic groups was also reported (Hepworth, 2001). A more recent survey of local authorities in Scotland suggested that the provision of respite care or short breaks is well below recommended levels of provision (Murphy and Archibald, 2004). These authors also explored the range of breaks available and found that one-quarter of Scottish local authorities only provided breaks in residential and/or nursing homes (Murphy and Archibald, 2004).

## 2.5 Policy and research implications

The data presented in this chapter indicate that a range of models of respite care and short breaks are available in the UK, but raise questions about the extent to which a choice of services is available locally. It has been argued that a range of services is required to meet the varied needs of people with dementia and carers (Archibald, 1996; Mountain and Godfrey, 1995). Since 1999, over £1 billion of additional funding has been available through the Carers Grant to stimulate development of support services for carers, including the provision of respite care and short breaks (Department of Health, 1999; HM Government, 2008). Available evidence suggests that innovation and service development has been patchy (Hepworth, 2001; King's Fund, 2001; MacGregor, 2000). Although some service models are well-established in some areas or for service users with particular needs (for example, adult family placement services for people with learning disabilities) there have been difficulties in replicating these models. For

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example, in trying to replicate the 'Time to Share' project (Figure 3), problems were encountered with staff recruitment and uptake of the service (Archibald, 1996). Further understanding of the factors influencing the introduction of innovative models of respite care and short breaks in new areas would facilitate replication of such services. Research is also needed to establish the reasons for the lack of innovation and to understand how best to tailor services to fit the local geographic, demographic and administrative context (Gibson, 1996; Innes *et al.*, 2005; Kelly and Williams, 2007).

Further investment in respite care and breaks is planned as part of the new Carers Strategy (HM Government, 2008). This will include collating innovative approaches to short breaks and dissemination of models of good practice. There may be benefits in conducting a comprehensive mapping exercise to identify the full range of models and their availability. The Carers Strategy emphasises the involvement of carers in reviewing local plans for the provision of respite care and short breaks (HM Government, 2008). Additional information will be needed on the views and preferences of people with dementia to ensure that short breaks provide a positive experience for service users (Social Care Institute for Excellence and National Institute for Health and Clinical Excellence, 2007; Weightman, 1999). Despite the value placed on opportunities for couples to enjoy activities together (Searson *et al.*, 2008; Sheard, 2004; Weightman, 1999), there is a continuing emphasis on services that separate people with dementia and carers, suggesting that this is an area that might require special attention.

The diversity of models of respite care and short breaks, and of the characteristics of services within the different models, adds to the complexity of evaluating the effectiveness and cost effectiveness of such services. Whilst not always identified as an explicit aim of services, the provision of person-centred care was perceived as relevant to all services and therefore represents a unifying theme. This highlights the potential of using person-centredness as the focus of future service evaluations. In order to exploit this potential, a detailed understanding of the meanings of person-centred care is required and this is addressed in Chapter 3. Key findings from the current chapter are summarised in Figure 4.

### **Figure 4. Key findings on models of respite care and short breaks**

- There is a continuing emphasis on traditional forms of respite care and short breaks, with restricted choice at a local level
- Despite considerable investment in respite care and short breaks, innovation and service development has been limited in many locations

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## 3 Components of person-centred care

### 3.1 Summary

This chapter describes the development of a framework of components of person-centred care. A review of the literature on centred care suggested that ten components underpinned the concepts of person-, patient-, family-, client- and relationship-centred care (Hughes *et al.*, 2008). Focus groups and face-to-face focused interviews with people with dementia, carers, front-line staff and service managers identified their perspectives on person-centred care in the context of respite care and short breaks. Thematic analysis of the transcripts of focus groups and interviews confirmed the importance of many of the components identified in the literature and indicated their relevance to people with dementia, carers and staff. This draft framework of components of person-centred care was then 'validated' through analysis of the transcripts of field notes from non-participant observation. The final nine components of person-centred care (see Table 6) are:

- respecting individuality and values
- enhancing psychological well-being
- promoting autonomy
- promoting a sense of shared responsibility
- fostering social context and relationships
- enhancing communication
- meeting physical and personal needs
- developing therapeutic alliance
- valuing expertise.

In this chapter we describe the relevance of each of these components of person-centred care to people with dementia, carers and staff, highlighting any differences in emphasis. The chapter also highlights the multifaceted nature of person-centred care and the need to address all components in order to deliver high quality respite care and short breaks. Data from the focus groups and interviews indicate considerable variation in the extent to which the components of person-centred care are met during respite care and short breaks. This suggests variability in service quality, with even basic physical and personal needs not being met consistently.

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### 3.2 Introduction

The delivery of person-centred care is a central policy objective (Department of Health, 2001a), yet there is little consensus over the precise meaning of person-centred care, (Downs *et al.*, 2006; Edvardsson *et al.*, 2008; Innes *et al.*, 2006; Leplege *et al.*, 2007). It has been argued that person-centred care can be perceived as a value base; a set of techniques for working with people with dementia; or as a synonym for individualised care (Brooker, 2007b). Much of the work on the meanings of person-centred care has focused on concept analysis or literature reviews (Hughes *et al.*, 2008; McCormack, 2004).

The literature review of centred care described in Appendix 1 was conducted as part of another project. We reviewed papers describing the components of person-, client-, family-, patient-, and relationship-centred care (Hughes *et al.*, 2008). In common with others, we found relatively little empirical work in which service users, carers or front-line staff were involved in defining the meanings of centred care (Glynn *et al.*, 2008; Hughes *et al.*, 2008). An overview of the components of person-centred care, based on the key literature, is presented in Table 5. Hughes *et al.* (2008) is used as a reference point for the other literature since it represents the most recent and comprehensive review of the current literature relating to centredness. The other papers summarised in Table 5 have been included because they identify the components of person-centred care highlighted in UK policy (Department of Health, 2001a), or are well known frameworks developed specifically for people with dementia (Brooker, 2004; Brooker, 2007b), or have been developed from empirical data (Glynn *et al.*, 2008; Innes *et al.*, 2006; Nolan *et al.*, 2004; Nolan *et al.*, 2001). In producing Table 5, we are mindful that the elements of person-centred care often have permeable boundaries. For example, in the senses framework (Nolan *et al.*, 2001) the sense of purpose includes 'to exercise discretionary choice' and therefore is related to autonomy. However, a sense of purpose also includes 'opportunities to engage in purposeful activity facilitating the constructive passage of time', which may perhaps fit more closely with an inclusive model of health and well-being. Where elements identified in other frameworks potentially relate to more than one of the components identified by Hughes *et al.* (2008) we have, for simplicity, selected the most relevant component. Each of the senses described in the senses framework (Nolan *et al.*, 2001) is applicable to older people, carers and professionals. A single sense may be interpreted in different ways depending on the stakeholder group under consideration and the context in which it is used. For example, a sense of belonging for older people very clearly relates to the component 'social context and relationships'. However, a sense of belonging for staff relates to the component 'shared responsibility'; and a sense of belonging for carers relates to both of these components. In Table 5 we have focused on the senses framework as applied to older people.

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**Table 5. Components of person-centred care: overview of key literature**

| Author                       | Hughes 2008                              | Department of Health 2001  | Brooker 2004, 2007  | Nolan 2001, Nolan 2004  | Innes 2006  | Glynn 2008   |
|------------------------------|--|--|---|---|---|--|
| <b>Title of framework</b>    |  |  | VIPS framework  | Senses framework  |   |  |
| <b>Source of framework</b>   | Thematic analysis of existing literature |  | Literature review   | Empirical work with older people, carers, front-line staff and managers | Literature review, empirical work with service users and front-line staff | Empirical work with disabled people, front-line staff and managers |
| <b>Components identified</b> | Respect for individuality & values       | Respect for privacy & dignity, recognise individual differences & specific needs | Valuing people<br>Individualised approach, recognising uniqueness | Sense of significance;<br>sense of continuity                           |   | Flexibility  |
|                              | Meaning<br>Therapeutic alliance          |  |   |   | Management of relationships between staff and family members              | A positive approach  |
|                              | Social context & relationships           | Involve & support carers   |   | Sense of belonging  | Supporting family relationships   | Importance of relationships  |
|                              | Inclusive model of health & well-being   | Provide co-ordinated & integrated service response                               | Social environment that supports psychological needs              | Sense of security;<br>Sense of achievement                              |   |  |
|                              | Expert lay knowledge                     |  |   |   | Involving service users   | Learning   |
|                              | Shared responsibility                    |  |   |   | Collaborative/team philosophy   | Setting goals  |
|                              | Communication                            | Listen   | Understanding the world from the perspective of the service user  |   | Skilled communication   | Listening;<br>information  |
|                              | Autonomy                                 | Enable choices   |   | Sense of purpose  | Promotes independence and autonomy  | Choice & control   |
|                              | Professional as person                   |  |   | All six senses  |   |  |

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Two key points relating to person-centred care are highlighted in Table 5. First, the recurrence of certain key themes across studies (e.g. respect for individuality and values). This consistency has been noted in previous reviews (e.g. Hughes *et al.*, 2008; McCormack, 2004). Second, the variation in level of abstraction used to describe components of person-centred care. While some frameworks focus on a concrete, practical level (Department of Health, 2001a; Glynn *et al.*, 2008), others are more abstract (Nolan *et al.*, 2001).

In view of the lack of consensus over the meaning of person-centred care it is not surprising that there are few reliable and valid instruments to measure person-centred care (Crandall *et al.*, 2007; Edvardsson *et al.*, 2008). Before such tools can be developed, a clear understanding of the components of person-centred care is required. This chapter describes the development and validation of the framework of components of person-centred care using a range of methods and involving people with dementia, carers and professionals.

### 3.3 Resumé of method

A full account of the research methods used is provided in Appendix 1. The process of developing and validating the components of person-centred care is summarised in Figure 5. Three sources of data were used in this process:

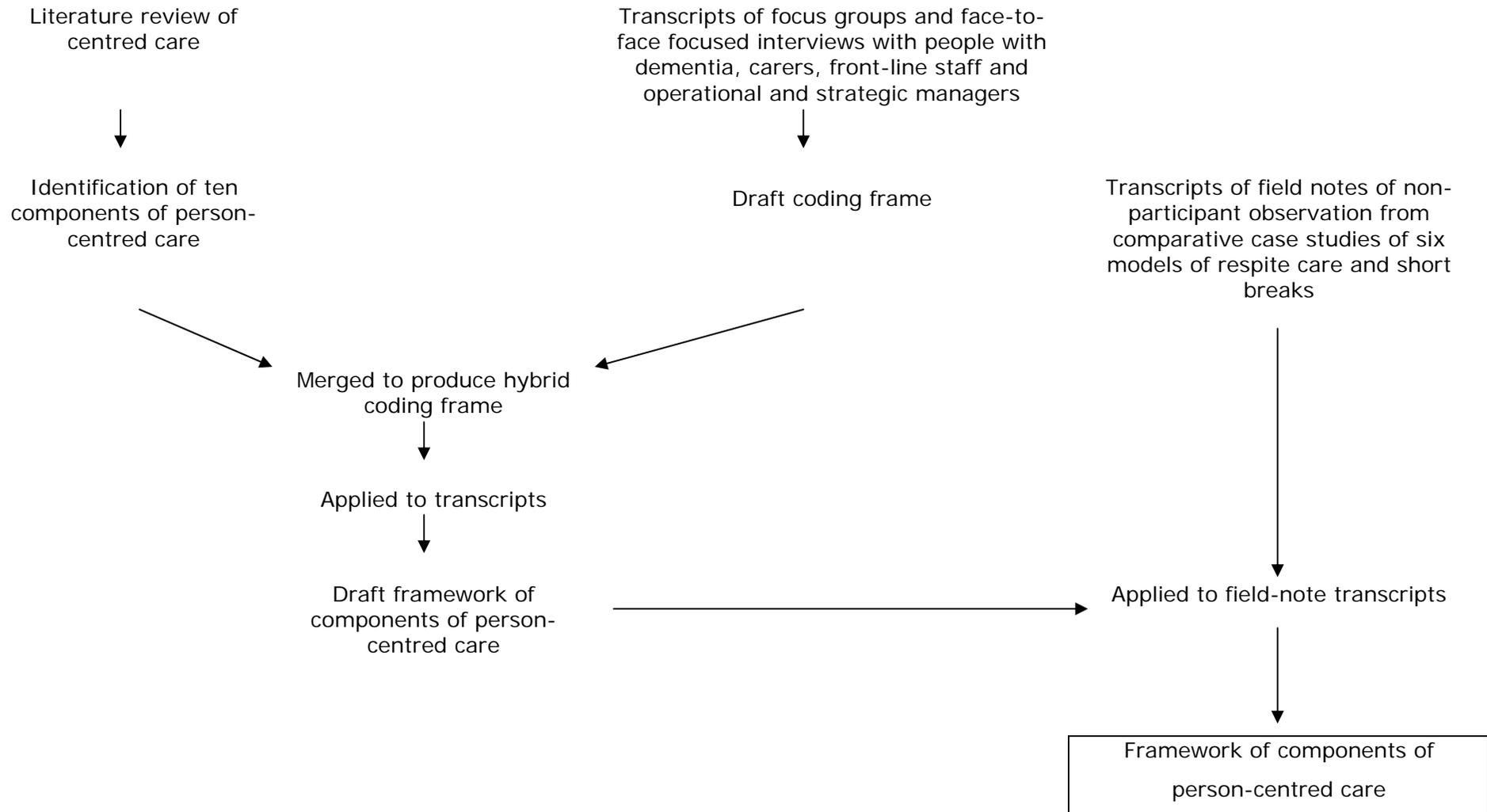
- literature review of person-centred care
- transcripts of focus groups and face-to-face focused interviews with people with dementia, carers, front-line staff and operational and strategic managers
- transcripts of field notes of non-participant observation from the comparative case studies of six services providing respite care and short breaks.

From the literature review we identified a number of components of person-centred care. Although the process of searching and reading the literature started before the focus groups and face-to-face interviews, the literature review was not complete and did not explicitly inform our interview guides. However it obviously influenced our thinking.

The transcripts of focus groups and face-to-face interviews were reviewed by members of the project team in a series of 'data workshops' which produced a draft coding frame. The components of person-centred care identified in the literature review were then merged with the draft coding frame to produce a 'hybrid' coding frame. The transcripts of the focus groups and face-to-face focused interviews were then coded using the 'hybrid' coding frame and a thematic analysis of the transcripts completed. The draft framework of components of person-centred care was then 'validated' through an analysis of the transcripts of field notes of the non-participant observation completed as part of the comparative case studies in six services providing respite care and short breaks.

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**Figure 5. Process of developing the framework of components of person-centred care**



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### 3.4 Framework of components of person-centred care

The draft framework of components of person-centred care comprised nine components of person-centred care. The process of developing the hybrid coding frame (Figure 5), resulted in three key changes to the framework derived from the literature (Hughes *et al.*, 2008):

- the component 'inclusive model of health and well-being' was split into two components, one focusing on physical well-being ('meeting physical and personal needs') and the other focusing on psychological well-being
- the component 'meaning' appeared less relevant within the context of social care and was therefore incorporated into psychological well-being
- the component 'professional as person' was discarded in favour of relating the remaining components to staff, as well as to people with dementia and carers.

The non-participant observation indicated that the framework successfully captured all important aspects of care within the services observed. There were some slight differences in emphases between the data from focus groups and interviews and data from non-participant observation and additional subthemes were identified for some components. The final framework, incorporating these minor amendments, is summarised in Table 6 and described in detail below.

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**Table 6. Framework of components of person-centred care**

| <b>Component</b>                           | <b>Definition</b>  |
|--|--|
| Respecting individuality and values        | Recognises the importance of valuing people as individuals with awareness of differences, values, culture, their unique strengths, needs and rights, including the right to dignity and privacy. The validity of the individual's subjective experience, including self-defined goals, is recognised.  |
| Enhancing psychological well-being         | Recognises the importance of happiness and contentment and the potential to experience well-being in the context of challenging health and social circumstances.   |
| Promoting autonomy                         | This includes the person's ability to make his or her own decisions and to take part in normal activities and routines as desired. Recognises that risk is a normal part of everyday life and promotes a balance of independence, assistance and risk. The principles of self-determination apply to the process of receiving care, so that service users have a say over when and how services are delivered. |
| Promoting a sense of shared responsibility | This suggests the sharing of power, responsibility and control, with mutual agreement on plans and reciprocity, with involvement in decision-making. The possibility of consensus through negotiation, compromise and active participation is encouraged.  |
| Fostering social context & relationships   | Attends to our social nature as people, with an emphasis on relationships, on our situated context of interpersonal, interconnected, mutual interdependence. The importance of seeing the network of relationships as a whole is crucial. The relevance of roles and life stages is recognized.  |
| Enhancing communication                    | This theme encourages communication with careful, sensitive, interactional dialogue, observational skills and authentic contact, including attentive listening. It includes the provision of accessible and unbiased information in ways that are affirming and useful.  |
| Meeting physical & personal needs          | Ensures that the basic physical needs for nutrition, warmth and cleanliness are met in ways that are sensitive and consistent with the other components of person-centred care.  |
| Developing a therapeutic alliance          | Involves the possibility of genuine empathy and unconditional positive regard. Therapeutic alliance is based on respect for personhood, with warmth, trust, openness, care, honesty, the instillation of hope and confidence. The professional facilitates non-judgemental relationships which encourage competency and belonging.   |
| Valuing expertise                          | Recognises the legitimacy and complementarity of the expert knowledge and experience held by all stakeholders. This knowledge is applied to both the care of individual service users and their families and to service and professional development.  |

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The frequency with which each of the above components was discussed in relation to people with dementia and carers is shown in Table 7. This includes coding references from the focus groups and interviews with all stakeholders (i.e. people with dementia, carers, front-line staff and managers).

**Table 7. Coding references to components of person-centred care in focus groups and interviews**

|  | % of coding references relating to: |       |      |
|--|-------------------------------------|-------|------|
|  | Person with dementia                | Carer | All  |
| Respecting individuality & values          | 29.1                                | 8.1   | 21.8 |
| Enhancing psychological well-being         | 20.7                                | 15.8  | 19.0 |
| Promoting autonomy                         | 14.3                                | 17.6  | 15.4 |
| Promoting a sense of shared responsibility | 1.2                                 | 30.3  | 11.3 |
| Fostering social context & relationships   | 12.7                                | 6.2   | 10.5 |
| Enhancing communication                    | 7.2                                 | 11.2  | 8.6  |
| Meeting physical & personal needs          | 8.3                                 | 3.3   | 6.6  |
| Developing a therapeutic alliance          | 5.5                                 | 4.6   | 5.2  |
| Valuing expertise                          | 0.9                                 | 2.9   | 1.6  |
| Total number of coding references          | 911                                 | 482   | 1393 |

Most of the components were also relevant to staff providing and managing services, although this was rarely explicitly discussed. In describing each component, we highlight key subthemes and dimensions and describe how the component applies to people with dementia, carers and staff respectively. We then compare the relative emphasis placed on the component by different stakeholders and in different models of respite care and short breaks. Finally, we draw attention to additional insights from the non-participant observation.

Further examples, drawn from the non-participant observation, which illustrate how each component can be achieved or undermined in relation to the person with dementia, carer and staff, are provided in Appendix 2.

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### 3.4.1 Respecting individuality and values

The themes comprising respecting individuality and values are summarised in Figure 6. Tailoring services to meet individual needs, preferences and circumstances was frequently discussed. Some participants emphasised the importance of allowing people with dementia and carers to define their own needs. An explicit contrast was sometimes drawn between approaches that were systems-based or task-focused and those that focused on individual service users:

‘It’s all centred around the ambulance drivers, it’s all centred around staff, it’s all centred around activities [...] it might not fit in with the work pattern of the person at home, there’s no flexibility, there’s no weekends, there’s no night time’ (WP2 Prof 3, Manager ESMI home providing respite care and day care)

#### Figure 6. Respecting individuality and values

- Tailoring services to individuals

‘there was nothing that was actually for (person with dementia); he was being slotted into places that could possibly cope with him.’  
(Carer 1)

- Respecting cultural diversity

‘And basically it’s being individually person-centric because no two people are going to want the same thing. And just because two Jamaican people are sitting there, doesn’t mean they both have the same needs, it’s the individual’. (DT111. Care attendant co-ordinator of specialist service for black carers)

- Focus on skills and strengths

‘You could talk about it as a celebration of the person and all their fullness’ (SC15. Independent dementia consultant and trainer)

- Recognition of shared humanity

‘I’ve always kept that divide of me and them. But I think person-centred is not seeing that at all, it’s just seeing somebody who’s the same as you, who perhaps needs different things than you do’ (DT304. Manager, NHS day care for people with dementia)

- Dignity

‘Is somebody being put into their night clothes in the afternoon, because you’re not going to have the staff to do it later on?’

(WP2 Prof2. Manager ESMI home providing respite care)

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### ***People with dementia***

Detailed information on the person with dementia's life history, preferences, hobbies and interests was seen as fundamental to individualised care.

There was recognition that valuing individuality should ensure that cultural diversity was respected and that the specific needs and circumstances of younger people with dementia were taken into account. Recognising diversity within black and minority ethnic groups was emphasised by several participants (Figure 6). There was some discussion of the relative merits of specialist or mainstream services for black and minority ethnic groups. In common with some previous studies (Bowes and Wilkinson, 2003; Iliffe and Manthorpe, 2004), improved mainstream services with a good understanding of cultural needs were preferred. The absence of specialist provision for younger people with dementia could result in a lack of attention to their individual needs (Figure 6).

Another aspect of respecting individuality was recognising that the person with dementia could not be encapsulated simply by their diagnosis, symptoms or behaviour. This could be achieved by focusing on the skills and strengths of the person with dementia, not just their deficits and difficulties. Front-line staff and managers (staff) were more likely to raise this issue than people with dementia or carers.

Some staff thought it was important to recognise the common ground shared by themselves and service users (Figure 6). This emphasis on interdependency also situated the person with dementia as an individual who had something to contribute, in addition to needing support.

The right to dignity and privacy was often articulated in terms of 'treating others as you would wish to be treated'. This issue was discussed in the focus group with people with dementia:

- Pwd1 : 'some know better how to treat you than others do'  
 I: 'so how do you like to be treated?'  
 Pwd1: 'like a human being'  
 Pwd3: 'we're still on this earth [...]'  
 Pwd1: 'not like something weird, that's not the same as they are'  
 (Pwd focus group)

### ***Carers***

Similar themes were discussed in relation to carers. Most attention was paid to the first two themes (tailoring services and respecting cultural diversity). Less emphasis was placed on skills and strengths or shared humanity. These aspects of personhood are less likely to be threatened for carers than people with dementia. Nevertheless there were examples of respect being undermined by the use of derogatory terms or negative labelling of carers:

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'A lot of the carers who come through my service have already been labelled as "awkward", "difficult", "hard", "uncaring", and it's really interesting because when I go and see them, that's not my impression at all [.....] They are bereft, desperate, exhausted, ill, depressed, struggling, extraordinarily hard working, incredibly skilled people, but they are just on their knees.' (DT309. Carer Support Coordinator, Social Care Trust)

There was also less emphasis on privacy and dignity in relation to carers. This is likely to reflect the different types of support provided to people with dementia and carers.

Staff often discussed tensions in simultaneously meeting the needs of people with dementia and their carers. This is discussed in more detail in Chapter 4.

### **Staff**

The relevance of respecting individuality and values of staff largely focused on recognising the importance of their work. The undervaluing of care work at a societal level is well documented (Innes *et al.*, 2006). There was recognition that financial remuneration rarely reflected the value of staff work. Other ways of valuing staff were identified, for example, providing the right working conditions, opportunities for training, and listening to and acting on their suggestions for service development. This could sometimes result in mixed messages as illustrated in the following extract from field notes:

'When I arrived at [Service 4] and met the manager, she explained that she had arranged for the officer in charge to come in to talk to me after lunch. I only found out later that it was her day off and she was not being reimbursed for her time'. (Field notes, Service 4: 5-7)

On the one hand this indicates the manager's regard for the officer in charge, since she had identified her as a key individual that the researcher needed to talk to. On the other hand it suggests a complete disregard for the officer in charge's free time and other commitments.

### **Comparative analysis**

Although this component was discussed most frequently overall, it appeared to be far more salient in relation to people with dementia than to carers (see Table 7). Considerably more emphasis was placed on respecting the individuality and values of people with dementia by staff than carers, with people with dementia discussing this component least frequently. Staff also gave more weight to respecting carers than carers did themselves. Respecting individuality and values was perceived as relevant to all models of respite care and short breaks.

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### ***Additional insights from observation***

Examples of each of the themes described above were recorded in the field notes. The main challenges to respecting individuality and values we observed related to the provision of personal care. While this was often negotiated in a sensitive and respectful manner, there were occasions when dignity was undermined:

‘Previously I had noticed that the person with dementia seemed to be sitting on a continence pad, which was spread out on the chair. During the hoisting (to transfer the person with dementia from her wheelchair to the chair), I looked up and had a view of the person with dementia’s bare bottom. She didn’t have any underwear on or indeed anything on her bottom half. When she sat down her bottom half was covered with a crocheted blanket, although it was still possible to see the edges of the continence pad.’ (Field notes, Service 3: 1446-1451)

### **3.4.2 Enhancing psychological well-being**

Enhancing psychological well-being comprised two simple themes: promoting positive emotions (e.g. happiness, engagement, belonging, achievement, hope); and managing or minimising negative emotions (e.g. depression, anxiety, guilt, frustration) (Figure 7). Communication skills were fundamental to the achievement of these themes, since people with dementia did not necessarily communicate their feelings directly, but often expressed them through behaviour. Discussion in the focus groups and interviews tended to focus on practical strategies for achieving well-being.

#### **Figure 7. Enhancing psychological well-being**

- Promoting positive emotions

- Belonging
- Enjoyment
- Engagement

‘I’ve tried some of them and I’m not calling any of them, it’s just that I didn’t fit in. I didn’t feel I fitted in, or that I would fit in. I kept thinking about this place you see and I feel alright here.’ (PwD 3, pwd focus group)

- Managing or minimising negative emotions

- Anxiety
- Depression
- Guilt

‘A lot of carers do feel very guilty, especially when they’ve not had any other services in before, or their relatives have not been supported in any other way. So quite often you will get carers who can be distressed that their husband or wife is having to come to day care because they feel that they can’t cope.’ (DT110. Local manager of national organisation for older people)

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***People with dementia***

The positive emotions given greatest emphasis in relation to people with dementia were: belonging, enjoyment and engagement. Belonging could relate to a sense of community membership (particularly for people with dementia using one-to-one support services), but more frequently related to membership of a group of people with dementia. An advantage of communal services was the opportunity for people with dementia to meet others in the same position and to gain a sense of belonging. This was an important theme for people with dementia.

Within the context of day care, and sometimes one-to-one support, activities were seen as a key strategy in promoting positive emotions. Maintaining existing hobbies was only valued where such hobbies continued to promote positive emotions. In situations where the person with dementia was aware of their loss of skills, previously enjoyed hobbies could become demoralising. In these circumstances, there was an emphasis on identifying alternative activities, or on modifying existing activities in ways that were acceptable to the person with dementia and provided a sense of achievement and engagement:

'He couldn't paint to the standard that he'd painted at when he was well and he didn't want to paint anymore. He wanted to do something entirely different.' (Staff 21, Lead Care manager for older people, Social Services)

While it was recognised that activity holidays would not suit everyone, the opportunities they provided to try new activities and physical challenges were valuable in promoting enjoyment and a sense of achievement for some people with dementia:

'It's very good because it demands something of you, and you have to take risks. You're going to jump on the trip wire or go climbing or whatever. It's about risk and choice and making new friendships. Those are the things that come up time and time again. Then the people go home and say "God, I've done things I'd never thought I'd do" [...] and people have wanted to maintain some of that "I must do things" afterwards. So we do feel that that's been really very beneficial.' (WP2, Prof 1. Social worker, specialist team for younger people with dementia)

Positive emotions could also be promoted through opportunities for people with dementia to make a contribution, rather than solely being 'positioned' (Sabat, 2001) as a service user:

'People are encouraged to be part of it. Everybody helps with the washing up, setting the tables and particularly on a Wednesday we often make our own lunch and everybody's part of that' (DT304. Manager, NHS day care for people with dementia)

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The two major negative emotions discussed in relation to people with dementia were anxiety and depression. A key advantage of home-based services was the minimal disruption caused. The structure and activities provided by some services were seen as beneficial in managing anxiety for some people with dementia:

'part way through the week she started to get very anxious about not being at home, and she is a very anxious lady anyway, but they couldn't provide enough stimulation to keep her distracted. We had to abandon the respite part way through the week because she was so distressed. I think at that stage in the illness if she'd been somewhere where there was more going on, I think she would have been distracted more easily.' (WP2, Prof 1. Social worker, specialist team for younger people with dementia)

### **Carers**

Carers often welcomed an opportunity to be cared for. The differing emphasis on being cared for expressed by carers and people with dementia probably reflects their usual roles. People with dementia value opportunities for reciprocity while carers are keen to have a break from looking after someone else:

'They say it constantly: "It's so nice to sit down", "It's so nice to have a drink made for me", "It's so nice to be able to come and just talk about myself."' (DT309. Carer Support Coordinator, Social Care Trust)

There was less emphasis on promoting positive emotions in relation to carers. Issues of 'belonging' mainly focused on carer support groups, which were seen as a key intervention in facilitating contact between carers and providing opportunities for mutual support.

The most frequently discussed negative emotions in relation to carers were guilt and anxiety. Carers often felt guilty about using services and sometimes felt they had 'failed' or let the person with dementia down (see Figure 7).

Carers' anxiety often focused on the quality of care received by the person with dementia. This anxiety could be alleviated by addressing other components of person-centred care, in particular, through developing a sense of shared responsibility and a therapeutic alliance between staff and the carer. An additional issue raised only in relation to carers was adjustment:

'The carers' needs for adjustment to the relative's increased impairment, not just the instrumental support such as being able to take a break from them, but also how you adjust to changed circumstances.' (SC16. Academic with expertise in dementia care)

Consistent with existing literature (Brodaty, 2007; Perry and Bontinen, 2001; Ryan *et al.*, 2008), there was a strong emphasis on the interdependence of the psychological well-being of the carer and person

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with dementia. It was clear that most carers only valued respite if they were confident that the person with dementia was also having a positive experience:

'because he enjoys going out I can sit back and relax. I mean I wouldn't want him to go anywhere he didn't want to go and he was unhappy, I wouldn't force him into going anywhere at all, because I couldn't have settled with that. Whereas he does enjoy going, so you know as far as I'm concerned that's what I think is a good respite.'  
(Carer 12, carer focus group 2)

### **Staff**

Little was said in the focus groups and interviews concerning promoting positive emotions in relation to staff. There was some recognition of the need to nurture and support staff. The main theme for staff relating to negative emotions was the opportunity to offload after difficult experiences:

'I visited someone in respite last Friday and there were quite a lot of issues about this visit. And as soon as I came out, I rang my team leader and he actually supported me because it was a bit emotional for me as well.'  
(Staff 11, Front-line staff, one-to-one support service, Staff focus group 2)

Avoiding burnout was also discussed. The risk of burnout was perceived to be more likely for individual staff with a person-centred approach in non-person-centred teams:

'everyone will go to that one person, because they know that she or he does a good job [.....] but that one person gets exhausted and then you don't see her anymore. She's in the job for a year, a year and a half and then she goes because she's exhausted.'  
(DT111. Care attendant co-ordinator of specialist service for black carers)

### **Comparative analysis**

This emerged as the second most frequently mentioned component overall, but received more emphasis in relation to people with dementia than carers (Table 7). This component appeared equally salient to all stakeholder groups, both in relation to people with dementia and carers. While similar emphasis was given to enhancing the psychological well-being of people with dementia in all service types, this component was less frequently discussed in relation to carers using day care.

The lack of any discussion about adjustment in relation to people with dementia is surprising. One possible explanation relates to the timing of respite care and short breaks. The majority of psychosocial interventions for people with dementia focus on the period following diagnosis (Husband, 1999; Lees, 2006; Mason *et al.*, 2006; Snyder *et al.*, 2007; Zarit *et al.*, 2004) Respite care and short breaks are often not accessed until considerably later. Alternatively, the lack of discussion of adjustment in

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relation to people with dementia may just reflect the types of services included in the sample.

### ***Additional insights from observation***

The main issue identified through observation related to group dynamics in communal services, and how these could facilitate or undermine psychological well-being.

'All four people with dementia seemed to value one another (and the hostess) and were respectful of each other, for example [...] when either of the two quieter people with dementia said anything, the two more vocal service users immediately stopped talking to listen to what they were saying and then responded in some way.' (Field notes, Service 2: 109-114)

We also noticed the variability in the skills available to staff to manage negative emotions. The focus groups and interviews tended to emphasise the positive strategies used, whereas we also observed the use of punitive or negative strategies to manage challenging behaviour (for example, isolating the person with dementia). The issue of staff skills is discussed in more detail in Chapter 4. There was also considerable variation in the level of activity within different services. While some services emphasised activities as a key means of supporting psychological well-being, in other services activities were given a much lower priority. This could result in long periods of time where people with dementia were left to their own devices. While such periods were valued by some individuals, the lack of structure and activity could result in rising levels of anxiety for others.

### **3.4.3 Promoting autonomy**

Three main subthemes were identified relating to autonomy. The first, which was most commonly discussed, related to choice, the second was concerned with balancing risk, independence and assistance, and the third with access to normal routines (Figure 8).

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### Figure 8. Promoting autonomy

- Choice and control
 

‘most people do tend to go out when we go out on the outing, [...] but there’s no alternative at the moment, because obviously I can’t facilitate the centre being open and going out in the community’ (DT110. Local manager of national organisation for older people)
- Balancing risk, assistance and independence
 

‘they also want you to have a bit of freedom, so unless you do something stupid or out of order, they accept everything’ (Pwd 6)
- Access to normal routines and activities
 

‘Because he’s used to going out when he’s at home, if he suddenly has to stay inside for two weeks solid, it tends to make him quite anxious. In fact last time he was in one of the respite care places, he hit somebody with his walking stick and then another day he threw a cup of cold water over somebody. I honestly don’t think it was him being bad, I think he was just frustrated because he kept saying “I want to go out, I want to go out”’ (Carer 6)

#### ***People with dementia***

At a basic level the extent to which people with dementia had a choice over whether or not to use respite care and short breaks was highlighted. While some people with dementia had been able to ‘vote with their feet’, this option was not always available. This issue over whether or not to use services was an area in which there could be tension between people with dementia and their carers. Managing this tension, and trying to identify solutions that were acceptable to both people, was seen as a key role for service providers:

‘There’s often quite a healthy debate about someone saying they don’t want to come and the carer is more or less saying “well we want them to come [...] we can’t cope if they don’t come”. And then having to be able to explore that area with them’ (DT205. Manager, Social Services resource centre for people with dementia)

Some people with dementia wanted a choice of location for respite care and short breaks. For example, some people who lived in a city would have enjoyed a break in the countryside.

A second level of choice concerned the extent to which people with dementia had a say in the practical delivery of services. This centred on the extent to which they took an active role in choosing how to spend their time during service provision. Where services offered pre-defined activities, the only choice for the person with dementia was to opt out of the activity and even this was not always possible (Figure 8). In other services, people with dementia took a more active role in choosing activities, either by selecting their preferred option from a range presented by professionals or, less

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frequently, by being asked to suggest activities. There were specific issues concerning decision-making in group settings, where it could be difficult to gain agreement or to obtain the views of quieter or less dominant group members. In such situations, decisions were often negotiated between a member of staff and the more vocal member(s) of the group.

A second theme within autonomy related to the balancing of risk, assistance and independence. For staff there was an emphasis on risk as a normal part of everyday life. Balancing independence and assistance was seen as important, but sometimes at odds with the historical nursing focus on 'looking after' patients. Concerns over loss of independence during respite care and short breaks of a few days or longer were raised by several carers:

'I think it might be the slight knock on effect of coming out of respite care. Where he's got constant attention and there's somebody there all the time. And then he came out on Saturday afternoon and I think that sometimes for the first couple of days it's almost as though he's not even capable of switching the kettle on, when normally he may be able to.' (Carer 6)

While some people with dementia were resigned to doing less than they felt capable of, others thought staff struck the right balance of independence and assistance. For some people with dementia there was a sense of security in knowing that staff would set boundaries (Figure 8).

The final theme relating to autonomy was having access to usual routines and activities for the person with dementia. The extent to which this was achieved varied significantly between services. While one service went to considerable lengths to enable a person with dementia to follow his usual routines during a respite stay, opportunities to maintain routines were sometimes overlooked by staff. For example, one person with dementia staying in a specialist resource centre was invited out for a drink by staff and taken to a local working men's club. Whilst he had enjoyed this, he commented:

'I'm not a club person actually, I'm a pub person' (PwD 5)

Staff recognised that there could sometimes be tension between the wishes of a person with dementia to continue with the same routine each week and the desire of staff to introduce variety and new activities:

'I have one chap when we go, and he does the same thing, bump, bump, bump, every week, but he's happy with that. And we do try and make him do something different, so it's better for him, but he's happy with that.' (Staff 10, Front-line staff, one-to-one support service, staff focus group 2)

Examples were given which illustrated how different components of person-centred care were interrelated. For example, lack of access to usual routines could create anxiety and result in challenging behaviour (Figure 8).

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### **Carers**

In relation to carers, choice often focused on the availability of a range of models of respite care and short breaks. The lack of choice, particularly in relation to emergency services, was widely recognised:

'We don't have provision set up for emergency respite, we don't have respite set up for people that is perhaps out of the ordinary, i.e. in terms of out of hours or weekends. Even when people engage with services and there are sitting services or home respite services, usually it's the service availability that dictates when that person can have their three hours' (DT102. Local Dementia Care Services Manager of national organisation for people with dementia)

As expected, the break from caring activities enabled carers to choose how to spend their time. Carers chose to undertake a wide range of activities, including socialising, catching up with jobs, medical and dental appointments, supporting other family members and having some time to themselves. Having a say in the delivery of services for carers primarily centred around issues of the timing and duration of services. Services that fitted around other commitments were valued by carers. The duration of services was important to carers since it affected the types of activities that could be undertaken and the extent to which they felt they had to 'clock watch' during the break:

'It's better for me because the other situation of three hours, half past nine until half past twelve, hardly gave me any time at all. I mean it's not that I want to do a lot, but it's just that bit of time on your own really. I used to go off to town and I would have a coffee or something and then I'd have to be back for half past twelve which wasn't very much time at all' (Carer 2)

Carers often held contradictory views regarding issues of risk and independence. For example, one carer emphasised the importance of helping people with dementia to maintain their independence, but then described how she liked to supervise her mother in the bath, despite explicitly saying that her mother could get in and out of the bath and wash herself. Little attention was given to access to normal routines and activities beyond the need for services to fit in with other commitments. This reflects the different levels of support needed by people with dementia and carers; it is assumed that carers are capable of maintaining routines and activities once alternative care is available. The value placed by carers on freedom and normality have been highlighted in previous studies (Ashworth and Baker, 2000; Nicholas and Patmore, 1999; Nolan *et al.*, 2002). It was suggested that dyads may sometimes need support to maintain typical activities, such as going out together:

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'I don't think it just needs to be tailored that we need to take somebody out of the environment or that we go is so the carer can go out. I think you need to respect the relationship and perhaps provide something for both' (DT304. Manager, NHS day care for people with dementia)

### **Staff**

For staff, autonomy was concerned with the ability to make decisions and to use their own judgement where appropriate. It was also to do with being able to understand how they could use their own individuality in delivering care to people with dementia and dyads. This did not mean that policies were not required, but that there was scope for flexibility in implementation, and a recognition that the process of providing care was not something that could be standardised for different members of staff. Autonomy for staff was usually framed in terms of providing the most appropriate service for people with dementia:

'I think I know what I'm supposed to do and what I'm not supposed to do and don't really break rules but I might bend them' (Staff 22, front-line staff, host-family respite service, mixed focus group 1)

### **Comparative analysis**

This was a relatively unusual component in that it was perceived as being equally relevant to people with dementia and carers (Table 7). Discussion of the autonomy of people with dementia was more frequent in focus groups and interviews with people with dementia than other stakeholders. Previous research has similarly reported a greater emphasis on self-determination and freedom by people with dementia than professionals (Gerritsen *et al.*, 2007). Autonomy of both people with dementia and carers was given similar weight in all service types. Relatively few references were made concerning the autonomy of staff.

### **Additional insights from observation**

A consistent theme that emerged across all communal services was the lack of autonomy around mealtimes. People with dementia often were not offered a choice of meal (although there were sometimes options on the menu, the orders in one service had to be placed before the people with dementia arrived at day care, with the result that staff decided the number of each option to order). All of the meals we observed were plated up by staff; there was no opportunity for people with dementia to serve vegetables or even to decide the quantity of gravy. Although staff clearly used their knowledge of individual people with dementia to decide on appropriate portion sizes (and often seemed to do this very accurately), mealtimes seemed to be an area where there was considerable scope for promoting autonomy:

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'Food was brought from the kitchen already plated and everyone was given the same amount. P305 was concerned by the portion size. She asked if she had to eat it all and said that she didn't want the potatoes. V304 told her just to leave them. However when the P305 became upset by the potatoes on her plate, V304 suggested that she put them on the side plate. This seemed to make P305 more relaxed.' (Field notes, Service 3: 577-581)

### 3.4.4 Promoting a sense of shared responsibility

This component comprised a number of subthemes (Figure 9), the majority of which were more relevant to carers than to people with dementia. Unusually, one of the themes related not just to immediate services, but to the underlying principle of the welfare state and the balance between individual and state responsibilities. There was sometimes a discrepancy between the underlying concept of shared responsibility and **how** staff talked about it. For example, it was not uncommon for staff to talk about 'allowing' people with dementia or carers to be involved in their own care (see Figure 9).

#### Figure 9. Promoting a sense of shared responsibility

- Inclusion in decision making  
'When we talked about person-centred care, they said "look, it's a bit like you lot deciding. We're supposed to be the important people, but you all decide what's best for us anyway"' (DT117. Chief executive of local charity for people with dementia)
- Confidence in the service  
'Then you can go away relaxed knowing that they're being looked after as you would look after them, and they're not just a number 2474, that's your number and you're in that little box down that corridor' (Carer 5)
- Access to support when needed  
'We had a chap who used to come for respite care, but his wife used to have terrible problems at home, and sometimes she would ring you up and say 'I need to get him out of this house'. She said she didn't want him away for extra respite care, she didn't want him away permanently, she just wanted a couple of hours to herself where she didn't have to worry about him' (Staff 2, Manager ESMI home providing respite care)
- Confidence in the welfare state  
'I often wonder what happened if something happened to me. I'm not talking about death, I'm talking about illness, because I don't think it's fair on my children, they work. I'm sorry but the state has got to take over if that ever happens' (Carer 8, focus group 1)
- Opportunities for shared care  
'It's allowing the carer to feel involved. This is the person who has lived with someone for x number of years. It's to ensure that they are not excluded from the process that they are going through' (DT104. Local day care manager of national organisation for people with dementia)

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### ***People with dementia***

Involvement in decision-making and confidence in the service, were the main themes articulated in relation to people with dementia. The marginalisation of people with dementia from decision-making in the context of medical care has been documented (Hughes, 2001; Shah and Dickenson, 1999; Silberfeld *et al.*, 1996; Woods and Pratt, 2005). There was some evidence of similar barriers to achieving shared responsibility in social care services (Figure 9). This was an area where practice was variable. Some professionals emphasised the importance of open discussion with the dyad. In contrast, in other services people with dementia were not always involved in review meetings or in even deciding whether or not to participate in such meetings:

‘If we feel from discussions or from assessment that the client is able to participate without feeling anxious, disorientated, then they can be involved’ (DT104. Local day care manager of national organisation for people with dementia)

A sense of trust or confidence in the service was also seen as important for people with dementia. This often related to opportunities to become familiar with members of staff and the setting prior to formally using the service, and applied to all types of services, not only those based outside the home.

The issue of reciprocity was raised on several occasions and enabling people with dementia to take the lead in activities could be an example of sharing responsibility. For example, staff at one day centre described how a person with dementia stepped in to call the numbers in a game of bingo when staff were taking care of another service user who was suddenly taken ill. Opportunities like this were relatively rare, but could highlight the skills retained by people with dementia and provide a sense of achievement.

### ***Carers***

While there was evidence that people with dementia sometimes felt that their views were not heard, there was no evidence that carers did not have enough involvement in decision-making. This suggests that the management of the tensions within the dyad tends to prioritise carers’ wishes over those of the person with dementia. This was explicitly acknowledged by some services, with some staff expressing concern over the lack of emphasis given to the views of the person with dementia.

For respite care and short breaks to be a positive experience for the carer, a sense of confidence or trust in the service was essential. There was recognition that a trusting relationship with the carer was often a prerequisite to service use and that developing such relationships could take a considerable period of time. Some carers emphasised the importance of the quality of care provided being of a similar standard to the care they provided.

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A sense of shared responsibility for carers also implied a sense of not being isolated in their caring role, but having access to support to help with problems or to provide care in emergencies. Some services were able to fulfil this role (Figure 9), while others saw it as outside their remit.

A related, but slightly different theme, was confidence that the welfare state would provide care in an equitable and fair way should the need arise (Figure 9). This included a feeling that carers should not suffer financially because of their role:

'I think there should be something within the funding of the NHS which differentiates between the type of respite care that we're talking about. Because there's respite care when I might go fishing for a fortnight and there's respite care when I'm unavoidably taken ill. And the system doesn't differentiate between the two and it should. I don't see why [wife] and I should be faced with a tremendous expense just because I had the misfortune to become ill' (Carer 7)

A final aspect of shared responsibility concerned the involvement of carers during respite care or short breaks away from home. Some carers wanted to maintain contact with, or continue to provide care for, the person with dementia. The extent to which this was possible varied between services. Traditionally, respite care and short breaks have focused on relieving carers entirely of their responsibilities. Many professionals, however, recognised that it could be difficult for carers to withdraw completely from providing care (Figure 9).

### **Staff**

In relation to staff, shared responsibility centred on access to support from colleagues and managers. Access to senior staff when support was needed, including out of hours for staff who worked shifts, was valued. Opportunities to share problems and discuss possible solutions could be informal, a part of formal supervision, or could be integrated into regular team meetings:

'I mentioned earlier on about this gentleman came in and he didn't seem to be able to keep his hands to himself, and part of the team wanted to talk about it: "Perhaps he shouldn't be coming" and other team members were saying "No, no, no, we should be able to deal with this and how can we do it?"' (DT205. Manager, Social Services resource centre for people with dementia)

### **Comparative analysis**

This component was rarely discussed in relation to people with dementia, but was the most frequently discussed component for carers (Table 7). There were no differences in the frequency with which this component was discussed in relation to people with dementia by different stakeholders or in the context of different types of services. In contrast, a sense of shared responsibility in relation to carers was given more emphasis by carers than professionals. It was also discussed slightly more frequently in the context

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of home-based services than either day care or overnight respite services. Shared care was particularly emphasised in services providing overnight respite stays, either in wards providing continuing care or specialist resource centres. In contrast, there was relatively little discussion of shared care in day care services; this is likely to reflect in part the different clientele using the different types of services. Within day care services, the role of carers was often viewed primarily as the provision of information.

### ***Additional insights from observation***

Observation added little to the description of shared responsibility derived from the focus groups and interviews. This was perhaps not surprising since we did not observe activities such as assessment or review meetings which offer opportunities for shared responsibility for people with dementia. We observed some examples of shared responsibility in relation to carers and staff, and these reflected the themes described above:

‘P303 had not gone on the trip (possibly because she was not feeling very well.) I overheard V306 saying that C303 had only agreed to go on the trip, if she promised to stay with P303 the whole time.’ (Field notes, Service 3: 1403-1404)

### **3.4.5 Fostering social context and relationships**

The way in which a diagnosis of dementia could lead to loss of relationships and isolation for both people with dementia and their carers, was emphasised by a number of participants. Three themes relating to social context and relationships were identified (Figure 10).

**Figure 10. Fostering social context and relationships**

- Maintaining existing social networks
 

‘We help them very often to keep the family links going, you know, far-flung families and helping them keep in touch and remember birthdays and grandchildren and all these kinds of things.’ (DT106. Local branch manager of national organisation for people with dementia)
- Developing new relationships
 

‘Well the lasting benefits are the fact that we enjoyed it; it’s the camaraderie, the friendship and the get together in the common room and in the dining room in the evening, and in the morning, breakfast time, because we’re all the same’ (PWD 6)
- Maintaining community links
 

‘a few years ago they used to go and have a round of golf with somebody. He was very impaired in every other aspect of his life except, he had a frontal lobe dementia, he still had this ability to play a round of golf. He’d lost the social skills and he didn’t understand to wait at one golf, one bit you know for anybody else that went but he could still do that and again it gave him some enjoyment and it gave his wife a break’ (WP2, Prof1. Social worker, specialist team for younger people with dementia)

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***People with dementia***

Maintaining existing relationships was particularly relevant to one-to-one support services both in terms of maintaining face-to-face contact and keeping in touch with friends and relatives who did not live locally (Figure 10). At the same time, there was recognition that sometimes the existing social circle needed expanding, particularly where there were restricted social networks, and a lot of time was spent with one other person. Variety was seen as important, but it was the quality of the relationships and genuine caring that was valued most:

‘Well there’s somebody to talk to, isn’t there? When you’re on your own, mind I’ve got my son, but he’s not much company’ (PWD4, people with dementia focus group)

There was some discussion of the relative merits of specialist or integrated services for people with dementia. Some participants felt that integrated services offered a broader range of experience:

‘I would want a lot more activity ideally centred around people with dementia and people who are old having the company of a range of people of different ages, and giving them a wider perspective rather than narrowing down their opportunities and their experiences in a way that sometimes I think services move towards. Grouping particular people together, putting them in particular kind of boxes and particular situations.’ (Carer 4)

Other participants valued the acceptance and sense of shared experience that characterised specialist groups. One person with dementia who had been on several outward bound holidays emphasised the sense of camaraderie experienced (Figure 10). It was relatively rare for service users to meet up outside services. Although one younger person with dementia made friends through a day centre, it proved difficult to sustain these relationships in the community.

The issue of maintaining links with the local community was also discussed. For buildings-based services, community involvement was fostered through both trips out and inviting visitors into the service. However, there was a recognition that going out as a large group often positioned people with dementia as ‘onlookers’ rather than community members. In contrast, informal, individual trips either to local shops or community resources could foster a sense of community membership:

‘What I would like to do is start using the community more and for clients to actually access hobbies and interests that they like individually.’ (DT110. Local manager of national organisation for older people)

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### ***Carers***

The issue of social context and relationship for carers often overlapped with promoting psychological well-being. For example, there was an emphasis on support groups which were seen as reducing social isolation and also providing an opportunity for carers to share experiences with others in a similar situation:

'You can talk about anything, and no-one is judging you and you can say how horrible things have been.' (Carer 9, Carer focus group 1)

In addition to providing a welcome break from caring, services could also support the dyad by providing people with dementia and carers with something to talk about. Some dyads had historically always done activities together and were keen to continue this pattern. Opportunities for couples to do activities together, rather than being separated, were highlighted by several participants. Outings with other people affected by dementia were attractive to some carers who welcomed the relief of socialising with others who had some understanding and experience of dementia:

'if you're like me and you worry about annoying other people or getting in their way or something like that, it would be a good thing to have people there with you who you know are going through the same sort of things as you and would understand and you wouldn't have to be thinking, "oh dear they'll be thinking he's this, he's that". We'd all be in the same boat' (Carer 11, focus group 2)

### ***Comparative analysis***

This component of person-centred care received most emphasis in relation to the person with dementia, particularly by people with dementia. There was less emphasis on this component in one-to-one support services than in day care or overnight respite. Less attention was paid to social context and relationship for carers (Table 7). There were no differences in the frequency with which this component was discussed in relation to carers, either by different stakeholders or in the context of different types of services. This component did not apply to staff in the same way as most of the other components. Although work often provides company and social relationships for staff, the purpose of work is not to enable staff to broaden their social circle. In relation to staff therefore this component centres on their role in fostering social context and relationships for people with dementia and carers.

### ***Additional insights from observation***

One of the issues highlighted in the observation was the mismatch between the description and observation of events. For example, the manager of one service described how the minibus called in at a local supermarket to collect bread and milk on the way to the day centre. This could potentially foster social inclusion by involving people with dementia in typical routines

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and activities. However, observation on the minibus revealed that the people with dementia sat on the minibus in the car park while a member of staff went to buy the bread and milk. The observation also confirmed the importance of social contact and relationships to people with dementia:

'While we were waiting for a member of staff to start the activity, there was general discussion about how the group members liked to be happy and to have a laugh ("it's better than crying") and how when they got together they liked to chat. This seemed to be a recurrent theme as it came up again during the activity and in the lounge after lunch' (Field notes, Service 5: 24-28)

### 3.4.6 Enhancing communication

The interconnectedness of the different components of person-centred care becomes particularly clear when considering communication. Clearly communication underpins the successful achievement of many of the other components of person-centred care. Nevertheless we have chosen to keep it as a separate component in view of the fundamental importance of communication in providing person-centred care. A number of separate issues relating to enhancing communication were identified (Figure 11).

#### Figure 11. Enhancing communication

- Understanding behaviour as communication

'We are working with people who may have difficulty in expressing their needs. They may have difficulty in expressing how they want to do something or what it is that they are feeling or what it is that they are doing. So quite often we get confused behaviour or confused speech and what we have to try and do is discover what's the meaning behind the words or the actions' (DT113. Local manager of national provider of housing, care and support services for older people)

- Strategies to facilitate communication

'The OT there wrote a little note; put it in my mum's bag, to tell me what my mum had been doing that day. It meant so much to me that I got feedback. I knew what she had been doing, so therefore I was able to talk to her about what she had been doing that day' (Carer 3)

- Tailoring communication style

'Oh she's magic her. She's blunt and she's forward, there's no beating around the bush, well she calls a spade a spade and I like that attitude. Lay your cards out, then you know how the land lies'. (PWD5)

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### ***People with dementia***

Considerable emphasis was placed on the need to understand the behaviour of people with dementia as a way of communication (Figure 11).

Development of successful communication strategies was seen as a key role of staff, and the value of detailed knowledge of the person with dementia in identifying appropriate approaches was emphasised:

'She didn't want her dad to go into care, but the trouble was that he would often wake up quite early in the morning, which was a habit. As a driver, his routine would be: go down to the depot; collect his lorry; and go off and do his deliveries. And that's often what he would do, and he forgot that he'd retired. He'd sometimes go out with no clothes on, the neighbours would be up in arms, there'd be sort of a riot really, the police would be involved and all the rest of it [...] she said "my dad was such a stickler for the highway code, he wouldn't go through a red light, he'd just obey the rules of the road, he was just so good". So the strategy that worked was putting a no entry sign on the back of the front door. He'd come down and then, you can't go through here that's what it says, so he would turn back, so he didn't actually go out.' (DT205. Manager, Social Services resource centre for people with dementia)

The importance of tailoring communication style according to individual people with dementia and their relationships with staff was also highlighted. Consistent with the emphasis on respecting individuality and values, a range of styles were seen as appropriate in different contexts and with different individuals. One person with dementia described how he particularly liked the communication style of one member of staff (Figure 11).

### ***Carers***

Whilst the issue of interpreting behaviour was most frequently raised in relation to people with dementia, the same techniques were sometimes applied to carers' behaviour. In the following extract, a service manager had been asked to intervene because a carer would not let staff into the house to help his wife:

'When I went to see the carer about this, he was saying "well I feel like I'm being sidelined, there are all these people coming to the house, it's like a circus, one minute so-and-so's coming in and somebody else is coming to do this". And he felt completely overwhelmed [...] his way of protesting was to start sabotaging what they were doing, so he would lie in bed and they wouldn't be able to get in the front door and things like that. But it was all resolved, but it was about them taking him seriously.' (DT205. Manager, Social Services resource centre for people with dementia)

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While most strategies focused on communication with people with dementia, there was also some attention to identifying effective ways of communicating with carers. For example through notes placed in the person with dementia's pocket or through text messages. These strategies were a simple way of letting the carer know what the person with dementia had been doing and were a way of enhancing communication within the person with dementia-carer dyad (Figure 11). There was little discussion of tailoring communication style to carers.

### **Staff**

Relatively few comments were made concerning communication between professionals, with the main focus relating to strategies for sharing information between team members:

'What systems do they have in place for saying that Mrs X doesn't like sugar in her tea, and Mr Y doesn't like tea at all and always has coffee?' (Carer 1)

### **Comparative analysis**

Enhancing communication was raised in relation to all stakeholder groups, although it was given more emphasis in relation to carers than people with dementia (Table 7). Staff placed more weight on communication in relation to both people with dementia and carers than other stakeholders. As would be expected, enhancing communication was raised in discussions concerning all models of respite care and short breaks, confirming the relevance of this component regardless of the characteristics of services, though there were some differences in emphasis. Communication in relation to people with dementia was discussed most frequently in the context of one-to-one support services. In contrast, communication in relation to carers was given most emphasis in discussion of day care.

### **Additional insights from observation**

We observed many examples of good communication skills being used by staff. There was some variability, however, in the extent to which the behaviour of people with dementia was understood as a form of communication:

'A further example was then given of a female client whose moods were very volatile. Both members of staff described how difficult it was to 'get round her' and to identify 'tactics' which worked for her. Again an example was given of difficulties arising during personal care: "you try and have her go to the toilet, pulling her knickers down or helping her, and she would sort of freak out"' (Field notes, Service 4: 187-190)

One factor which enhanced communication was staff knowledge of the local area. On several occasions we observed how staff were able to use their local knowledge to facilitate communication, for example, to help people with dementia remember activities and events from the past.

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### 3.4.7 Maximising physical and personal well-being

Whilst the value placed on this component of person-centred care was clear, there was also recognition that meeting physical needs alone was not sufficient:

'We're looking after the person. We are making sure they are fed and watered and changed if they need to be or whatever. I know there's nothing wrong with that in one way, but it doesn't, it minimises the potential of the person, certainly with dementia and it may also feed into more negatives to be attached about dementia "well they can't do anything", "there's nothing you can do", you know, "you can't do anything with this person"' (DT205. Manager, Social Services resources centre for people with dementia)

Four separate themes relating to this component were identified (Figure 12).

#### Figure 12. Maximising physical and personal well-being

- Managing basic physical & personal care needs  
'So I'm looking for him to be well looked after, kept clean, all his daily care you know? I hope they shave him every morning, he's a very smart man, wears tailored clothes [...] I take pride in how he looks because that's how he's always looked.' (Carer 8, Carer focus group 1)
- Meeting sensory needs  
'Sometimes she hadn't got the hearing aid in or sometimes she might have it in and it would be left in all night, and her ear would be sore, and then they would say "she has not been communicating today"' (Carer 3)
- Management of other medical conditions  
'At present we're actually supporting a gentleman with his wife who comes on a Wednesday and stays the full 24 hours because he's having some chemo treatment at the moment. And he's said that he's found that so invaluable because she comes in on a Wednesday at half past nine [in the morning] and then he picks her up after his treatment on a Thursday about half seven at night.' (DT201. Manager, Social Services extended day care for people with dementia)
- Compliance with health & safety regulations  
'We couldn't ignore the fact that he [the carer] had a bad back. We'd observed how he used to put her [the person with dementia] into the car and it wasn't safe for him and it wasn't particularly safe for her. We got the physiotherapists involved, we tried to get different sorts of implements to help him. But he went down one weekend with a real serious back problem, so the transport then became an issue. And what we said was "you can't bring your mum in because of the danger to her and the danger to you"' (WP2, Prof 2. Manager, ESMI home providing respite care)

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***People with dementia***

Aspects of physical and personal well-being discussed only in relation to people with dementia included: personal hygiene; nutrition; exercise; and sensory needs. The implicit assumption was that carers and staff were able to manage these needs unaided (or, in the case of carers, were the responsibility of other services). All of these needs were valued by carers, who often emphasised personal hygiene. This was sometimes due to their own difficulties in providing such care but sometimes reflected their desire to see the standards of the person with dementia maintained (Figure 12).

An important benefit of services for carers who did not live with the person with dementia related to the provision of adequate nutrition. Such carers were often unsure of the quality and quantity of the person with dementia's diet:

'one big concern is that she won't remember to eat, and we just don't know how well she does that when we are not backing it up, but I fear that the diet would be very badly neglected if she didn't have a lot of back up from various quarters.' (Carer 4)

The issue of exercise was raised by only one carer but was clearly a significant issue for younger people with dementia and highlighted the difficulties in meeting the needs of fitter and more energetic people with dementia in the context of services catering predominantly for older, frailer people. Another key issue, again raised by only one carer, concerned ensuring that the sensory needs of people with dementia were met (Figure 12).

The management of concomitant medical conditions was also highlighted. This could take the form of direct provision of care, or helping the person with dementia to access other services which could provide appropriate care. Failure to recognise and treat physical symptoms could lead to significant distress:

'but the unqualified staff didn't know really. I mean they hadn't got a hoist so they were transferring her from chair to wheelchair to chair and she was screaming because at that time she was in a lot of acute arthritic pain but she was never put on pain killers, she was never on anything. [...] I now realise that being at home for a while she has been on those anti-inflammatory tablets, and what a difference they have made to her, she is not in pain now.' (Carer 3)

The issue of a secure environment and opportunities to go outside was raised by several carers. While some carers had experience of the person with dementia going missing during respite care and short breaks, others felt that people with dementia needed opportunities to go out for walks rather than being confined. This highlights the need for flexible policies which focus on the needs of individual people with dementia. The importance of support and supervision during activity holidays was also recognised:

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'You can go out, whether it's walking or climbing or abseiling on the cables. They've certainly got the equipment there, and they've got the back up and they've got safety people at the critical areas. So I think it's very good. It's a challenge, but it's properly done.' (PWD 6)

### **Carers**

Discussion of the physical and personal well-being of carers focused on two main areas: the management of carer's medical conditions and health and safety issues. Both carers and professionals acknowledged that carers tended to neglect their own health:

'I mean sometimes what happens is you go and pick up the client and the staff will notice that the carer is not very well. And they'll sit and talk to the carer and say "is there anything we can help?" and it may be taking them a hot meal, it may be accessing and saying to their GP we are a bit concerned about Mrs so and so, and we feel they may need a visit, because we know the elderly don't always want to bother'. (DT201. Manager, Social Services extended day care for people with dementia).

Providing a flexible service to enable carers to attend hospital appointments was another aspect of this component of person-centred care. Often this centred around outpatient appointments, but one service described how they supported a carer undergoing chemotherapy by providing overnight care in addition to day care (Figure 12).

Issues regarding health and safety often centred around carer practices perceived as unsafe by professionals (Figure 12). As illustrated, while services often tried to address the problems, this was not always successful.

### **Staff**

During the focus groups and interviews little attention was paid to the physical well-being of staff beyond issues relating to health and safety regulations.

### **Comparative analysis**

Overall, this component of person-centred care received relatively little attention, being discussed most frequently in relation to people with dementia (Table 7). Carers placed more emphasis on physical and personal well-being than other stakeholder groups, both in relation to the person with dementia and themselves. Issues relating to the physical and personal well-being of the person with dementia were more likely to be discussed in the context of overnight respite services. Issues relating to the physical and personal well-being of carers and staff focused predominantly on health and safety concerns.

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### ***Additional insights from observation***

The quality of staff attention to physical and personal well-being was variable, confirming that this aspect of care cannot be taken for granted. Not all staff seemed to have insight into how it might feel to be dependent on other people for help with personal care. However, others were thoughtful and sensitive when providing personal such care:

‘There were some subtle episodes of helping people with dementia to the toilet. One person with dementia [...] seemed to have no problems with being helped to the toilet by the volunteer. A second person with dementia went to the toilet alone and I noticed two volunteers exchanging glances and one commenting that he would be alright. A third volunteer then came over and quietly approached another person with dementia to ask whether she needed to go to the toilet’ (Field notes, Service 3: 1273-1278)

### **3.4.8 Developing a therapeutic alliance**

Three main themes relating to developing a therapeutic alliance were identified (Figure 13): the need for a non-judgemental approach; the importance of relationship building; and the process of negotiating boundaries.

**Figure 13. Developing a therapeutic alliance**

- Empathic and non-judgemental approach
 

‘She puts up with anything he does. He [person with dementia] likes dancing and they’ll be in a queue waiting for their coffee, and there’ll be music, and he gets hold of her handbag, puts it down and starts jiving with her.’ (Carer 8, Carer focus group 1)
- Investing time in relationship building
 

‘I always get butterflies, even to this day, when I’m walking up somebody’s path for the first time and their impression of me and the remarks I get, “what’s this bloke doing here?” you know. You have to work on it, you have to just show them total trust and honesty and I can honestly say in seven years that I’ve been doing it, we’ve had moments but we’ve always worked through them.’ (Staff 8, Front-line staff, one-to-one support service, Staff focus group 1)
- Negotiating boundaries
 

‘On the other hand the person with dementia feels slightly bad that I’m doing personal things for her, taking her to the toilet, because we have a kind of friendship really, and so she looks at me more of somebody who visits her as a friend, and then she feels slightly awkward that I take her to the toilet.’ (Staff 9, Front-line staff, adult family placement scheme, Staff focus group 2)

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### ***People with dementia***

One aspect of being non-judgemental related to the ability of staff to fully engage with the person with dementia, sometimes in unconventional ways (Figure 13). The process of developing relationships often took place over a period of years. Continuity of care and a willingness to work through problems were important factors in developing a therapeutic alliance (Figure 13).

While these close relationships were valued by all participants, tensions could arise. For example, one carer expressed relief when new support workers were introduced when the usual member of staff was unwell:

'I was quite pleased with that. In fact I think it was a good thing that she did have a change because she was getting too attached' (Carer 7)

Although he reported that his wife got on with all of the support workers, it is unclear whether his wife shared his relief or was disappointed at the loss of a significant relationship.

### ***Carers***

The importance of an empathic approach to carers was emphasised:

'You get relatives who maybe only come in once in a blue moon [...] and I'll say "don't judge them, because you don't know what's gone on before." And it's really hard if you've gone say six months and you haven't been in in six months and every month that passes it becomes harder to come in' (WP2, Prof 2. Manager, ESMI home providing respite care)

Staff stressed the importance of relationship building with carers; failure to develop a positive relationship was perceived as a significant barrier to person-centred care (see Chapter 4). The success of relationship building was illustrated by the fact that a number of carers participating in the study described how professionals sometimes felt like friends or family members:

'The thing that makes it work is that it's always the same support worker, so you can build up a relationship and that. They're not seen as a support worker, I don't think, I think they're just seen as a friend.' (Carer 1)

While carers generally valued the close relationship between the person with dementia and members of staff, there could sometimes be tensions, if the relationship was perceived to challenge the closeness between the dyad:

'If the primary carer is envious of the relationship that our carer has got, they have to be aware of the dynamics, and work with the dynamics so that everybody is happy, otherwise it undermines what the service user gets out of it' (DT207. Senior Practitioner, Adult Family Placement Service)

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***Comparative analysis***

This component was discussed relatively infrequently, but appeared to be equally relevant to people with dementia and carers (Table 7).

Professionals placed less emphasis on therapeutic alliance with people with dementia than other stakeholders. In contrast, professionals were most likely to discuss therapeutic alliance with carers. A similar emphasis was given to developing a therapeutic alliance with people with dementia in all service types. Not surprisingly, detailed examples and comments relating to therapeutic alliance were most frequently made by professionals working in services such as adult family placement, one-to-one support services or wards providing continuing care which had offered extensive shared care to people with dementia and their families.

There was no discussion of staff as the recipients of therapeutic alliance. This would be anticipated since the role of staff is to facilitate therapeutic alliance with people with dementia and carers, rather than to develop therapeutic relationships between themselves and their colleagues and/or manager. Although the issues of valuing and supporting staff were discussed, these have been incorporated into other, more appropriate, components such as respecting individuality and enhancing psychological well-being.

***Additional insights from observation***

Most of the examples of therapeutic alliance observed concerned light hearted joking and laughter, which demonstrated the close relationships between people with dementia, carers and professionals:

‘Throughout the whole time I was present, there was continuous banter, teasing, joke telling, serious and fun conversation, making fun of themselves, the hostess and close relatives’ (Field notes, Service 2: 123-125)

It is not surprising that we did not observe many more serious instances of therapeutic alliance, since these are likely to take place in private, rather than in the public arena in which observation took place.

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### 3.4.9 Valuing expertise

Three distinct, but complementary, themes were identified: expertise relating to the individual person with dementia; services; and dementia (Figure 14).

**Figure 14. Valuing expertise**

- Expertise relating to the individual person with dementia
 

‘You can ask the person with dementia, and of course that’s the right thing to do. But you don’t necessarily get a coherent answer at all. The carer is usually the vocal expert on the care needs of the service user’ (DT112. Director of local branch of national organisation for carers)
- Expertise relating to services
 

‘We have [...] guest led meetings where we will sit down and they tell us what they think should be going on and what they think they don’t like and so everything is discussed and any new ideas or any requests that are put forward, we try and provide’ (DT101, Local branch manager of national organisation for people with dementia)
- Expertise relating to dementia
 

‘We were getting high rejection rates, and a high number of complaints from workers within those services about people living with the experience of dementia, and then acting as advocates for people we began to uncover there was an issue around education and training, and so we identified that there was a need for staff to understand more about dementia, not just from the medical model point of view about ‘what is dementia?’ but more importantly how it impacts on the lives of the people who are living with that experience’ (DT102. Local Dementia Care Services Manager of national organisation for people with dementia)

#### ***People with dementia***

Somewhat surprisingly, there was very little discussion of the expertise of people with dementia either about their own lives or about dementia. Discussion relating to the expertise of people with dementia focused mainly on their views and experiences as a service user. The involvement of people with dementia in service review and development most frequently took place through regular meetings (Figure 14). People with dementia were also sometimes involved in making decisions about how to spend money obtained through fund raising:

‘That is going to purchase a digital camera because that’s what the members wanted. So that when they’ve taken a photograph, they can go onto the computer and download and run the photographs off themselves. So they are quite specific about what they want to use the money for’ (DT110. Local manager of national organisation for older people)

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### **Carers**

Carers were generally seen as the primary source of expertise on the individual with dementia, particularly regarding the background and characteristics of the person with dementia. Although available evidence suggests that carers cannot simply be treated as unbiased proxy informants (Loewenstein *et al.*, 2001; Neumann *et al.*, 2000), there was a strong emphasis on relying on carers as key sources of information. At the same time, there was some recognition that the preferences and tastes of people with dementia can change, and therefore might be different from information previously reported by carers:

'I remember taking somebody strawberry picking, and I took him home and his wife said [...] "oh he's never liked strawberries." I said "well he does now." You know and tastes and things change for people with this illness' (Staff 8, Front-line staff, one-to-one support service, staff focus group 1)

In addition to evaluating services, carers were also occasionally involved in service development at a more strategic level. However, the difficulties of achieving meaningful involvement were recognised:

'Carers have to be involved in everything that we are doing, and I see an awful lot where they are not. There's a bit of talking with them, they are invited to go on a committee or something, but the voice of carers really isn't heard much and I think we really need to hear it' (DT304. Manager, NHS day care for people with dementia)

### **Staff**

Expertise in dementia was the most commonly discussed theme in relation to staff. Although some non-specialist services had a good knowledge of dementia, this was not always the case:

'One of the problems with the respite place [...] they were set up to help train people [with head injuries] to get back into society and they couldn't seem to get out of that mindset with [person with dementia]. You know they kept trying to modify his behaviour.' (Carer 1)

The value of bringing staff together from different services to enable them to share experiences and learn more about one another's work was recognised by one professional involved in providing training. Participants involved in training professionals in person-centred care emphasised the importance of personal reflection and awareness in developing an understanding of person-centred care. There was a strong emphasis that learning about person-centred care was not simply about acquiring knowledge and techniques:

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‘Our whole belief system is that person-centred care is not something you do. It’s something you are. And that therefore people have to have gone through a period of reflection about themselves, about why you work with people with dementia, about their own emotional journeys in their life’ (SC15. Independent dementia consultant and trainer)

### ***Comparative analysis***

This component was rarely discussed in relation to the person with dementia, but received more emphasis in relation to carers (Table 7). The expertise of people with dementia was almost exclusively discussed by staff, whereas both carers and staff recognised the expertise of carers. A similar emphasis to recognising and valuing expertise occurred in all service types. This component was most frequently discussed in relation to staff.

### ***Additional insights from observation***

Valuing expertise is largely concerned with involvement in service development and review for people with dementia and carers. It was therefore not surprising that few instances of this component were observed. The importance of acting on information provided was highlighted:

‘C307 commented that he had suggested on numerous occasions that the entertainment should start earlier (e.g. 7pm or 7.30pm rather than 8pm), but that nothing had ever been done in response.’ (Field notes, Service 3: 1220-1222)

The pooling of expertise between staff was regularly observed, confirming that this is not limited to formal training events or supervision, but is an exchange of information on a routine basis.

## **3.5 Discussion and policy implications**

Key findings from the focus groups and interviews about the meaning of person-centred care are summarised in Figure 15. Consistent with previous studies, it was clear that the term person-centred care was unfamiliar to most people with dementia and carers (Glynn *et al.*, 2008; Innes *et al.*, 2006). Whilst all staff had heard of the term, understanding of person-centred care was variable amongst both managers and front-line staff. A superficial understanding of person-centred care could have significant implications, for example, resulting in a lack of insight over the potential for service development; this is discussed further in Chapter 4.

Much of the previous work on the components of person-centred care has been literature based (Hughes *et al.*, 2008; McCormack, 2004).

Comparison of the components identified from a literature review with those identified from a thematic analysis of focus group and interview transcripts, confirmed the relevance of most components of person-centred care. There were, however, some important differences of emphasis between the

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literature and interview based data. For example, some frameworks of person-centred care derived from the literature have included a component of 'professional as person' (Hughes *et al.*, 2008; Mead and Bower, 2000). Our analyses suggested that the components of person-centred care were relevant to the person with dementia, carer and staff. This provided a richer representation of the data and is consistent with previous work on person-centred care in social care (Brooker, 2004; Nolan *et al.*, 2004; Packer, 2000a).

Person-centred care is a multifaceted concept that highlights the range of components needing to be addressed in order to deliver good quality care. Although different studies tend to emphasise and group together themes relating to person-centred care in slightly different ways (see for example, Table 5), there now appear to be a number of robust underlying themes which consistently emerge from empirical work.

Involving stakeholders in defining person-centred care resulted in a list of components covering both the process and outcomes of care. This is consistent with previous studies showing that for services users and carers the process of service delivery is as important as the outcome (Glynn *et al.*, 2008; Qureshi, 2001). The breadth of the concept is of particular salience to policy, since it covers both basic aspects of care (such as physical well-being) and sets out the range of aspects of care to which services can aspire. Whilst we have identified more components of person-centred care than previous studies (Brooker, 2004; Nolan *et al.*, 2004), we thought the inclusion of more components would facilitate the process of identifying and developing tools.

The findings, from interviews, focus groups and observation, also confirm the persistence of unacceptable variability in services. It is clear that even basic physical needs are not consistently being met. This highlights the potential value of tools which could be used to identify areas for improvement. Such tools should be wide ranging so that they address basic needs as well as more subtle aspects of person-centred care for services that are already performing well.

### Figure 15. Key findings on person-centred care

- The assumption that conceptual terms such as 'person centred care' are widely understood is unwarranted
- Nine components of person-centred care were identified, most of which are relevant to people with dementia, carers and staff
- There was evidence of unacceptable variation in services, with even basic physical and personal needs not always being met.

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## 4 Facilitators and barriers to person-centred care

### 4.1 Summary

This chapter focuses specifically on the barriers and facilitators to person-centred care in services providing respite care and short breaks using data from the telephone surveys, focus groups and interviews and field notes of observation from the six case studies. The chapter includes the perspectives of a range of stakeholders adding to the existing literature particularly the perspectives of people with dementia, carers and front-line staff. The chapter highlights the impact that the characteristics of actors engaged in respite care and short breaks - people with dementia, staff and carers - have on person-centred care. The relationship and interaction between the person with dementia-carer dyad also influenced person-centred care. Finally organisational factors and service ethos and organisational culture, including the depth of understanding of person-centred care, were highlighted as major barriers or facilitators of person-centred care within the context of respite care and short breaks.

The barriers and facilitators identified in the present study in relation to respite care and short breaks are largely consistent with those identified in the literature for a wide range of services for older people and people with dementia. The chapter highlights differences with other studies.

### 4.2 Introduction

Concerns over the quality and acceptability of respite care and short breaks are well documented (Arksey *et al.*, 2004). These concerns have often acted as a barrier to service use, with carers preferring to forgo a break than to use available services. In this chapter we focus on facilitators and barriers to the delivery of person-centred care, rather than barriers to service use per se. Although there is a considerable literature on the barriers to person-centred care (Dowling *et al.*, 2006), there is relatively little empirical work on the perspectives of service users and front-line staff. Key obstacles identified in the literature include traditional models of service delivery (Dowling *et al.*, 2006); a focus on impairments, losses and dependency (Sheard, 2004); ageism and the stigma associated with dementia (Brooker, 2007b); and issues relating to resources and staffing within social care (Dowling *et al.*, 2006).

Two recent empirical studies have examined barriers to person-centred care from the perspectives of service users and front-line staff (e.g. Glynn *et al.*, 2008; Innes *et al.*, 2006), the latter study also included managers. Little is known about carers' perceptions of the barriers to person-centred care. Available studies have not focused specifically on respite care and short

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breaks or on services for people with dementia. Relatively little information is therefore available on barriers to person-centred care in such services for people with dementia.

The telephone surveys of services providing respite care and short breaks (see Chapter 2) highlighted factors that facilitated or hindered the provision of person-centred care within a range of service models. The focus groups and interviews to identify the components of person-centred care (see Chapter 3) often included extensive discussion of facilitators and barriers. We therefore decided to extend our original research proposal by conducting a detailed analysis of these factors and using this analysis to inform the development of the tools for evaluating person-centred care. This chapter therefore presents an analysis of the barriers to person-centred care in a range of models of respite care and short breaks from the perspectives of people with dementia, carers, front-line staff and managers.

### 4.3 Resumé of method

The procedures for sampling, recruitment and data collection are described in Appendix 1. The approach to the analysis was similar to that used for the identification of components of person-centred care. The transcripts formed the data for formal analysis. The data workshops to develop a coding frame focused on the components of person-centred care and on facilitators and barriers to such care. A draft coding frame was developed by the research team and populated with illustrative examples from the transcripts. Following a period of double coding, where two members of the team compared codes assigned to the same transcripts, the coding frame was finalised. One member of the team (CK) took the lead in coding the transcripts. Nvivo was used to code the data and coding reports were produced at regular intervals and discussed by two members of the team (CK and CB). Where there was disagreement over the codes, the transcript was discussed until consensus was reached. Any necessary clarification of the coding frame was then made.

Once all of the transcripts and field notes had been coded, a second phase of analysis focused on examining the coherence and boundaries of each code and understanding the relationships between codes. A summary of this second phase of analysis was presented to: the broader research team for discussion; a conference to an audience including a range of stakeholders (Thorne, 2008); and members of the Reference Group for comments and feedback.

### 4.4 Overview of facilitators and barriers

Four main groups of facilitators and barriers were identified, relating to: individuals; the person with dementia-carer dyad; organisational factors; and service ethos or culture. Most of these broad categories comprised a number of themes (Table 8), described in detail below.

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**Table 8. Facilitators and barriers to person-centred care**

| <b>Key themes</b>               | <b>Subthemes</b>                      | <b>Section</b> |
|---------------------------------|---------------------------------------|----------------|
| Individuals                     | Staff                                 | 4.5.1          |
|                                 | People with dementia                  | 4.5.2          |
|                                 | Carers                                | 4.5.3          |
| Person with dementia-carer dyad |                                       | 4.6            |
| Organisational factors          | External constraints                  | 4.7.1          |
|                                 | Exchanging and using information      | 4.7.2          |
| Service ethos and culture       | Understandings of person-centred care | 4.8.1          |
|                                 | Prioritising staff development        | 4.8.2          |
|                                 | Embracing reflection and change       | 4.8.3          |

## 4.5 Individuals

### 4.5.1 Staff

Consistent with previous studies (Glynn *et al.*, 2008; Innes *et al.*, 2006), staff were universally identified as the key to the delivery of person-centred care. Two separate themes were identified: personal qualities, and skills and knowledge. The importance of personal qualities of staff has been highlighted in a number of previous studies (e.g. Francis and Netten, 2004; Glynn *et al.*, 2008; Godfrey, 2000; Innes *et al.*, 2006). Staff ability and motivation have been identified as important barriers to the implementation of person-centred care (James, 2007). Participants in the present study identified a range of qualities as important for the delivery of person-centred care (Figure 16).

There was some discussion of whether the ability to provide person-centred care was intuitive or could be learned. The above qualities were seen as central to an intuitive approach to person-centred care:

‘One of our best support workers walked in that job and he didn’t have any training, and he did that job as though he’d done it for years, and I think he did it on the way he wanted to be treated. And he always said to me it was common sense, and he is absolutely marvellous.’  
(Staff 11, Front-line staff, one-to-one support service, staff focus group 2)

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**Figure 16. Personal qualities of staff which facilitate person-centred care**

Caring about individual people with dementia

'Consistency so that person feels very sure with the person and that makes the carer feel, have complete peace of mind because you know there is a lovely person who really cares' (Carer 4)

Caring about the service as a whole

'I think a lot of services fall down because you've not necessarily got carers, you've got people who have got a job' (Staff 7, Front-line staff providing sitting service, day care, host-family respite, staff focus group 1)

Patience

'They [staff] listen to their worries and could give them answers, reasons, even if it was a hundred times over' (Staff 7, Front-line staff providing sitting service, day care, host-family respite, staff focus group 1)

Willingness to experiment and to learn

'We did try various strategies, because it's always trial and error, and you know it's rarely you can say well do this and it will work' (DT 205. Manager, Social Services extended day care for people with dementia)

Ability to listen

'Well, the most specific thing to the person with dementia is to have a friendly face, is to have someone that can understand what they're trying to say' (Carer 5)

Being motivated to 'go the extra mile'

'It just is a very high quality and fairly bespoke service for each individual. The amount of trouble that the staff go to is remarkable and it surprises even me.' (DT106. Local branch manager of national organisation for people with dementia)

Attention to detail

'They want to know every little detail about my mother and her interests, and she reads poetry to her and because I told her that my mum likes poetry' (Carer 3)

Trustworthiness

'I would want staff involved who I could really trust to have assessed the situation with the person with the old age condition and the carers. I'd want somebody who was really well trained and really thoughtful about that particular situation' (Carer 4)

Shared background or local knowledge

'P104 then named some of the dance halls she used to go to and again the member of staff was able to prompt her with some other ones.' (Field notes, Service 1: 460-462)

In the absence of such qualities, some respondents thought training would have little impact. Nevertheless, specialist skills and knowledge also facilitated the delivery of person-centred care. In addition to knowledge about dementia, nursing knowledge was necessary to ensure appropriate physical care:

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'There are issues to do with people's intimate personal care [...] wounds and pressure sores etc etc, where we don't know what we are doing, so as a consequence we can't do it.' (DT113. Local manager of national provider of housing, care and support services for older people)

### 4.5.2 People with dementia

The reluctance of some people with dementia to use services was a significant barrier to person-centred care. This reluctance could be regarding the use of any services, the use of specific services or could just relate to how people with dementia felt on a particular day. It could also relate to the person with dementia's reluctance to be separated from their carer or to go into long-term care. This perhaps reflected an underlying anxiety that permanent admission was planned rather than a short break. Although autonomy was identified as a key component of person-centred care, people with dementia often had very little choice over whether or not to use services. Carers (sometimes encouraged by staff) occasionally resorted to subterfuge to persuade people with dementia to use services:

'We initially persuaded (person with dementia) to go because he could be helpful. You know he could help push wheelchairs around and that sort of thing.' (Carer 1)

A number of professionals acknowledged that services were often designed around carers' needs for a break, rather than providing a meaningful experience for the person with dementia. Previous studies have identified traditional models of service delivery as a barrier to person-centred care (Dowling *et al.*, 2006). People with dementia sometimes used services in recognition of the fact that their carer needed a break, even though they would have preferred to stay at home:

'I can think of a comment that I remember a carer making some years ago about her husband. He attended this activity club and he also went to Social Service day care a couple of other days. The Social Services day care, that's where he went because he knew his wife needed some respite from looking after him. He went there because he felt he should do. But he looked forward to going to this other one' (SC06. National organisation for people with dementia)

Where people with dementia refused to use services at all, carers were unable to have a break from caring. This conflict between autonomy for the person with dementia and autonomy for the carer was a key tension in delivering person-centred care. Positive experiences of services could sometimes help to overcome the reluctance of people with dementia to attend.

Initiating service use was confirmed as a crucial transition requiring careful management (Murphy and Archibald, 2004). Phased introduction of services gave people with dementia a greater sense of control over the transition and facilitated the development of relationships. Attendance with

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the carer was another way of facilitating the transition both for the person with dementia and the carer (see Section 4.5.3). Although a gradual introduction was not always possible, it was valued particularly in services involving overnight stays away from home:

'I think the other thing we did with the anxious lady [was to] have a weekend where her daughter stayed with her as well and that was to try and ease her in and there is the facility to do that there and what the daughter kept doing was finding excuses to go off for the day or "I'm popping to work mum", "I'll just do the shopping". So she was there for her at night to reassure her but during the day she was tending to leave her with the carers and letting her get on with things' (WP2, Prof 1. Social worker, specialist team for younger people with dementia)

The severity of cognitive impairment was thought to impact on person-centred care, with the majority of participants feeling that it was easier to provide person-centred care to people with milder impairment. For example, offering choices was viewed as more complex for people with severe cognitive impairment. Nevertheless, professionals often found ways of promoting autonomy despite difficulties with communication:

'And there's different ways as well, for example at meal times. Obviously some clients are not going to be able to respond verbally, if you're verbally describing what's on offer for the meal. But it's a matter of showing or taking the client up to the dining room before, so they can visibly see what food is on offer' (DT308. Manager, care home providing respite and day care)

Developing a therapeutic alliance between the person with dementia and staff was facilitated by opportunities to get to know the person with dementia at an earlier stage of the disease. At this point the person, rather than the dementia, is more visible and staff are less reliant on the carer to broker the relationship by providing background information. Being involved at an earlier stage of the disease also enables staff to adjust to changes in the person with dementia gradually and to explore and learn ways of interacting that are most acceptable to the person with dementia. Although staff explicitly recognised the value of earlier intervention, some carers were sceptical about the availability of services at an early stage:

'I think if we can get people early enough where they feel comfortable with us [...] if you can get to support people where there is some memory impairment, there are some difficulties, but there's still enough of that personality around to sort of tap into, then you can maintain that for far longer' (Interview, Deputy manager, multipurpose day care)

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'You do need to get in early in people with a degenerative illness, so that you can build up a relationship. So that if they get worse, there's a level of trust there, that you can't build up later. But you try telling Social Services that we have to get in early and use that window of opportunity.' (Carer 1)

It was not always possible to establish a satisfactory relationship with the person with dementia, particularly when the person with dementia had become very dependent on the carer:

'He doesn't realise that they are the same people that are coming to take him out [each week]. And he's very defensive, he's frightened, he's very frightened that he's going to be taken away. I think what's happening with him in his way, he's fighting the disease and he's fighting against them you know sort of taking him away from home and from me' (Carer 15, focus group 2)

A choice of models of respite care and short breaks was also thought to promote person-centred care since it enabled individual preferences and needs to be met. Consistent with previous studies (Archibald, 1996), different models were seen as more appropriate at different stages of the illness. For example, when one person with dementia was asked his views on day care, he responded:

'Some people would benefit from that. I would be bored stiff, I'm sure. [Int: So who do you think might benefit from it?] People of a more advanced stage probably.' (PwD7, mixed focus group)

There was evidence that people with dementia had low expectations of services and were grateful for even very basic assistance:

'The meals are quite nice, I enjoy them, you get ample. You can help yourself to tea, make yourself a cup of tea, and there's a fridge there with the milk, you know available for you. And if you're hungry, you get a biscuit. Well what more could you ask for?' (PwD 5)

The people with dementia who participated in the focus group had previously contributed to a number of service development exercises, and explicitly recognised the value of giving frank and honest opinions:

'It's no good people saying 'oh yes, it's wonderful' when really they think it's horrible' (PwD 1, people with dementia focus group)

### 4.5.3 Carers

Many of the barriers identified relating to carers appeared at first glance to focus on access to services, rather than person-centred care. However, the barriers were often based on perceptions that services did not address valued components of person-centred care and are therefore relevant to this chapter. A number of factors contributed to carer reluctance to use respite care and short breaks (Figure 17). Similar barriers have previously been reported (Ashworth and Baker, 2000; Gilmour, 2002; Parahoo *et al.*, 2002) and there is evidence to suggest that acceptability of services to the

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person with dementia is more important to spouse carers than other carers (Cotrell, 1996).

**Figure 17. Reasons for carer reluctance to use respite care and short breaks**

|   |
|---|
| <p>Ambivalence over relinquishing care</p> <p>'I'm happier when she's at home. I know where she is, and I know what she's doing, and I can care for her better than anybody.' (Carer 7)</p> <p>Issues relating to perceived person-centredness of services</p> <p>'You tend to get the impression that they're just sitting round in a big circle in a lounge. And that doesn't suit everybody. It certainly wouldn't suit my dad' (Carer 6)</p> <p>Financial costs</p> <p>'I mean this is a huge worry, how much is it going to cost? Do I sell the house?' (Carer 8, focus group 1)</p> <p>Potential impact of service use on person with dementia</p> <p>'From my point of view, it would be handy if she did have some respite but I couldn't possibly send her as she is now because she is more or less in early / moderate stages. She'd think I was trying to get shot of her. I think from my point of view, I'd have to wait until some time when she doesn't recognise me at all, before I would consider that' (Carer 10, Carer focus group 1)</p> <p>Guilt</p> <p>'[Carers] tend to feel that when we get involved [...] they've let their partner down' (DT401. Manager, Day Centre run by national charity for older people)</p> |
|---|

With the exception of financial costs, all of these barriers to service use could be managed by addressing one or more of the components of person-centred care described in Chapter 3. The determination of some carers to manage without the help of services could result in risk to their psychological well-being and physical health:

'She [carer] will not let him go anywhere, and she's going to have a nervous breakdown; you can't get through to her' (Staff 10, Front-line staff, one-to-one support service, staff focus group 2)

Two components of person-centred care – developing a therapeutic alliance and promoting a sense of shared responsibility – were seen as crucial in enabling carers to accept help. The phrase 'you can't get through to her' in the above quote, suggests that neither of these had been successfully achieved in the example given. The main barrier to developing positive relationships was where the carer perceived staff as competitors, rather than collaborative partners in providing care. The importance of developing relationships over a period of time was emphasised by staff. Again, delays

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in accessing services at an early stage could act as a barrier to person-centred care.

The ability and willingness of carers to try new approaches or activities with the people with dementia to improve care was sometimes a significant barrier. Carers often perceive themselves as the person who knows the people with dementia best and therefore able to provide the best care. It can be difficult for carers to accept that other people also have expertise and specialist knowledge without feeling that their own expertise is undermined:

- S21 'I think it's a difficult balance with carers because you need to get enough trust so that they can let go and let you look after the person. But then if you do too well, they are almost sometimes angry that [...] they haven't been missed more and you know what I mean?'
- S22 'Yes, I know, you're damned if you do and damned if you don't!' (Lead Care Manager and Care Services Manager for older people, Staff focus group 5)

Carers' perceptions of dementia impacted on person-centred care since some carers saw little benefit to providing activities or social opportunities as they perceived the person with dementia as being 'too far gone':

- 'I don't think that people with dementia actually enjoy anything, they are not capable of actually enjoyment anymore.' (Carer 2, focus group 2)

This detachment was sometimes perceived by staff as a defence mechanism needed to help the carer to continue to support the person with dementia.

Carers' low expectations about services were seen as a barrier to person-centred care. Although carers could be a valuable potential source of feedback, there was widespread recognition that carers were reluctant to criticise services:

- 'We try very hard to get objective criticism about our group. It's very difficult, I think carers only really get crumbs that fall off the table and we are one of those crumbs. So when you ask for, you know somebody could give you an idea of how we could improve our service, they'll always say that it's great, it's wonderful.' (Interview, Manager, NHS day care for people with dementia)

Examples of low expectations were voiced a number of times in the focus groups and interviews with carers:

- 'One thing I did notice. I was particularly thrilled about [Service name 3], there was no smell of urine and there was no institutional cooking smell.' (Carer 8, focus group 1)

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#### 4.6 Person with dementia – carer dyad

The relationship between the person with dementia and carer could both facilitate and undermine person-centred care. In many situations the well-being of both individuals was interdependent and staff often emphasised that both parties wanted similar outcomes:

‘Invariably, carers’ needs are different from those of person with the experience of dementia but there is a common core and that is about quality of life and people being in a state of well-being’ (DT102. Local Dementia Care Service Manager of national organisation for people with dementia)

There was also recognition that it was important not to idealise the relationship between the person with dementia and carer, but to recognise that there could be problems which predated the development of dementia. A recurrent theme concerned the tension that often arose because of the different needs and wishes of people with dementia and carers. Consistent with the literature, numerous examples were given of conflict between people with dementia and carers (Archibald, 1996; Innes *et al.*, 2006), and staff perceived themselves as having a key role in managing this conflict. Often the conflict raised ethical and practical issues:

‘We recently visited a lady who used to smoke, be a fairly heavy smoker. She had a spell in hospital and came out of hospital not smoking, which was great. After a while, when we were on our visits, the lady wanted to buy cigarettes, but the carer had given everybody clear instructions, we mustn’t do that. The carer was really, really clear, “Don’t lets start smoking again.” The lady wanted cigarettes and wanted to smoke. So the way that we dealt with that is [...] we discuss it as a team and look at the ethics and moral sort of considerations there. And then we meet with the carer and the person with dementia, and then we talk about it really, and we talk about rights and we talk about conflicts and hopefully, not always get a solution, but hopefully they are sort of able to see our position and where we are coming from and also it makes it much more of a rounded sort of discussion.’ (DT305. Assistant Clinical Director of Dementia Services)

As in the above example, staff sometimes saw themselves as advocating for the person with dementia against the carer’s wishes; but there were also occasions where the emphasis was on encouraging the person with dementia to acquiesce with the carer’s preferences (particularly in relation to using services). On occasion, the carer’s need for a break was so great that the person with dementia had no choice in the matter and it was only later that their perspective was considered:

‘It’s only with hindsight that I thought how tough it must have been on [person with dementia]. Even if he didn’t remember it, at the time he must really have wondered what on earth was going on.’ (Carer 1)

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Even during respite care and short breaks, tensions between autonomy of the person with dementia and the autonomy of the carer could continue. For example, carers sometimes vetoed a home visit during respite, on the grounds that it would distress the person with dementia. Socialising with other people with dementia could be another area of tension. Some carers were reluctant for the person with dementia to mix with other service users whom they perceived as being more impaired:

'I remember a chap who came in who had been bed bound at home. The daughter, because she comes in and sees all these people milling about with dementia, she wanted her father cared for in his room, and she didn't want him to come out [...] he wanted his meals in the dining room, and we had to sensitively say "your dad's enjoying this"' (Staff 20, Care services manager for older people, Social Services)

The challenges of communicating with dyads were raised by several participants. The difficulties of triadic encounters involving people with dementia have been highlighted in previous research (Adams and Gardiner, 2005; Bamford *et al.*, 2007). Similar issues of carers speaking for service users have been reported in other contexts (Glynn *et al.*, 2008; Innes *et al.*, 2006; Keywood *et al.*, 1999). A number of staff emphasised the importance of separating the person with dementia and their carer in order to hear the views of each person clearly, particularly during initial assessment:

'Sometimes you've got to be quite careful when you are doing the assessments so that you get the opportunity to listen to what everybody wants really and not let the carer, although they are being well meaning, answer for the person that they are caring for' (SC12, Manager, local organisation for people with dementia)

'I am a big advocate of talking to the person with dementia away from the family [yes] and the carer as well. The joint assessments I see as a bit of a waste of time, they are useful but if you really want to hear what's happening you need to talk to the individuals themselves and get their story really.' (Interview, Carer Support Coordinator, Social Care Trust)

## 4.7 Organisational factors

### 4.7.1 External constraints

A range of external constraints were identified which influenced the delivery of person-centred care (Figure 18). The ways in which bureaucratic structures and the legacy of traditional service models can act as barriers to person-centred care are well recognised (Dowling *et al.*, 2006; Innes *et al.*, 2006).

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**Figure 18. External constraints which influence the delivery of person-centred care**

Historical context of respite care and short breaks

Staffing issues

- Number of staff
- Continuity of staff
- Matching staff to individual people with dementia and carers

Use of volunteers

Service characteristics

- Communal services
- Continuity of service
- Service availability

Health and safety regulations

- Transport

### ***Historical context of respite care and short breaks***

Historically, services providing respite care and short breaks have focused on the needs of carers, rather than providing an enriching experience for the person with dementia (Levin *et al.*, 1994). Although there is a growing emphasis on the need to refocus services to provide a positive experience for people with dementia (Weightman, 1999), a significant number of participants still perceived carers as the primary beneficiaries of services:

‘And basically it was finding somewhere safe to park (person with dementia), so the rest of the family could have some quality time together. And it seemed to me that it worked much better if there was also some consideration given to what (person with dementia) would get out of it.’ (Carer 1)

The historical emphasis on a ‘one size fits all’ approach, which denies diversity or difference, is also at odds with the implementation of person-centred care (Dowling *et al.*, 2006; Ray, 1999).

### ***Staffing issues***

The most common facilitator of person-centred care identified in the focus groups and interviews was the number of staff available. The availability of more staff was thought to enable:

- small group community visits
- access to community resources
- one-to-one time
- safety for people with dementia
- increased continuity of staff over holiday periods.

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While one-to-one services were able to offer the first three activities routinely, staffing issues were still relevant to such services, since the person with dementia might require assistance from two people:

'When her mobility was better, then one person would take her out and have a little walk. But that's not possible now, unless they took the wheelchair, but then it would need two of them and because [of] the staffing difficulties that the department is experiencing, it's a one-to-one visit' (Carer 7)

A number of difficulties in providing person-centred care in communal services were highlighted. It was widely recognised that treating people as individuals was challenging in services with a large number of service users. In these services a good staffing level was seen as essential:

'There's too many clients and not enough carers available, so it becomes too much of a squash them all in and one fits all. And it's not a one fits all situation I'm afraid with people that have got forms of dementia' (Carer 5)

'If you want to give a good quality of care you've got to have the staff to do it. If you've got two staff you're struggling, but if you've got four staff it just makes everything so much easier' (Staff 16, Front-line staff, specialist resource centre, staff focus group 4)

However, there was also recognition that increased numbers of staff did not necessarily improve person-centred care, since staff may spend increased time together, rather than with people with dementia. As highlighted in the literature, staffing levels were also affected by sickness, holidays and poor staff retention, with poor pay perceived as a barrier to recruitment of staff (Innes *et al.*, 2006).

The balance of continuity and variety of staff was also identified as an important factor. Previous studies have noted individual differences in service-user preferences for continuity of staff (Francis and Netten, 2004). In the present study, continuity was thought to facilitate person-centred care since the staff member was able to develop a good relationship and detailed knowledge of the people with dementia. Variety was also valued, partly for practical reasons, relating to cover for holidays and illness, so that when the preferred member of staff was on leave, cover could be provided by other members of staff who were at least known to the people with dementia:

'We might have three different people visiting that one person. And the reason we do this is to build up the relationships, because if you have someone twice a week and then, like me, I've gone away for a month in the winter, then they've got to cover that person [...] so now they have a different support worker and actually it works out well because they've all got different ideas.' (Staff 10, Front-line staff, one-to-one support service, staff focus group 2)

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Positive relationships between people with dementia and staff were also fostered by careful matching of staff and service users. This was emphasised in one-to-one services, but was rarely discussed in relation to other types of services (presumably because in most other services there were a range of staff with whom people with dementia could form relationships):

'It's going to be the right person for the right fit, their character has to fit. Because somebody might want somebody bubbly, I'll send a certain person. Somebody might want a more subdued, more mature person, then I'll send a certain person. Or they want someone who's more get up and go'. (DT111. Care attendant co-ordinator of specialist service for black carers)

Having a range of members of staff was essential to meet individual preferences and requirements. The importance of meeting the language and cultural needs of service users from black and minority ethnic groups has previously been highlighted (Bowes and Wilkinson, 2003; Innes *et al.*, 2006). In addition to ethnicity and culture, gender was also confirmed as important for some service users:

'I remember I went once and there were about three male carers and they used to do the toileting and my mum would never use the toilet [...] she liked them but for her it was just a stranger and these were her private functions and I think she was embarrassed.' (Carer 3)

### ***Use of volunteers***

Person-centred care can be facilitated by using volunteers.

- S15 'It's true, when you're on about the staffing level, because you can do all the caring for the person like cleanliness and things like that, but they want you to sit with them on a one-to-one.'
- S18 'That's why volunteers are fabulous people, you know they'll come and they'll say to me, "I feel awful, I haven't done anything today", I'll say, "God you've sat and talked to people" and the staff haven't got time to sit and talk, volunteers are brilliant, just to come along and sit and talk.' (Front-line staff, specialist resource centre and Manager, non-statutory day centre for older people, Staff focus group 4)

During the fieldwork to validate the components of person-centred care, we observed wide variation in the use of volunteers. The extensive use of volunteers in the holiday service enabled each dyad to be allocated an individual volunteer who was responsible for providing personal care for the person with dementia, befriending the couple, helping with practical issues and supporting the carer. In this service, volunteers had far more day-to-day contact with the service users than paid members of staff. Two significant barriers to the use of volunteers were identified: resources for recruitment, training and management of volunteers; and the process of

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obtaining Criminal Records Bureau (CRB) checks. The delays in obtaining CRB checks were perceived as off-putting to potential volunteers who could start volunteering in other services straight away.

### ***Service characteristics***

The nature of the service can also influence the achievement of person-centred care. Communal services provided opportunities for social contact and to develop new friendships. However, relationships between people with dementia in communal services were not always positive. People with dementia sometimes treated one another disrespectfully:

'Dad went into the (pause) games room I suppose it would be where they've got a snooker table. He used to be a reasonable snooker player at one time, but two chaps came in who were obviously not as far deteriorated as he was, and they said "Oh we don't want to play with him, because he's daft". And he remembered that and that rather upset him.' (Carer 13, focus group 2)

Managing relationships between service users could therefore be crucial in determining the extent to which person-centred care was experienced. The attention paid to these relationships varied. Few examples were given of direct interventions to try to address conflict between people with dementia (beyond physically separating people). In some situations, it was thought that people who did not 'fit in' would leave, solving the problem:

'Of course you'll always get this odd mix of people. And one thing for sure, if you do get a mix of different categories of people, if certain people do not fit in, they'll not like it, and so they'll not go and so the problem itself will be sorted because the people themselves will sort it won't they?' (Carer 2)

A second significant characteristic of services related to the continuity of service provision. Some services had a clear commitment to providing care to the person with dementia and carer until such time as the person with dementia died or was admitted to long-term care. However, other services (most frequently day care) were sometimes only appropriate for people in the earlier stages of dementia. As the person with dementia became more impaired, the service was no longer seen as appropriate and the person was 'moved on':

'All of the day centres worked well until [name of pwd] got worse and then more or less at the time that I felt I needed them most, they backed out. For understandable reasons, but nonetheless. At the time, I thought it quite entertaining that they had a purpose-built centre and maybe four adults, four carers, four 'with it' people to care for about a dozen 'non with it' people. They couldn't cope with [name of pwd], so they sent him home to me, in a normal semi-detached house, with two primary school children and a dog' (Carer 1)

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There was tension between providing appropriate care for people with dementia at different points on the illness trajectory and providing continuity of care. The way in which people with dementia were 'moved on' from one service to another could potentially be disruptive:

'He has to have routine [...] and if routine is thrown sometimes then of course he can't cope with it. He cannot cope at all with anything, any changes that are thrust upon him' (Carer 2, mixed focus group)

On the other hand, different services were able to meet changing needs. The following extract highlights the benefits of different types of services and illustrates how continuity can be achieved by providing a combination of services rather than simply replacing one service with another:

'She gets a one-to-one carer who goes out and does all the things she loves, going to garden centres, and buying little pots and potting plants and stuff like that. But she has also started going to day care and that's around the fact that she's living on her own, her mood gets very depressed at times and we felt she was probably having too long periods between carers going in, on her own. And again she's quite hard work I think; she's a very anxious, very moody person. And I think for one-to-one it can get quite tiring, and then you don't want to get her and the carer feeling they've had enough of each other. So we started two days of day care for her as well to run alongside. And I think then sometimes the ability to move from activity to activity and the move to different relationships within that group is then helpful.'

(Prof 1, Social worker, specialist team for younger people with dementia)

The limited flexibility of many services meant that there was often discontinuity of care when emergencies or additional support needs arose, with people with dementia having to use completely different services, often with new members of staff and in an unfamiliar setting. Generally services were withdrawn when people with dementia moved from the community to 24 hour institutional care. Where services had been used for a long period, this sudden withdrawal could be difficult for the person with dementia, carer and staff and could undermine person-centred care. Some exceptions were made for people who were able to pay privately for extra services or in special circumstances. Even where a service was prepared to waive payment because the person with dementia was a long-standing service user, practical arrangements could not always be made:

'He can come to us for the day if he wants, if somebody else will bring him and take him home. We will have him for the day because he's been to us for fifteen years [...] we would, but there's nobody to bring him.'

(Staff 18, Manager, non-statutory day centre for older people, staff focus group 4)

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### ***Service availability***

The need for a range of respite care and short break services has been emphasised in a number of reports (Archibald, 1996; Mountain and Godfrey, 1995; Weightman, 1999). In discussing the vignettes describing different service models, it was clear that people with dementia and carers had strong and varied views about the appropriateness and acceptability of different types of respite care and short breaks. The need for services to be flexible in order to meet varied individual preferences was clear. The following quotes are from two carers using the same one-to-one support service:

'These visits are usually between three and three and a half, maybe four hours. Sometimes it might be of benefit if two shorter visits were exchanged for one longer visit' (Carer 7, interview)

'I don't think three and a half hours is even now long enough actually' (Carer 3, interview)

While some carers had positive views about host-family respite services, others viewed this as imposing on another family, despite reassurances that the host family had volunteered and were reimbursed. Similarly views on services where the carer could accompany the person with dementia were mixed:

Carer 2 'The fact that carers can also attend, I think that would be very helpful because you can then do things together'

Carer 4 'But doesn't that defeat the object of respite if you've got to go along with them?' (Carer focus group 2)

For people with dementia, a key requirement of respite care or short breaks was that it provided a change from usual routines and environments:

'I don't want to just get off the chair here and go along and sit somewhere else. There's not much point in that, is there?' (PWD 3)

It is clear from the above examples that individuals had varying needs and preferences. While the examples in the vignettes were attractive to some people with dementia or carers such services were not always available locally or, on occasion, were available but participants were not aware of them. The services used by some participants did not fully meet their needs but were nevertheless used in the absence of any alternatives. Limited availability of services was also highlighted in the cognitive interviews with carers reported in Chapter 7. For example, one carer who had difficulty in arranging care for her husband when she was due to go into hospital for a planned operation and subsequent recuperation commented that:

'The operation was a doddle. It was nothing compared with the stress beforehand of trying to get [husband] into somewhere. It was only at the last minute, the week before, that they told me they'd got a place for him.' (C405)

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Another carer, who had approached Social Services for an evening sitting service for his wife to enable him to continue to attend his choir, was offered two days of day care instead. A lack of choice over the services available could act as a significant barrier to person-centred care with people with dementia and carers being slotted into available services rather than having access to services tailored to their individual needs.

### ***Health and safety regulations***

Issues relating to health and safety clearly had an impact on service flexibility and the abilities to provide person-centred care:

'I mean it's like outings [...] you've got to do a risk assessment, health and safety, to take somebody out. You've got to have all that and plan it all and do it in the morning if you were going to take a group out. And then well is it worth all the hassle of doing it? So that activity went out of window' (Staff 7, Front-line staff providing sitting service, day care, host-family respite, staff focus group 1)

The tension between the perceived responsibility of staff to ensure the safety of service users and supporting positive risk has been highlighted in previous studies (Glynn *et al.*, 2008).

### ***Transport***

A number of issues relating to transport were raised in the focus groups and interviews, most of which were concerned with accessibility and service availability rather than person-centred care. It was clear that the provision of transport was crucial in enabling many people with dementia to access services such as day care. However, transport arrangements could also impact on person-centred care. The only contact between carers and staff for some services (particularly day care) often took place when the person with dementia was collected and dropped off. Furthermore, transport provided the transition from home to the service, therefore issues such as having a familiar driver, being welcomed in the morning and settled safely back at home at the end of the day, were perceived as contributing to the delivery of person-centred care:

'and then they bring her back and kind of lovely members of staff see her into her gate and see her into her house, so they follow it up completely to make sure she is safe and happily in there.' (Carer 4)

Consistent with previous studies (Social Services Inspectorate, 1999) some people with dementia found the transport arrangements (usually to and from day care) problematic and a difficult journey home was thought to undermine the benefits of the service:

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'I was thinking about her and I did think to myself this is too much for her. When the dark nights started drawing in in October, I thought this is going to be too much for my mum now that she is not as well as she was. And she is frightened of the dark, she is registered blind as well and I thought I am going to have to drop that one day because its not fair to her' (Carer 3)

### 4.7.2 Exchanging and using information

The ways in which information was provided, gathered and used could impact significantly on person-centred care. Each of these issues is described below.

#### ***Provision of information***

It has been suggested that autonomy should be based on 'clear, comprehensive information' (Cass *et al.*, 2008 p60); such information was not always available to people with dementia or carers. Previous studies have highlighted the importance of access to good quality, up to date, accessible information (Glynn *et al.*, 2008). Criticisms were made of the difficulties in getting the full range of information. Carers in the present study preferred to be able to access information from a single point of contact, rather than having to contact a number of different people, or wait for a member of staff to clarify issues with colleagues. Poor quality of information could result in disappointing outcomes:

'We haven't been on holiday for ten years together. But the Princess Royal Carers Trust I went with them on holiday last year, but I didn't know I could have taken my wife. I know it was a break for me but I felt lonely because I had left her [...] I wish I had taken her.' (Carer 14, focus group 2)

The importance of providing carers with feedback about the experience of the person with dementia during service use was highlighted in Chapter 3. Organisational factors could influence the quality of information available. For example, where staff worked shifts, handover meetings and written records were essential to enable staff on duty to respond to any queries made by carers:

'You don't want to be told things like "Oh I wasn't on this morning, so I don't know how much she had."' (Carer 3)

#### ***Assessment***

The process of assessment was a key tool in getting to know individuals and facilitating the delivery of person-centred care. There was also an emphasis on life history work which could provide detailed information about personal background (La Fontaine, 2004). Consistent with previous studies (Glynn *et al.*, 2008), there was an emphasis on enabling service users to set their own goals and identify their own needs:

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'It's basically going from what that person needs. It's not having your own model or ideal about what you think that person needs. It's listening and being attentive to what they actually want.' (SC22. Local manager, Specialist Community Services)

A range of communication skills were needed for assessment:

- active listening
- attending to non-verbal cues
- seeing people with dementia and carer individually as well as together
- negotiating and building rapport to understand the viewpoints of both people with dementia and carer.

The specific issues relating to balancing the needs of people with dementia and carers have already been discussed (Section 4.6). The place of assessment may also be important, with some participants feeling that people opened up more if seen at home. There could be tensions between assessment and person-centred care, for example, where assessment was perceived as trying to fit people into the form, or where carers were left to fill in forms alone with no opportunity for discussion. The need to see assessment as an ongoing process, rather than a one-off event, was stressed. This enabled further information and details to be added as they became available:

'And the other thing that's really difficult is because it's a degenerative illness you're always chasing a moving target. You're trying to fit something to cope with the way they were two weeks ago or a month ago' (Carer 1)

In addition to providing the basis for individual care plans, assessment could facilitate person-centred care in other ways. For example, the paperwork could be used to brief new members of staff or those with no previous contact with the person with dementia and to facilitate handover both within and between agencies:

'We do a pen picture of them [the person with dementia] in their notes and it's in the front of the notes, so anyone that actually goes in as a new member of staff or a different member of staff, they actually read the pen picture.' (Staff 11, front-line staff, one-to-one support service, staff focus group 2)

While other authors have drawn attention to the need for assessment to focus on abilities and potential, rather than problems, impairments, losses and dependency (Sheard, 2004), this was not an issue that was specifically raised in the present study.

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### **Review**

Review was valuable since it recognised that the situation was likely to change and provided an opportunity to check whether existing services still met the needs of the people with dementia and carer. Scheduled review could facilitate the process of person-centred care, but could also act as a barrier if it meant that little attention was paid to changes occurring between formal reviews. A key benefit of review was in identifying and meeting additional support needs:

'So within the first six weeks we are constantly sort of assessing and trying to find out and trying to build on that relationship because [...] you can't just go in there and have a tick box and do a risk assessment or do a care plan. It's about getting to know people and so this is something that evolves. So we review every six months.'

(SC22. Local manager, Specialist Community Services)

### **Use of information**

Assessment and review per se did not necessarily enhance person-centred care, since the information gathered was not always acted upon. For example, detailed information was sometimes available which was never used by staff:

'I always encourage carers to write a life story, and have a photograph album, life memory stuff to follow people with dementia into the services. But it's quite unusual if that's requested by staff in those services' (Interview, NHS Carer Support Manager)

Carers were frustrated when they provided information which was not taken into account. Even basic information was not always passed on or used:

'On the Sunday, when she'd been in two days, the lady I spoke to said "We find that she's not got a very big appetite." I say "In what way?" She says "Well she's not eating." I say "But she can't feed herself." "Oh, they weren't aware of that." But all that information had been passed on. So I think there's communication difficulties, that didn't get to the people who were at the sharp end and so for probably two days they had left her to her own devices and she wasn't eating'

(Carer 6)

## **4.8 Service ethos or culture**

Participants who seemed to have a more detailed understanding of person-centred care tended to emphasise the importance of a shared ethos or culture which permeated all levels of the organisation:

'Not just the front-line staff [...] for example, if you are talking about the NHS, from the top consultant [...] down to the cleaner that's going into the hospital, so that they all know, they are all singing off the same hymn sheet' (DT111. Care attendant co-ordinator of specialist service for black carers)

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The service ethos could be promoted in team and staff meetings, and some services used a logo to publicise their underlying ethos. This shared ethos could have an instrumental role in facilitating person-centred care (Pool, 2006; Sheard, 2004; Zoutewelle-Morris, 2006). For example, an underlying value base of 'treat others as you would wish to be treated yourself' was seen as facilitating person-centred care. Previous studies have highlighted the importance of core values and principles in supporting person-centred care (Brooker, 2007b; Glynn *et al.*, 2008; Sheard, 2004). It was suggested that it was difficult for individual members of staff to sustain person-centred practice in the absence of a shared ethos, since the overall running of the service would not support this approach. Three separate strands relating to service ethos or culture were identified, each containing a number of subthemes (Figure 19).

**Figure 19. Aspects of service ethos influencing person-centred care**

### Staff understanding of person-centred care

- Political expediency vs. shared values

### Prioritising staff development

- Enabling management style
- Training opportunities
- Informal support
- Supervision

### Embracing reflection and change

- Formal collection of feedback
- Recognising scope for improvement
- Managing the process of change

#### 4.8.1 Staff understanding of person-centred care

It was clear that front-line staff did not necessarily have to be able to articulate or define person-centred care in order to provide such care. However, a poor understanding of person-centred care in service managers could be a barrier to such care. The policy emphasis on person-centred care placed pressure on services to describe themselves as person-centred. This could result in services adding a label of 'person-centred care' to their existing activities, without any real knowledge or understanding of the term (Packer, 2000c). The wide variability in understandings of person-centred care was apparent during the detailed telephone survey and confirms previous findings (Pool, 2006). This was not necessarily evident through the ways in which professionals described person-centred care, but was

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related to the extent to which they could readily provide examples of person-centred care.

### 4.8.2 Prioritising staff development

Staff are the 'tools' by which the service provides person-centred care. Hence, the organisation needs to be set up in ways that support the delivery of person-centred care (Packer, 2000a). Given the importance of the personal qualities of staff, a key aspect for improving services is to identify ways of developing staff which builds on their existing skills. This could be achieved through: an enabling management style; informal support and formal supervision; and the provision of training opportunities.

#### *Enabling management style*

Staff need to be managed in a person-centred way in order to provide person-centred care (Packer, 2000a; Ryan *et al.*, 2004; Sheard, 2004). One key role of managers was to lead by example. This could facilitate person-centred care through demonstration of person-centred care in action. At the same time there was recognition that staff needed opportunities to develop their own style of working and to use their initiative, rather than being told what to do and how to do it. Some participants felt it was difficult to sustain good practice when a good manager moved on. Poor leadership has been identified as a significant barrier to the implementation of person-centred care in care homes (James, 2007). Similar issues are likely to characterise respite care and short break services.

#### *Informal support and formal supervision*

In addition to opportunities to meet informally for discussion as and when required, regular supervision was identified as an important facilitator of person-centred care (La Fontaine, 2004; Packer, 2000a; Packer, 2001). Supervision needed to be long enough to allow staff to be reflective, and also needed to provide emotional support and opportunities for staff to ventilate their feelings appropriately. In addition to individual supervision, opportunities to meet as a staff team to share good practice, to talk honestly about their experience of the job and provide a forum for debate were valued:

'At these meetings though we normally have a 'what if?' session, and if something has happened, she explains it to everybody and then we analyse it and see if anybody would have done anything different or handled it differently. And then we come up with some good solutions, don't we? And everybody helps one another.' (Staff 10, Front-line staff, one-to-one support service, staff focus group 2)

Such meetings could facilitate person-centred care by providing opportunities to share skills, so that techniques used successfully with one person with dementia could be adapted and tried with others.

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While the main focus was on promoting good practice, the need to reject poor practice was also recognised. This could include rejecting negative terminology:

'in a way somebody with dementia is very quickly labelled, so you've got the term 'wanderer', 'aggressive', 'violent'... you know these phrases, the old phrases that used to haunt us from the old institutional services, still get used.' (DT309. Carer Support Coordinator, Social Care Trust)

Many participants saw poor practice as unintentional, often as a result of a lack of up to date training or lack of awareness. Nevertheless, the resistance of some staff to change was recognised:

'You've still got people in that form of work, who, that was what they did years ago, and they're not going to change and that's what they are going to continue to do. And you can try to get them to move forward, and it isn't going to work. So you just have to pray they take early retirement.' (DT115. Manager of local charity for people with dementia)

### ***Providing training opportunities***

Participants emphasised the need for training to focus on improving the quality of care, rather than achieving specific targets (e.g. all staff completing NVQ Level 2). The importance of being proactive in identifying gaps in knowledge and identifying specific training needs was stressed. Barriers to training included staff turnover and availability (Innes *et al.*, 2006), and the need for managers to facilitate the provision of training to was highlighted. Clearly training needed to be tailored to the specific individual and context:

'We identified that there was a need for staff to understand more about dementia. Not just from the medical model point of view [...] but more importantly, how it impacts on the lives of the people who are living with that experience' (DT102. Local Dementia Care Services Manager of national organisation for people with dementia)

While special courses were important sources of training, participants also emphasised the need for training to permeate day-to-day practice (Packer, 2000b). The impact of training on person-centred care may be enhanced by pro-social learning examples. Courses needed to be put into practice by applying new knowledge or skills through a process of supervised practical work and debriefing:

'We've got increasingly frustrated at the lack of transference of training onto the actual ground [...] we are doing a lot more training, actually for want of a better word, directly on the floor, where we are working to change the way people occupy people by mentoring, working with them in lounges and dining rooms and then debriefing them. Doing it that way, rather than just workshop based.' (SC15. Independent dementia consultant and trainer)

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There was a general agreement that training on person-centred care should focus on understanding rather than transfer of knowledge and that a similar standard of understanding of person-centred care should be expected of all staff within the organisation. It was suggested that managers were not always aware of their own training needs relating to person-centred care. Such needs could be met through the provision of specialist courses covering similar ground to general training courses on person-centred care, but targeted specifically at managers.

Consistent with previous studies (Godfrey, 2000; Innes *et al.*, 2006), there was disagreement about the impact of training, with some participants emphasising the importance of common sense or personal qualities. Overall professionals suggested that ideally staff would have an intuitive approach to the care of the person with dementia which would be enhanced with specific training. Carers' views on the importance of training were inconsistent and often contradictory. Some specific training was thought necessary in relation to certain aspects of care (often medically related), but generally carers valued the personal qualities of staff over formal training. Similar priorities have been reported by service users in other studies (Francis and Netten, 2004; Godfrey, 2000).

### 4.8.3 Approach to reflection and change

This includes the ways in which the organisation, and individuals within it, evaluate and change their practice.

#### ***Recognition of scope for improvement***

Underpinning reflection and change was the recognition of scope for improvement. There was wide variation between managers participating in the telephone survey in the extent to which opportunities for service development were recognised. This seemed to be linked to the level of understanding of person-centred care. Managers with a deeper understanding of person-centred care seemed more aware of the potential for improvement, sometimes linking this to new policy developments. In contrast, managers who seemed to have a more superficial understanding of person-centred care often found it difficult to identify areas for service development beyond increased resources:

'They were saying about the new Capacity Act. We need to look at how we are facilitating that process, because the Act starts with the emphasis that the person is alright until you find differently, so how can we actually you know, build on that really in terms of our own work. So there's lots of challenges I think [...] I don't feel we can sort of sit on our laurels and say "oh we've done, we know all there is to know about this" because there is new research, you know coming up all the time, there's new approaches and so on.' (DT205. Manager, Social Services resource centre for people with dementia)

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'If we had more money, more time, and more staff [...] That's the only way I think we could make it more person-centred.' (DT105. Local branch manager of national organisation for people with dementia)

The assumption among some staff that people with dementia would vote with their feet, and therefore their continued attendance implied positive views about the service, acted as a barrier to person-centred care. Such an assumption implied a greater degree of choice over attendance than many people with dementia actually had, and is based on an implicit assumption that people with dementia have to fit in and adapt to the existing service, rather than recognising that the service needs to adapt and change to meet individual needs.

### **Collection of feedback**

Person-centred care was facilitated in organisations with an attitude of welcoming complaints, collecting and acting on feedback. The process of collecting feedback from people with dementia was facilitated by asking more able people with dementia about the service, using photographs or more creative options, and meeting with service users to discuss what changes they would like to see:

'The staff do regular service user meetings when they get feedback. I tried to do one last night, it didn't go too successfully to be honest with you, nobody wanted to sit and chat to us, they just all wanted to have a wander round, so I got half way through one. But it gives them a chance to say what they think of things, whether it's the building or the standard of food, and there's even a section where they can bring up any issues that they might have with staff as well. And then whatever they say, depending on what they say, it's got to be acted on. You know if they say something has gone wrong with a member of staff and they try to find out what that is and try and put it right. Same with everything they bring up. And they don't seem too shy about bringing up issues either' (Staff 17, Front-line staff, specialist resource centre, staff focus group 4)

The reluctance of people with dementia and carers to criticise services could reduce the value of feedback. A number of strategies for encouraging a more critical stance were suggested: the use of an intermediary to collect data, rather than a member of staff directly involved in service provision (e.g. a voluntary organisation or carer support worker); or a carer forum where opportunities for mutual support could encourage frankness. Previous studies have emphasised the need for support to enable service users to contribute effectively to service development (Glynn *et al.*, 2008). On a less formal basis, person-centred care was facilitated by encouraging carers to request specific adjustments to the care provided to ensure that the service was tailored to the individual's needs and circumstances. Staff could find it difficult to criticise services because of a lack of comparator. Additional feedback could be obtained from students, visitors, audit and Dementia Care Mapping (see Section 5.5).

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### ***Management of change***

The way in which the organisation managed change also had a significant impact on the delivery of person-centred care. Even when individuals are willing and able to change, organisational support is needed to action change. Barriers to change included staff being used to current ways of working and reluctant to change, or staff feeling stressed and overwhelmed by existing work and thus not having the resources to be able to implement change. The lack of resources could act as a barrier to change in two ways. In some cases, changes cannot be implemented without additional resources; in others, the assumption that resources are needed to implement change can act as a barrier to creative thinking. In thinking creatively, staff can often improve the delivery of service without the use of additional resources. For example, a common misconception was that person-centred care equated to having a choice of activities. As this will always be resource intensive any attempts to think about ways that the service can be improved are abandoned. Some staff commented that it was the quality of day-to-day interactions that was most important:

‘I think person-centredness is as much about knowing the detail of someone’s everyday life as it is about the activities they like to do. So its much more about getting down to the absolute detail of what they like to do at home and the way they like to do it and what time they like to do it, which I think is much more easily facilitated. [...] it’s much more important to know that (person’s name) likes to rise at six thirty and she likes to have a cup of tea in bed before she gets up and she likes it to be Lady Grey and it’s got one sugar in [...] but she doesn’t take sugar in the rest of her tea all day’ (Staff 20, Care services manager for older people, Social Services, staff focus group 5)

There was often an assumption that the obstacles in changing services were so great that there was little point in trying, or that any poor care was caused solely by a lack of resources. Change was facilitated by a reflective cycle of thinking, trying, evaluating and thinking again. Dementia Care Mapping (see Section 5.5) was perceived as a useful tool in helping staff to see things from a different perspective and thus challenge existing attitudes.

## **4.9 Discussion and policy implications**

The barriers and facilitators to person-centred care identified in the present study were largely consistent with those reported in the literature. In particular, the strong emphasis on the personal qualities of staff has been reported in a number of previous studies (Francis and Netten, 2004; Glynn *et al.*, 2008; Godfrey, 2000; Innes *et al.*, 2006). Similarly, the importance of a shared culture or ethos which permeates the whole organisation has previously been highlighted (Brooker, 2007b; Pool, 2006; Sheard, 2004). Key barriers and facilitators identified in the present study are summarised in Figure 20.

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There were some discrepancies in the components of person-centred care and barriers identified in different studies. For example, communication was identified as a barrier in a previous study (Glynn *et al.*, 2008), whereas we included it as a component of person-centred care. Clearly communication can act as a barrier to person-centred care, however, in our view, communication is fundamental to person-centred care and therefore merits inclusion as a component.

There were some differences in emphases on some barriers to person-centred care. Funding, for example, appeared to have greater prominence in previous studies. Many of the issues relating to funding are particularly relevant to services such as home care (e.g. the amount of time allocated for certain activities, changes in contracts and working conditions). The relative lack of emphasis on funding as a barrier may reflect our focus on respite care and short breaks, which did not appear to be under the same pressure as home care. While there was a strong emphasis on managing staff in a person-centred way in the present study, there were few negative comments about management arrangements. Participants generally felt well supported, found their manager accessible and felt that managers understood and valued their role. In contrast, large differences in individual experiences regarding support were reported by Innes (2006). Again, it is difficult to know whether this reflects differences in management styles between different services or is simply due to the specific individuals who took part.

Although Direct Payments and user-led services have been identified as facilitators of person-centred care (Glynn *et al.*, 2008), these were not mentioned in the present study. This is likely to reflect the differing levels of politicisation among participants.

### **Figure 20. Key findings on facilitators and barriers to person-centred care**

- Personal qualities of staff are key to delivering person centred care, highlighting the need for good recruitment, development and retention procedures
- A shared culture is crucial to the delivery of person centred care
- The historical emphasis of respite services on a 'one size fits all' approach, which denies diversity or difference, is at odds with the implementation of person-centred care.

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## 5 Identifying potential structure, process and outcome measures for person-centred respite care and short breaks

### 5.1 Summary

This chapter reports a structured review of structure, process and outcome (Donabedian, 1980) measures suitable for evaluating person-centred care for people with dementia. The purpose of the review was to identify measures that had either been used to evaluate respite care and short breaks or which were potentially suitable for use in such evaluations. A range of measures was sought including self-completion rating scales and questionnaires for use by people with dementia or formal or informal carers and observational measures used by front-line staff or managers, independent auditors, inspectors or researchers.

Measures identified were assessed against a set of standard criteria for judging the quality of structure, process and outcome measures (Fitzpatrick *et al.*, 1998a; Fitzpatrick *et al.*, 1998b) and the components of person-centred care presented in Chapter 3. The review concluded that:

- no single existing measure was considered relevant for evaluation of person-centred respite care or short breaks in the UK
- items from some existing measures could be modified to develop new tools for the evaluation of person-centred care from the perspective of people with dementia, carers, and front-line staff in a range of services providing respite care and short breaks.

### 5.2 Introduction

The measurement of structure, process and outcome is now well embedded in the evaluation of health and social care interventions and services for people with dementia and their carers. However reviews have highlighted that a high proportion of measures used are inappropriate (Gill and Feinstein, 1994). During the last 10 years a number of condition-specific health-related quality of life measures have been developed for use as generic measures in the evaluation of dementia care (Brod *et al.*, 1999a; Brod *et al.*, 1999b; Ettema *et al.*, 2005; Ettema *et al.*, 2007a; Ettema *et al.*, 2007b; Gwyther, 1997; Kane, 1997; Rabins *et al.*, 1999; Revell *et al.*, 2002; Selai and Trimble, 1999; Sloane *et al.*, 2005; Smith *et al.*, 2005; Teno *et al.*, 1997; Trigg *et al.*, 2007). Although most would be suitable for use in evaluations of respite care and short breaks, none of these measures are designed to capture the key components of person-centred care.

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There are at least eight important considerations in choosing measures for the evaluation of dementia services: appropriateness, acceptability, reliability, validity, responsiveness, precision, interpretability and feasibility (Fitzpatrick *et al.*, 1998b).

### ***Appropriateness***

The appropriateness and relevance of the selected measure to people with dementia and their carers and the nature of the intervention proposed are perhaps the most fundamental considerations in selecting measures. In relation to people with dementia a major dilemma has been who determines appropriateness: the individual themselves; their carer; or the researcher? In the past there has been a bias towards the perspectives of researchers and carers. Reflecting the cultural and professional beliefs about the nature of the disease, the perspective of the person with dementia has, until recently, been ignored (Cotrell and Schulz, 1993). For this study, appropriate measures are those which encompass the components of person-centred care described in Chapter 3.

### ***Acceptability***

Unless a measure is acceptable to the person completing it, judgements about its quality are irrelevant. Measures need to be both relevant to the participant and culturally appropriate since there is an increased likelihood of response bias if they are not. Response bias can also be exacerbated by poor quality administration, presentation and length of instruments. It is self-evident that people with poorer health status are less likely to complete measures than those with better health status. It is therefore essential to consider the acceptability of any measure to people with dementia or their carers.

### ***Reliability***

There are a number of different aspects to the assessment of reliability: internal consistency, inter-rater reliability and repeatability. In general most measures are based on a single construct such as activities of daily living or social isolation. It has long been recognised that measures based on a number of related items are more likely to produce a reliable estimate than a single item. For this to be the case, items need to be sufficiently homogenous and therefore have high inter-item correlations or high internal consistency (Cronbach, 1951). It is important that items are not too highly correlated otherwise they will be measuring a very restricted aspect.

For measures administered by individuals we also need to estimate the bias generated by using one or more raters in their administration. In dementia research inter-rater reliability has been a focus of attention in the development of screening and diagnostic tools. Inter-rater reliability has generally been estimated using coefficients of agreement such as Kappa (Cohen, 1960; Cohen, 1968) or intra-class correlation coefficients.

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The third aspect of reliability is reproducibility, the importance of a measure yielding the same result on repeated applications assuming that there have not been any real changes in the person's situation. A concern of longitudinal research designs and the use of repeated measures is that participants may 'learn' the measures and remember their answers from previous administration. Reproducibility, however, is usually assessed by comparing two administrations of the measure a short time apart.

### ***Validity***

Since most measures are based on the perceptions of individuals there is no gold standard with which to compare. Criterion validity is therefore rarely estimated. Two other approaches to validity are equally important: content and construct validity. Content validity, sometimes referred to as face validity, concerns the inclusion of a diversity of items which cover the whole range of experience of individuals. Content validity can be qualitatively judged by consensus but it would be important to include not only researchers and carers but also people with dementia themselves.

Construct validity can be examined quantitatively by examining patterns of relationships with a range of other variables with which there are theoretical links.

### ***Responsiveness***

Increasingly research aims to capture changes over time. A key issue is therefore the ability of the selected measure to detect relevant changes over time. Judgements about the responsiveness of measures are often contested. Some studies have examined the degree of association between different variables over time in a similar way to determining construct validity. Another approach is to use a measure that is known to be responsive to a change in environmental factors such as an intervention of already proven effectiveness.

### ***Precision***

A challenge for all measures is the importance of covering the whole range of experience. Many commonly used measures have known ceiling and floor effects: being unable to detect improvements or deterioration beyond certain points on the measure. Precision is often more apparent than real. Most measures are ordinal but in analysis are inappropriately treated as if they are interval or ratio measures.

### ***Interpretability***

Many measures are not immediately intuitively understandable since it is not clear what any numerical value represents. Repeated use of reliable, valid and responsive measures aggregates experience within the research community which allows increasing familiarity with researchers and the audiences of research. Commonly used measures such as the Mini-Mental State Examination (MMSE, Folstein *et al.*, 1975) which is widely used to 'measure' cognitive function generate 'norms' that began as judgements

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based on individual research studies but which eventually become accepted as having shared meaning. Interpretability can be increased for new measures by calibrating scores against other theoretically relevant variables, existing measures or professional judgements. However there is a danger in the latter approach because the perspective of the researcher may not reflect that of the individual with dementia or their carer.

### ***Feasibility***

Last, but by no means least, is the importance of the use of measures being feasible. There are opportunity costs in data collection and analysis if measures are too complex or long. Brief measures may be feasible to administer but may be inappropriate. Feasibility is important but all too often cost considerations in the choice of a measure override the key consideration of appropriateness.

In dementia research few, if any, of the measures used satisfy adequately all of the above criteria, but they are often better than using nothing. For the purposes of this review we concentrated on appropriateness, acceptability and feasibility.

### **5.3 Resumé of methods**

The starting point for the identification of measures was a review of reviews. We used the search strategy used by Arksey *et al.* (2004) to identify evaluative studies of respite care and short breaks, adding the term 'measure' or 'measures' and applying review filters. We supplemented this with searches of: observational measures used with people with dementia; the Proqolid database (Patient reported outcome and quality of life instrument database); citations of key papers; and secondary references. Copies of papers and details of identified measures were then obtained.

A member of the research team (MP) summarised the characteristics of each measure identified against the quality criteria described above. A series of workshops including the full research team were then held to consider the relevance of the main domains of each measure to the nine components of person-centred care (Chapter 3).

### **5.4 Relevance of existing measures to person-centred care**

Over 350 measures were reviewed. Although many measures initially appeared to be relevant, further examination often indicated a poor match with the components of person-centred care.

One important finding was that many of the existing measures focused on individual characteristics of stakeholders, rather than on the practicalities and impact of service delivery. For people with dementia, this can be summarised as a tendency to focus upon deficits of the condition rather than how the service is designed around supporting the person. Similarly for carers, many existing measures captured the broader experiences of

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caring for a person with dementia such as burden, coping, implications for health and relationships, rather than how services impacted on such factors, for example how a service may enhance building new relationships, or share the burden of care.

For front-line staff, many measures focused on negative aspects of providing care for people with dementia, for example, exploring how problematic behavioural traits could result in burden and stresses for staff. Other measures considered task-oriented aspects of providing physical care. The focus of many measures did not, therefore fit well with our components of person-centred care.

Many measures had been designed for, or used with, participants in residential and nursing homes. Such measures were often more relevant to traditional respite services and were less compatible with more innovative approaches to respite care and short breaks.

The review of measures also indicated a change in emphasis over time, with older measures often focusing on the deficits and problems associated with dementia and caring for people with dementia while more recent measures considered the quality of life of the person with dementia and potential benefits and rewards for family carers and front-line staff.

No single measure was found which captured all of the components of person-centred care and could be applied to all models of respite care and short breaks. Overall, 24 measures were identified which included items relevant to person-centred care. Data on the development, acceptability and feasibility of measures containing domains or items relevant to person-centred care were summarised (see Section 5.5). Identified items were subsequently discussed in detail by small working groups of team members as part of the process of tool development (Chapter 6).

### **5.5 Measures including items relevant to person-centred care**

Some of the measures reviewed were grounded in explicit theoretical positions, while others provided no practical or theoretical basis for the selection of items. The administration of measures was varied and included self-completion questionnaires, observational measures and interviews. The majority of measures focused on the perspectives of staff and carers, most were from the US or UK and just under half had been developed specifically for use in dementia (Table 9).

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**Table 9. Summary of characteristics of measures containing items of relevance to the components of person-centred care**

|                                       | Number of measures<br>(n=24) |
|---------------------------------------|------------------------------|
| <b><i>Year of publication:</i></b>    |                              |
| Pre-1988                              | 2                            |
| 1988 – 1997                           | 7                            |
| 1998 – 2007                           | 15                           |
| <b><i>Mode of administration:</i></b> |                              |
| Postal survey                         | 3                            |
| Self-completion questionnaire         | 11                           |
| Interview                             | 7                            |
| Observation                           | 3                            |
| <b><i>Respondent:</i></b>             |                              |
| Older person                          | 3                            |
| Person with dementia                  | 2                            |
| Carer                                 | 9                            |
| Staff                                 | 10                           |
| <b><i>Country of origin:</i></b>      |                              |
| US                                    | 12                           |
| UK                                    | 9                            |
| Other European                        | 3                            |
| <b><i>Type of measure:</i></b>        |                              |
| Dementia specific                     | 10                           |
| Generic                               | 14                           |

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Although some of the 24 measures selected were not specifically designed for use in services providing respite care or short breaks, all selected measures had been used within services for people with dementia either with people with dementia themselves, their carers or front-line staff. Each of the 24 measures is briefly summarised below; information on acceptability, feasibility, reliability and validity is presented where available.

**Adult Day Service Benefits and Drawbacks Scale (ADS), (Jarrott *et al.*, 1999)**

This scale was developed to assess carers' positive and negative perceptions of adult day care services for older people with dementia in the US. The scale includes 12 items focusing on perceptions of: staff; service availability; cost; and activities provided. The scale is part of a broader measure which also assesses carer satisfaction. Both the Satisfaction Scale and Benefits and Drawbacks Scale were used to assess changes in carer experience over time (Jarrott *et al.*, 1999).

Response rates appear to be acceptable. The ADS scale was designed for use in face-to-face interviews, but a shorter version has been used for telephone interviews (Jarrott *et al.*, 1999).

**Assisted Living Family Member Satisfaction Scale (ALFMSS), (Edelman *et al.*, 2006)**

The ALFMSS scale was designed to assess carers' satisfaction with residential care for older adults with disabilities in the US. The measure includes 25 items grouped into five subscales: staff responsiveness; resident responsiveness; activities; transportation; and carer impact. Carers were involved in developing the measure. Items assessing direct and indirect experiences of care are included. For example, carers' perceptions of care given to their relative and their own experience of the staff are considered, as well as items pertaining to the direct impact for carers and how it impacts on their relationships with their relative.

No information is available on response rates, but the scale is reported to be reliable and valid (Edelman *et al.*, 2006).

**Assisted Living Resident Satisfaction Scale (ALRSS), (Edelman *et al.*, 2006)**

The scale was designed to assess residents' satisfaction with residential care for older adults with disabilities in the US. The scale consists of 18 items and nine subscales covering issues such as: safety/peace of mind; staff; autonomy; privacy and activities. Residents of assisted living facilities were involved in the development of the measure.

A response rate of 66 per cent was achieved, although 15 per cent of returned questionnaires included missing items. The scale is reported to be reliable and valid (Edelman *et al.*, 2006).

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### **Carers Assessment of Difficulties Index (CADI) (Nolan and Grant, 1992)**

This measure was developed to assess multiple dimensions of carer burden and was administered across a mixed range of carers in the UK. The measure comprises 30 items grouped into eight domains including aspects of social life; economic situation; professional and family support; and carer's reactions to the demands of caring. Carers rate whether each problem applies to them and, if so, how stressful they find it. The measure can be administered in a face-to-face interview or self-completion format.

Good internal consistency was reported for the eight subscales, however the authors note that a principal limitation of the measure is that all items are phrased negatively and suggest rephrasing as a means of future development. Acceptability to carers is unclear; carers were not directly involved in the development of the measure or individual items. A response rate of 35 per cent was reported to a mailing with a newsletter of a carers' association. Among carers of older people recruited through old age psychiatry services, 52 percent were reported to have difficulty responding (Malfullul, 2002).

Charlesworth *et al.* (2007) explored the psychometric properties of the CADI specifically with carers of people with dementia in the UK. The items included are described as meaningful to carers of people with dementia. There were few problems with missing data when carers were supported to complete the questionnaire. It has been suggested that further work is needed to explore criterion validity, test-retest reliability and sensitivity to change (Charlesworth *et al.*, 2007). Although the measure was not developed or tested for carers specifically accessing respite care or short breaks, items relating to carer health and well-being are relevant to the components of person-centred care.

### **Combined Assessment of Residential Environments (CARE) Profile (Relatives scale) (Faulkner *et al.*, 2006)**

The next three measures are all based on an events frequency approach to measure positive events from the perspectives of relatives, residents and staff in residential environments in the UK. Each of the scales consist of 30 items categorised by the 'senses' framework (Nolan *et al.*, 2004): a sense of security; a sense of belonging; a sense of continuity; a sense of purpose; a sense of achievement; and a sense of significance. Key stakeholders were involved in aspects of the development such as item generation and judgement of item inclusion in the measure.

Data on response rates to the Relatives scale is not available since the self-completion questionnaire was distributed by staff at participating homes. The scale had high internal consistency but there was a tendency towards a ceiling effect. The range of item non-response rates is not reported, although in excess of 30 per cent of relatives did not respond to one item. The authors conclude that the CARE profiles offer a reliable means of identifying positive events in care homes.

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### **Combined Assessment of Residential Environments (CARE) Profile (Residents scale) (Faulkner *et al.*, 2006)**

A brief description of this measure is given above. Response rates of 70 per cent were achieved to the Residents scale, suggesting that the measure is acceptable to residents. Internal consistency is reported to be acceptable. The measure is not dementia-specific and the authors note that the scale may not adequately represent the experiences of cognitively impaired residents. Although developed for use in residential care, several items were identified which were applicable to respite care and short breaks.

### **Combined Assessment of Residential Environments (CARE) Profile (Staff scale) (Faulkner *et al.*, 2006)**

This measure is described above. Response rates of 80 per cent were achieved for staff. Internal consistency is reported to be acceptable. Although developed for residential settings, some items were transferrable such as those relating to working with others, skills and feelings about work.

### **Carers of Older People in Europe COPE Index (McKee *et al.*, 2003)**

This measure was designed to assess positive and negative perceptions of caring among carers of older people in five European countries. The scale includes 15 items relating to support, relationships, coping, health and emotional well-being. The measure was reviewed by an expert panel and panels of carers.

Criterion validity was assessed against a 'gold standard' of instruments measuring mental health and quality of life with well-established validity and reliability. Satisfactory internal consistency was reported. The measure is neither dementia-specific, nor designed specifically for carers accessing respite care and short breaks; however items relating to concepts such as support are relevant to the components of person-centred care.

### **COPE Inventory (Carver *et al.*, 1989)**

This multi-dimensional coping inventory was developed with university students in the US to assess different ways people respond to stress. It includes 60 items grouped into 15 subscales. The measure considers active coping strategies and incorporates problem-focused coping and emotional-focused coping. Along with a range of other measures, this measure was utilised to assess how participants coped with stress as a result of caring for persons with dementia (Kosberg *et al.*, 2007).

The measure is reported to have good test-retest reliability.

### **Dementia Care Mapping (Brooker, 2005; Brooker and Surr, 2006; Kitwood and Bredin, 1992)**

Dementia Care Mapping is a well-established observational tool which is grounded in the theoretical perspective of person-centred care (Kitwood and Bredin, 1992). It is designed for use in communal services and has been used in day care services (Edelman *et al.*, 2005; Edelman *et al.*, 2004;

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Kuhn *et al.*, 2005; Surr and Bonde Neilson, 2003) and to evaluate a short holiday break service (Brooker, 2001). In view of the theoretical links to person-centred care and the extensive use of DCM, we conducted a detailed review of papers relating to this tool.

A trained observer ('mapper') observes five people with dementia and at the end of each five minute period assigns codes indicating:

- what the person with dementia has been doing in the time period using a list of 24 behaviour categories
- the level of well-being or ill-being of each person with dementia (based on their mood state and level of engagement).

The mapper also records any staff behaviours which support (personal enhancers) or undermine (personal detractors) the personhood of the person with dementia (Brooker and Surr, 2006).

Examination of the three coding frames used in DCM indicates that all of the components of person-centred care are represented (Table 10). However, the relationship between DCM codes and components of person-centred care is not straightforward since many DCM codes could relate to more than one component of person-centred care depending on the context. For example, celebration – a behaviour category summarised as recognising, supporting and taking delight in the skills and achievements of the person with dementia, could relate to respecting individuality, enhancing psychological well-being or developing a therapeutic alliance depending on the emphasis, tone and relationship between the person with dementia and staff member. It is therefore not possible to use DCM to produce quantitative data relating to each component of person-centred care. The emphasis given to different components of person-centred care varies in DCM, with a strong focus on psychological well-being and social context and relationships (Table 10).

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**Table 10. Relationship between components of person-centred care and codes used in Dementia Care Mapping**

| Components of person-centred care | DCM coding frame     |                        |                                   |
|-----------------------------------|----------------------|------------------------|-----------------------------------|
|                                   | Behaviour categories | Well-being / ill-being | Personal enhancers and detractors |
| Respect                           | ✓                    |                        | ✓                                 |
| Psychological well-being          | ✓                    | ✓                      | ✓                                 |
| Autonomy                          | ✓                    |                        | ✓                                 |
| Shared responsibility             |                      |                        | ✓                                 |
| Social context and relationships  | ✓                    | ✓                      | ✓                                 |
| Communication                     | ✓                    |                        | ✓                                 |
| Physical and personal needs       | ✓                    |                        |                                   |
| Therapeutic alliance              |                      |                        | ✓                                 |
| Valuing expertise                 |                      |                        | ✓                                 |

The acceptability of DCM is high (Brooker *et al.*, 1998) and it is said to have high face validity (Beavis *et al.*, 2002; Brooker *et al.*, 1998). It has been used successfully as a tool for practice development (Brooker *et al.*, 1998; Innes and Kelly, 2007). There are, however, a number of issues relating to the feasibility of DCM. An intensive three-day training course is required in order to qualify as a mapper. Although a continuous six hour period of mapping is recommended, a number of studies have explored the feasibility of using shorter time periods (Barnes, 2006; Fossey *et al.*, 2002; Fulton *et al.*, 2006). A streamlined version of DCM has been produced (Brooker, 2007a), but is not currently in the public domain.

Data regarding reliability are inconsistent; while some studies report acceptable levels of inter-rater reliability (Beavis *et al.*, 2002; Kuhn *et al.*, 2005; Kuhn *et al.*, 2002), other studies have found poor agreement between raters (Thornton *et al.*, 2004). Comparison of DCM with existing validated outcome measures has also produced inconsistent findings (Brooker, 2005; Chenoweth and Jeon, 2007; Edelman *et al.*, 2005). Much of the work on the psychometric properties of DCM has been based on version 7; this has now been replaced by version 8. Although version 8 has been shown to have concurrent validity with version 7, further validation work is needed (Brooker and Surr, 2006).

A number of shortcomings of DCM have been identified. The extent to which it captures the perspectives of people with dementia has been questioned (Capstick, 2003; Edelman *et al.*, 2005). The underlying assumptions regarding well-being may not be equally applicable to all

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people with dementia (Bamford and Bruce, 2000; Capstick, 2003), particularly those from non-Western cultures (Kwok, 2003). It has been suggested that staff may avoid the mapping area or maintain a caring role during mapping, giving an inaccurate picture of 'usual' care (Innes and Kelly, 2007). Allocating a summary code to each five minute period may fail to capture the subtleties of action and interaction (Innes and Kelly, 2007) and underestimate passive and withdrawn behaviours (Thornton *et al.*, 2004). In the context of the present study, a major limitation of DCM is that it has only been used in communal services.

In view of the relevance of the content of DCM to the components of person-centred care, it clearly has potential to inform the development of the tools in the present study.

### **DEMQOL (Smith *et al.*, 2005)**

This measure is a Health-related-Quality-of-Life measure for people with mild to moderate dementia and their carers (DEMQOL proxy). The measure includes 28 items in five domains: daily activities and looking after yourself; health and well-being; cognitive functioning; social relationships; and self-concept. People with dementia, carers and an expert panel were involved in developing the conceptual framework underpinning the measure. Although not specifically tested within services providing respite care and short breaks, DEMQOL has been used successfully in the community and residential, nursing, or dual-registered homes.

The measure is reported to meet liberal criterion for missing data in terms of acceptability. For reliability, high internal consistency and good test-retest reliability is reported. Content validity was ensured by developing items representing all aspects of the conceptual framework. Moderate evidence of convergent and discriminant validity were reported in support of construct validity.

### **Dementia Quality of Life Instrument (DQoL) (Brod *et al.*, 1999b)**

The Dementia Quality of Life measure was developed in the US for persons with mild to moderate dementia. The purpose of the measure is to allow the person with dementia to report on their own subjective state via direct interview. Items were generated with people with mild to moderate dementia, carers and health care providers to develop meaningful domains. The measure includes 29 items in five domains: aesthetics; positive affect/humour; absence of negative affect; self-esteem; and feelings of belonging.

Ninety-six per cent of people with mild to moderate dementia were able to respond to questions appropriately. The measure is reported to be both valid and reliable. Construct validity was explored by comparison with an established measure, and correlations amongst scales of each domain were applied. Item test-retest reliability, internal consistency for multi-dimensional scales and test-retest reliability were all considered. Although the measure was developed and tested within residential and nursing

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homes, items appear relevant to services providing respite care and short breaks.

### **Home Care Satisfaction Measure (Geron *et al.*, 2000)**

This measure of satisfaction was designed for use with frail older adults in the US receiving various services within their home such as assistance with health care, personal care and meals. The development of the measure was based on the perspectives of an ethnically diverse sample of home care clients. A total of 60 items relating to five subscales are included. Each subscale focuses on a particular service, for example, home health aides or home delivered meals. Although this measure is neither dementia nor respite specific, scales addressing general issues such as interaction with the service user and responsiveness to individual needs are relevant to services providing respite care and short breaks.

The measure is reported to be easy to administer in a face-to-face interview and a telephone version has also been developed. The authors report high test-retest reliability, good internal consistency and concurrent validity for overall scores and subscales.

### **Maslach Burnout Inventory (MBI) (Maslach and Jackson, 1981)**

This scale was originally developed in the US and administered to a range of human service professionals to measure burnout as a result of their role. Items were developed following an explanatory phase of research involving interviews, questionnaire surveys and observation. The MBI includes 25 items in three subscales: emotional exhaustion; depersonalization; and personal accomplishment. The scale includes items relating to the emotional and physical aspects of providing care and also considers the positive and negative aspects of care provision. Respondents rate the frequency and intensity of each item.

Convergent validity, external validity and discriminant validity were reported and reliability demonstrated. Although the original measure was not dementia-specific, the MBI has been used successfully with staff carers of people with dementia and intellectual disabilities in the US (McCallion *et al.*, 2006).

### **Nursing Home Hassles Scale (Stephens *et al.*, 1991)**

The Nursing Home Hassles scale was devised in the US to identify sources of stress for carers of persons with Alzheimer's disease who had made the transition from home to residential care. The 28 items are grouped into three subscales focusing on: interactions between family and staff; interactions between staff and the patients; and practical/logistical issues (e.g. driving to and from the nursing home). The items were derived from a literature review and discussions with carers whose family members lived in nursing homes. The scale is administered in a face-to-face interview and carers are asked to indicate whether an event has occurred recently and, if so, to rate how much of a hassle it was.

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The subscales have been demonstrated to have adequate internal consistency. Subsequent research has shown a relationship between the scale and measures of carer well-being and burnout (Almberg *et al.*, 2000).

### **Nursing Stress Scale (NSS) (Graytoft and Anderson, 1981)**

This scale was originally designed for nursing staff in the US to measure aspects of stress related to professional caring in the hospital environment. The scale consists of 34 items grouped into seven subscales and includes items relating to conflict with colleagues and lack of support. Subscales from the NSS were included in a questionnaire to assess staff morale in nursing and residential care for older people in the UK (Parker *et al.*, 2004). Individual items from subscales regarding workload and support were considered relevant to the present study.

Internal consistency and test-retest reliability are reported by the authors and validity of the original measure was determined by correlation with measures of stressors.

### **Nursing Unit Rating Scale (NURS) (Grant, 1996)**

The NURS scale was developed in the US to compare the social environment of specialised and non-specialised dementia care units. The scale includes 81 items relating to policy and programme features of the environment which are not easily observable. Six environmental dimensions are included: separation, stability, stimulation, complexity, control/tolerance, and continuity.

The subscales show moderate to high internal consistency and the scale has been shown to discriminate between integrated facilities and special care units for people with dementia (Morgan *et al.*, 2004).

### **The Organisation and Culture Questionnaire (Walker *et al.*, 2001)**

This measure is a self-completion questionnaire for staff providing day care for people with dementia in the UK. The purpose of the questionnaire is to allow staff to reflect on the culture within their particular organisation. It was adapted from an earlier questionnaire (Bate, 1994). The measure consists of 11 items focusing on shared values, team perspectives, teamwork, conflict/harmony, change and reflection, and communication.

Although the questionnaire was specifically designed for staff delivering dementia-specific day care, items were applicable to staff in all models of respite care and short breaks.

### **Pearlin Caregiving Measures for Carers for People with Alzheimer's (Pearlin *et al.*, 1990)**

This measure was designed in the US, and is a widely known and used measure, from which many studies and authors have used or adapted specific scales. The original measure was designed to outline a conceptual scheme of carer stress for carers of persons with Alzheimer's Disease and assessed multiple components of stress. The scale consists of 95 items

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grouped into 15 subscales. The subscales include a range of positive and negative items pertaining to primary and secondary stressors.

The majority of the subscales have been shown to have acceptable internal consistency. Little information is available on the validity of the scale.

### **PSSRU Day Care Questionnaire (Reilly *et al.*, 2006)**

This measure consists of a postal questionnaire designed for completion by providers of day hospitals and day centres for older people with dementia in the UK. The purpose of the questionnaire was to compare the types and standards of care provided. The questionnaire includes 55 questions relating to four main categories: service structure; care processes; service content; and service quality. The questionnaire takes approximately one hour to complete. Although many items require responses in tick box format, respondents are also asked to indicate their degree of confidence in the information provided.

A response rate of 76 per cent was achieved after one reminder. The questionnaire was found to have acceptable internal consistency. The authors report that the questionnaire was sufficiently reliable to allow an acceptable estimate of service quality. Although the questionnaire was designed for day care providers, items were considered relevant for assessing carers' perceptions of the timing, availability and flexibility of a range of respite care and short break services.

### **QUALIDEM (Ettema *et al.*, 2007b; Ettema *et al.*, 2007a)**

This measure is designed for use by healthcare professionals to produce a quality of life profile for people with all stages of dementia living in residential settings. The 49 items in the questionnaire describe observable behaviours and relate to nine subscales including affect, relationships and activity. Six of the subscales are relevant to people with severe dementia. Items were developed from a literature review, focus group with people with dementia and participant observation. The pool of items generated was then reviewed by expert panels.

The instrument is described as easy to administer, taking approximately 15 minutes to complete. Item non-response was low. Although one scale was reported to be weak, the remaining eight subscales showed moderate to strong scalability. The inter-rater reliability co-efficient was modest. The scale is reported as sufficiently reliable within residential settings to provide a QOL profile of persons with dementia.

### **Sheffield Care Environmental Assessment Matrix (SCEAM) (Parker *et al.*, 2004)**

SCEAM is an observational tool designed in the UK to assess the physical environment and building design of residential and nursing homes for older people. The tool is based on 11 domains (ten resident and one staff domain) and focuses on the impact of over 300 building features which can enhance quality of life. The ten resident domains evaluate universal

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(privacy, ability to personalise surroundings, choice and control, and connection with the wider community), physical (safety and health, support for physical frailty, comfort) and cognitive (support for cognitive frailty, awareness of outside world, domestic environment) requirements. The staff domain comprises seven items relating to provision for staff.

This tool is reported to have high face and content validity, good internal consistency and good inter-rater reliability. Significant positive associations were found between aspects of the built environment and residents' quality of life. Although designed as an observational measure, items regarding choice and control such as free access to outdoor spaces were considered relevant to the present study.

### **Satisfaction with Nursing Home Instrument (SNHI) (Ryden *et al.*, 2000)**

This scale was designed to assess feelings of satisfaction with various aspects of care provided to nursing home residents in the US. The scale consists of 29 items relating to six dimensions: respect; information; physical care; psychological care; involvement of family; and satisfaction with the environment. The relevance of the dimensions and clarity of questions were reviewed by nurses and focus groups with residents of nursing homes.

The scale is interviewer administered. Construct validity was reviewed by comparison with other theoretically-related measures. The measure was found to have acceptable internal consistency. Although this instrument was designed for use in residential settings and is non-dementia specific, many of the items were relevant to all models of respite care and short breaks.

### **Swedish Satisfaction with Nursing Care and Work Scale (SNCW) (Hallberg and Norberg, 1995)**

This measure was originally designed in Sweden to measure staff perceptions of their nursing role. The 35 items cover five domains: co-operation; development; quality of care; workload; and knowledge of patients. The items explore staff opinions about their individual work role as well as team working. There are a range of positive and negative items.

The Swedish version of the scale has been demonstrated to be reliable and valid. An English translation of the scale was used in a study of staff attitudes towards residents with dementia in Australian nursing homes, (Brodsky *et al.*, 2003). Good completion rates were reported (in excess of 95 per cent). Although the reliability and validity of the English translation has not been established, there was some evidence of construct validity with nurses with more negative attitudes towards people with dementia reporting less job satisfaction.

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## 5.6 Conclusions

Over 350 papers reported structure, process or outcome measures potentially suitable for the evaluation of services providing respite care and short breaks. However, there was a poor match between the content of existing measures and components of person-centred care identified in Chapter 3. Only 24 measures were identified which related to the components of person-centred care.

Many of the measures that we found unsuitable for these purposes focused on the difficulties and problems associated with dementia and providing dementia care with relatively little emphasis on the role of services in providing support to individuals and family carers. Some measures designed for use in services such as nursing homes were not necessarily suitable for innovative services delivered in the community. The key findings from the review of existing measures are highlighted in Figure 21.

### Figure 21. Key findings on existing measures

- There is a poor 'fit' between existing measures used to evaluate respite care and short breaks and the components of person-centred care
- Available measures tend to be of limited value in evaluating innovative models of respite care and short breaks
- Few existing tools were suitable for use or interpretation by professionals for routine evaluation of their practice.

In Chapter 6 we describe how we developed composite and new tools based on items and approaches identified within the 24 measures that reflected person-centred care.

## 6 Tool development

### 6.1 Summary

The previous chapter considered the extent to which measures used to evaluate respite care and short breaks for people with dementia addressed the components of person-centred care identified in Chapter 3. Although useful items were identified from existing measures, all required modification. We developed tools to explore the perspectives of all three key stakeholder groups (people with dementia, carers and staff). While self-completion questionnaires were thought appropriate for carers and staff, a conversational interview guide was developed for people with dementia. These structured tools were supplemented with two more open-ended approaches: vignettes for discussion by staff and unstructured observation. We developed a series of vignettes for discussion by small groups of staff as a means of exploring issues relating to service culture and implicit views and approaches to person-centred care (identified as important barriers to person-centred care in Chapter 4). Unstructured observation was included partly to 'validate' the framework of components of person-centred care (Chapter 3), partly to contribute to the process of testing the structured tools, and partly to explore the feasibility of using this approach in different models of respite care and short breaks. This chapter describes the process of developing the tools.

### 6.2 Introduction

An over-riding concern was the wish to be inclusive and comprehensive; consequently it was important for the tools to collect the views of all three key stakeholder groups: people with dementia; carers of people with dementia; and staff. The tools used a variety of methods (see Appendices 3 to 7 for the final versions of the tools):

- structured conversational interview guide for people with dementia
- self-completion questionnaire for carers
- self-completion questionnaire for staff and volunteers
- vignettes for discussion by staff
- observation.

The different sources of data were intended to complement each other and, when combined, to produce a detailed picture of person-centred care within services providing respite care or short breaks. Triangulation of data in this way helps ensure validity and reliability (Denzin, 1970).

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As described in Chapter 5, we identified a pool of items from existing measures which were potentially relevant to the components of person-centred care. All items required modification to render them appropriate to the aims of the research. Some of the measures selected were adapted from their intended use, for example, we reworded some of the questions from tools designed for carers so that they were applicable to the person with dementia (e.g. ADS Benefits and Drawbacks Scale, Jarrott *et al.*, 1999) or revised the format of items (e.g. items from the CARE Residents Scale, Faulkner 2006, were reworded to fit with an interview format). In view of the relatively poor 'fit' between existing measures and the components of person-centred care, a range of new items was also developed.

### 6.3 Developing the tools

#### 6.3.1 Structured conversational interview guide for people with dementia

It is critical to develop tools that enable people with dementia to express their views about respite care and short breaks. Of course, as dementia progresses, communication deteriorates and it can be increasingly difficult for people with dementia to express their views (Murphy *et al.*, 2007). However, the perspectives of third parties, for example carers acting as proxy informants for a person with dementia, are not a substitute for the latter's own assessment (Mozley *et al.*, 1999; Novella *et al.*, 2001; Smith *et al.*, 2005). For example, carers tended to rate the quality of life of people with dementia lower, and quality of services higher, relative to ratings by people with dementia themselves (Aggarwal *et al.*, 2003). Recent work has shown that it is possible for people with dementia to engage in conversation and have their say about service provision and its impact on their quality of life (Aggarwal *et al.*, 2003; Allan, 2001; Carroll *et al.*, 2005; Mozley *et al.*, 1999; Reid *et al.*, 2001).

Studies suggest that the use of innovative techniques such as photographs (Allan, 2001; Bamford and Bruce, 2000), asking the person with dementia how they would describe the service to a friend (Aggarwal *et al.*, 2003) or talking mats (Murphy *et al.*, 2007) can facilitate conversations with people with dementia. The assumption underlying the use of projective techniques, such as photographs or asking how a friend would feel, is that faced with an ambiguous situation, people will react in ways that reflect their own thoughts, feelings and beliefs (Tashakkari and Teddlie, 2002). Previous experience suggests that some people with dementia are able to express less socially desirable views when projecting their views onto the person depicted in the photograph (Allan, 2001). Talking mats provide an alternative technique to facilitate conversation. They consist of: a textured mat on which pictorial symbols are placed as the conversation proceeds; a visual scale indicating emotions with a happy face on one side of the mat and an unhappy face on the other; pictorial symbols of the topics to be discussed (for example, activities, the environment); and pictures of the options relating to the topic (for example, music, reading, TV). The person

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with dementia can use verbal and indirect communication to place the picture under the emotional symbol that best corresponds to how they feel about the topic (happy, sad, not sure) (Murphy *et al.*, 2007). A key advantage of talking mats is that they provide an alternative focus that can help with pacing and reduce pressure to conform to normal conversational conventions, such as turn-taking (Murphy *et al.*, 2007).

After considered debate within the research team, it was decided to produce a short, straightforward set of questions about experiences and views of respite care and short breaks that could be asked on a one-to-one basis with a person with dementia. In line with recommendations about interviewing with people with dementia, we chose to use a conversational approach (Murphy, 2007). The questions focused on opinions and feelings about the services used, rather than on recall of facts (Murphy, 2007). Whilst the questions were to be administered conversationally, we planned to develop pre-coded categories from the responses generated to facilitate future analysis and interpretation. Our intention was to ask the questions when the person with dementia was using the service, to facilitate recall and help in articulating their views. The importance of immediacy in terms of time and place has been highlighted (Murphy, 2007), and previous studies have often collected data within the setting of interest (Aggarwal *et al.*, 2003; Bamford and Bruce, 2000; Mozley *et al.*, 1999). As with all interviews and questionnaires a particular concern when developing the individual questions was to use appropriate vocabulary and clear and simple sentences.

The starting point for constructing the interview guide was the nine components of person-centred care: respecting individuality and values; enhancing psychological well-being; promoting autonomy; promoting a sense of shared responsibility; fostering social context and relationships; enhancing communication; meeting physical and personal needs; developing a therapeutic alliance; and valuing expertise (see Chapter 3). Relevant items, questions or statements from existing measures used to evaluate respite care and short breaks (see Chapter 5) were mapped onto these components with a view to identifying items which could potentially be used in the interview. Having produced an initial pool of items, these were then refined; for example, the wording was simplified, and/or they were reworded as questions. Wherever possible, the actual name of the service was incorporated into individual questions. In this way, a structured interview guide was produced. Table 11 shows the relationship between questions included and components of person-centred care. (The final structured interview guide is reproduced in Appendix 3, together with a table indicating how the questions relate to specific components of person-centred care). No questions relating to 'valuing expertise' were included. This component is concerned largely with relatively rare events, such as assessment, review, evaluation of services and consultations with service users. Since it was unlikely that people with dementia would be able to recall such events, we elected not to include any questions on this component.

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**Table 11. Examples of questions from the structured conversational interview guide for people with dementia relating to components of person-centred care**

| Component                                  | Questions <sup>1</sup>  |
|--|---|
| Respecting individuality and values        | Do you ever feel rushed here?                                   |
| Enhancing psychological well-being         | How do you feel about coming here?                              |
| Promoting autonomy                         | Can you go outside when you want?                               |
| Promoting a sense of shared responsibility | How much choice do you have over what you do when you are here? |
| Fostering social context & relationships   | How do you get on with the other people here?                   |
| Enhancing communication                    | Do people have time to listen to you?                           |
| Meeting physical & personal needs          | What are the meals like here?                                   |
| Developing a therapeutic alliance          | Do people take an interest in you?                              |

<sup>1</sup> The wording of the illustrative questions is taken from the direct questions for services provided outside the home

As can be seen from the list of questions in Table 11, the term 'people' was used rather than 'staff' (the term employed in the carer and staff questionnaires). This was because it was thought that people with dementia would not necessarily make a distinction between (other) service users and staff, and therefore would not know who was being referred to. If the service was usually provided by one particular member of staff (e.g. in one-to-one services), then we included the name the member of staff was known by within questions when appropriate. For example, 'Can you tell me some of the things you do when <carer name> comes here?'

Three different versions of the structured conversational interview guide for people with dementia were produced for different types of respite care and short breaks: services provided outside the home; home-based services; and services delivered in another person's home. This was to make it easier for the interviewers since they would not then have to articulate different phrases to accommodate different types of services during the interview. When appropriate, additional questions were included to address specific issues of relevance. For example, questions about sleeping arrangements were included for services providing overnight care.

The guided conversation for people with dementia focused solely on components of person-centred care. We avoided including questions relating to facilitators and barriers since we wished to minimise the length of the guided conversation and to avoid questions which were reliant on memory, since this could put participants under undue stress.

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Projective techniques, using 'indirect questions' and photographs of unknown individuals, were also tested. A range of photographs was obtained to enable the interviewer to match the gender, ethnic background and age of the person in the photograph to the characteristics of the person with dementia being interviewed (see Appendix 4). The person with dementia was then asked what they thought the individual in the picture might think or feel about particular aspects of respite care and short breaks.

Although talking mats have been used successfully with people with dementia (Murphy *et al.*, 2007), the abstract and conceptual nature of the components of person-centred care, do not easily lend themselves to being conveyed pictorially. The necessary development work to identify appropriate ways of presenting the components of person-centred care which would be interpreted consistently by people with dementia would be a significant undertaking and was outside the scope of the present study. The use of talking mats was therefore not explored in the study.

### 6.3.2 Self-completion questionnaire for carers

A self-completion questionnaire that carers could fill in at their own convenience, and which would be relatively economical and easy to administer and analyse was selected as the most appropriate method of data collection. The questionnaire was intended to be quick and easy to complete, containing 25-30 questions with pre-defined response options before concluding with a small number of open questions. Carers were asked to indicate the strength of agreement and disagreement, for example, on issues such as relationships with staff, service quality and the impact of the service on their own lives and on the person with dementia, using a five-point Likert rating scale. The purpose of the questionnaire was to identify key issues in the delivery of person-centred respite care and short breaks and elicit carers' views of the service, specifically focusing on issues relevant to the components of person-centred care (in relation to both the person with dementia and the carer).

Unlike the interview guide for people with dementia, just one generic or universal questionnaire was developed which could be used across the range of services providing respite care and short breaks. The name of the service being evaluated was included in the questionnaire. This was to help carers to focus specifically on the service in question, rather than the care package as a whole.

In developing the questionnaire, particular attention was given to the clarity of language used; the relevance of the questions; length and time taken for completion; 'friendliness'; and sensitivity. The questionnaire was developed to encourage participants to answer as honestly as possible and to feel able to make both positive and negative comments about the service they were evaluating.

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The questionnaire was set out on four sides of A4 paper. The front cover set out the purpose of the survey, brief instructions about how to complete the questions and contact details for the research team. The remaining three pages were devoted to the questions.

A similar process for developing the questionnaire to that used for the interview guide for people with dementia was adopted. The research team worked together to assess the relevance of items in existing measures identified through the literature review to the nine components of person-centred care. This provided an initial pool of items. Duplicates were removed and minor alterations to wording were made. This was in order to include both positive and negative statements to avoid response bias where participants tick the same response category for each item (McColl *et al.*, 2001; Oppenheim, 1992). In addition, it was necessary to standardise items so that they conformed to response scales and question stem. Where no suitable items were identified, the team developed new questions, following principles of questionnaire design (McColl *et al.*, 2001; Oppenheim, 1992). The items were then organised into three groups focusing on:

- carers' views and experiences of the respite service being evaluated
- the impact of using the service on the carer
- the impact of using the service on the person with dementia.

Questions relating to the impact of the service on the person with dementia were included since there was considerable evidence both from the present study and previous studies (Brodsky, 2007) that carers value interventions that have a positive effect on both their own quality of life and that of the person with dementia. In developing questions about the impact of the service on the person with dementia we aimed to include aspects which would be directly observable by carers.

Different response scales were used, but each took the form of a five-point Likert rating scale; participants were asked to circle their chosen answer. Two different response scales were used for questions relating to views and experiences of respite care and short breaks: a five-point scale from 'strongly agree' to 'strongly disagree'; and a five-point scale from 'always' to 'never'. Questions concerning the impact of respite care and short breaks on the carer had five response categories ranging from 'a lot better' to 'a lot worse'. The questions focusing on the impact of the service on the person with dementia used a five-point scale from 'always' to 'never'. The final five questions were open-ended and intended to encourage reflection. They asked carers for the best and worst thing for the service for themselves, and the person with dementia, respectively, and also for ideas about how the service could be improved. Finally, there was an invitation for carers to add in any other comments they would like to make about the service.

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Table 12 shows the relationship between the components of person-centred care and selected questionnaire items. (The final questionnaire is available in Appendix 5, together with a table indicating how the questions relate to specific components of person-centred care).

**Table 12. Examples of questions from the carer questionnaire relating to components of person-centred care**

| Component                                  | Question   |
|--|--|
| Respecting individuality and values        | Staff do not show enough appreciation of my role as a carer  |
| Enhancing psychological well-being         | As a result of using the respite service, my mood or spirits are .....                             |
| Promoting autonomy                         | As a result of using the respite service, the amount of control I have over my daily life is ..... |
| Promoting a sense of shared responsibility | I would like to be more involved in making decisions about my relative's care                      |
| Fostering social context & relationships   | As a result of using the respite service, I enjoy the time I spend with my relative .....          |
| Enhancing communication                    | I would like more information about how my relative is getting on at the service                   |
| Meeting physical & personal needs          | As a result of using the service, my physical well-being is .....                                  |
| Developing a therapeutic alliance          | Staff have a good understanding of what I am going through   |
| Valuing expertise                          | My views on how the service is run are taken seriously by staff                                    |

In addition to questions relating to the components of person-centred care, we included a small number of questions relating to those facilitators and barriers to person-centred care given most emphasis in the focus groups and interviews with carers. These related to issues of continuity and reliability (see Chapter 4).

### 6.3.3 Self-completion questionnaire for staff

The underlying principles for the staff self-completion questionnaire were similar to those of the carer questionnaire: the aim was to produce a short, friendly questionnaire comprising 25-30 questions with pre-defined response options, together with a small number of open questions at the end. Again, the questionnaire was intended to be generic so that it could be used not only in a range of models of respite care and short breaks but also with a range of staff (including front-line staff, managers and/or team leaders, night staff and catering staff). The sensitivity of questions was seen as a key issue, in particular the need to encourage frank and honest responses.

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The format for the initial version of the staff questionnaire was similar to that of the carer questionnaire, in that the cover page again explained its purpose, and included instructions for completion and contact information for the research team. However, the remaining pages contained questions grouped into the following topic areas:

- service organisation and delivery
- team working
- training, skills and supervision
- aims of the service
- aspects of person-centred care.

Two different response scales were used for questions relating to staff views and experiences: a five-point scale from 'strongly agree' to 'strongly disagree'; and a five-point scale from 'always' to 'never'. Questions relating to service aims and aspects of person-centred care included pre-specified lists of options (including an 'other' option) from which staff were asked to identify the aims/aspects of person-centred care they thought were most important. The questionnaire finished with two open questions asking for staff views on providing more person-centred care to people with dementia and carers of people with dementia, respectively. Finally, there was an invitation to add other comments.

Table 13 shows the relationship between the components of person-centred care and selected questionnaire items. (The final questionnaire is available in Appendix 6, together with a table indicating how the questions relate to specific components of person-centred care).

**Table 13. Examples of questions from the staff questionnaire relating to components of person-centred care**

| Component <sup>1</sup>                     | Questions  |
|--|--|
| Respecting individuality and values        | I feel appreciated by my manager                                       |
| Enhancing psychological well-being         | My duties at work are satisfying                                       |
| Promoting autonomy                         | There are opportunities to try out new ideas at work                   |
| Promoting a sense of shared responsibility | I can approach my manager if I have a problem at work                  |
| Fostering social context & relationships   | There is a friendly atmosphere in our team                             |
| Enhancing communication                    | There are opportunities to talk through difficult situations if needed |
| Meeting physical & personal needs          | I worry about being injured at work                                    |
| Valuing expertise                          | My opinions are considered when changes are made at work               |

<sup>1</sup> No questions relating to developing a therapeutic alliance were included since staff were not the recipients of therapeutic alliance

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In addition to including questions relating to the components of person-centred care (as applied to staff), we also developed questions relating to key facilitators and barriers to person-centred care (Table 14).

**Table 14. Examples of questions from the staff questionnaire relating to facilitators and barriers to person-centred care**

| <b>Facilitator or barrier</b>         | <b>Question</b>   |
|---------------------------------------|---|
| External constraints                  | It is difficult to get everything done in the time available  |
| Exchanging and using information      | I have all the information I need to care for service users   |
| Service ethos or culture              | What do you think are the three most important aims of the service?   |
| Supervision and training              | During supervision, I am given useful feedback about how I do my job  |
| Approach to reflection and change     | There is enough time to discuss ways of improving the service   |
| Understandings of person-centred care | What do you think are the three most important aspects of providing care for people with dementia and their carers? |

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### 6.3.4 Vignettes for staff discussion

The use of vignettes for data collection is a well-established technique in social science research. Vignettes in relation to quantitative research, have been described as 'short stories about hypothetical characters in specified circumstances, to whose situation the interviewee is invited to respond' (Finch, 1987). Vignettes can be used, either on an individual basis or within a focus group setting, to help elicit perceptions, opinions, beliefs and attitudes regarding the situations described in the vignettes (Barter and Renold, 1999). As with other methods used in attitudinal research the use of vignettes to help elicit participants' perceptions, beliefs, opinions or attitudes does not always reflect actual behaviour or real world responses to situations represented in the vignettes (Hughes, 1998).

In relation to the present study, vignettes were identified as a way to stimulate group discussion of person-centred care amongst front-line staff, for example in a team meeting. As well as facilitating discussion, the vignettes had other aims: to be educational; to illustrate different interpretations and levels of understanding of person-centred care; to help staff reflect on common issues that can arise when looking after a person with dementia; to prompt them to consider possible courses of action in response to the different situations; and to encourage them to think creatively about their own individual practice, and the practice of the team as a whole. It was thought that because they were commenting on hypothetical situations rather than their own (and/or colleagues') actual practice, they might be more critical, and/or less inhibited or self-conscious, in their responses.

A document containing vignettes, and an activity relating to a real situation, was produced. Three vignettes were constructed to cover diverse situations and a range of services, service users and home circumstances. The vignettes described situations where the main actor was the person with the dementia, but where a carer (e.g. partner or adult child) was also involved. The vignettes raised practical and ethical issues and dilemmas related to best practice when delivering person-centred care, for example addressing issues relating to choice, identity, independence, skills, social networks and friendships, finances, communication, risk taking, knowledge and understanding of the impact of dementia. The first vignette in the document is presented in Figure 22.

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**Figure 22. Example vignette**

### **Jack and Susan**

The Beeches is a day centre specifically for people with dementia.

- Jack is a 68 year old widower who lives alone. Until a few years ago, he had been a keen gardener, winning several prizes for the leeks he grew on his allotment. Jack was diagnosed with Alzheimer's disease a year ago. He no longer keeps in contact with his remaining friends from the allotment. Carers help him with cooking, shopping and washing. His daughter, Susan, has taken responsibility for Jack's financial affairs as he was no longer able to manage to pay his bills.
- Susan is a single parent who lives 40 miles away with her three young children. She feels upset that her dad has changed and that she now has to look after him. Susan feels guilty that she doesn't visit him more often, but it is difficult to find the time and the money.
- Jack's social worker felt that he was socially isolated and would benefit from day care at the Beeches. Jack settled in well as there are some other men there with similar interests. Staff at the Beeches have organised to take the group of men out to a National Trust garden for the day. The cost will be £15 per person for transport, lunch and admission. They approach Susan for the money who says that it would be pointless as Jack won't remember going and it will disrupt his routine.

Standardised questions to explore understandings of person-centred care were included at the end of each of the three vignettes. The questions encouraged staff to look at the same situation from the perspectives of the person with dementia (Jack), a family member (Susan), and the staff at the Beeches, respectively and explore what they felt were the important issues for these three stakeholders. Finally, they were asked to consider how staff might react and what they could do to improve the situation.

Possible solutions were provided for each of the three vignettes (on a different page of the document so that they were not immediately visible to readers). Again, these were intended to provoke debate rather than to be seen as the 'right' or only solutions. In the case of Jack and Susan, for example, it was suggested that: Jack could be asked what he wanted to do, and other options could be explored such as visiting his allotment with staff from the Beeches; alternative sources of funding could be explored to reduce costs of activities and outings; Susan could be provided with more support; communication between the Beeches and Susan could be improved; and an independent advocate could be brought in.

The final activity in the document built on the previous three hypothetical situations, by asking staff to consider a real event or situation involving a service user with dementia that had resulted in poor or disappointing outcomes. It was suggested, for example, that they might consider the last person with dementia who had left the service; a service user with whom staff found it difficult to establish rapport; a service user who did not seem to 'fit in' with other people; and a carer with whom it was difficult to

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establish a relationship. Staff were then asked to apply the techniques they had just been using to this real life situation, with a view to identifying alternative behaviours and practices they could adopt to manage the situation differently and in this way achieve better results.

The vignettes were fictional but were based on real experiences drawn from the interviews and focus groups conducted earlier in the study (see Chapters 3 and 4). We thought this would ensure that the stories appeared authentic and plausible. To further enhance validity, members of the Reference Group reviewed the vignettes and suggested a number of changes based on their own knowledge and expertise of dementia. One of the methodological challenges in developing the vignettes was in providing the right level of detail: too much information could stifle discussion; insufficient information which was vague or ambiguous could result in staff discussing the details rather than focusing on the standardised questions.

The intention was to use the vignettes in a group situation. The front cover of the document outlined the purpose of the exercise, and gave brief instructions for how to carry it out. It was suggested that the group discussions did not need to be facilitated, but that every effort should be made to make sure that everyone taking part had an opportunity to contribute.

### 6.3.5 Observation

Observation offers an inclusive approach to data collection since all people with dementia can take part, not only those who are willing and able to participate in a conversation. With the exception of Dementia Care Mapping (DCM, see Section 5.5) there was a poor 'fit' between observational measures and the components of person-centred care. While DCM could potentially be used to complement the data collected using the other tools, it was developed for communal services (Kitwood and Bredin, 1992). There is therefore a need to consider whether and how observational data can be collected in a way that is suitable for all models of respite care and short breaks. Given the training requirements for DCM, a less resource-intensive approach to observation may also be more feasible for some services.

The interview data reported in Chapters 3 and 4 provide examples of how the components of person-centred care were enacted in practice. However, the relative frequency of such events was unclear. As a first step to exploring the feasibility of developing a structured approach to observation specifically focusing on person-centred care, we therefore decided that a period of unstructured observation was required in order to increase our understanding of the ways in which routines, activities, interactions and the physical environment impacted on the delivery of person-centred care. As described in Appendix 1 we adopted an unstructured approach to observation to examine the:

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- nature of interactions (who interacted with whom; where and when interactions took place; the duration of interactions; who initiated and ended interactions; the focus of interactions)
- physical environment (how the nature of the physical environment impacted on routines, interactions and experiences of people with dementia, carers and staff)
- organisation and structure of the respite period (what happened, to whom and when; how decisions over activities were made; the purpose and beneficiaries of routines).

### 6.4 Conclusions

In drafting tools to evaluate person-centred care, we drew on existing instruments and items where possible, but considerable development work was needed. This included both changing the mode of administration of items and the intended respondents. It proved necessary to develop a range of new items to ensure that each of the nine components of person-centred care identified in Chapter 3 was addressed. Consistent with the finding that the components of person-centred care applied to people with dementia, carers and staff, we developed tools for each of these stakeholder groups. Key findings are summarised in Figure 23.

#### Figure 23. Key findings from the process of tool development

- Considerable development work was required to produce items relating to the nine components of person-centred care
- It proved essential to develop specific tools for each of the three key groups of stakeholders (i.e. people with dementia, carers and staff)

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## 7 Comparative case studies to field test the tools

### 7.1 Summary

In this chapter we report findings from the field testing of tools developed in Chapter 6 within six different models of respite care and short breaks: traditional overnight respite; home day care; day care; extended day care; one-to-one support; and holidays. An iterative approach was used to test the structured conversational interview guide for people with dementia, the self-completion questionnaire for carers, the self-completion questionnaire for staff and volunteers, vignettes for discussion by staff and observation. The process of testing the tools involved interviews with people with dementia, cognitive interviews with carers and staff, group discussions of vignettes with staff and observation.

The preliminary testing of the interview guides with people with dementia indicated that they were acceptable to participants. The process, however, highlighted a number of practical issues including recruitment in different services providing respite care and short breaks. It also highlighted the potential difficulties that could arise if staff conducted the interviews.

The cognitive interviews with both carers and staff facilitated the development of questionnaires in terms of content, question wording, scaling methods and practical challenges. Both carers and staff found the approach acceptable and feasible. A particular issue identified was the difficulty both groups of participants had in providing constructive criticism about services.

The vignette documents and the focus group discussion with staff were generally well received and the process highlighted a number of developments necessary before vignettes could be widely used within both evaluation and staff development. Key messages were the need to simplify the language and process so that it was more accessible to staff with lower levels of education and language ability and how to facilitate the process in routine practice.

It was beyond the scope of the present study to develop a formal observation tool. However, our experience of non-participant observation confirmed the potential of this approach and highlighted ways in which person-centred care could be enhanced or undermined. Drawing on our experience, we illustrate how observation of selected aspects of care can identify opportunities for enhancing the delivery of person-centred care.

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## 7.2 Introduction

The process of developing new tools includes a number of stages. In Chapter 5 we outlined eight important criteria for evaluating new and existing measures: appropriateness; acceptability; reliability; validity; responsiveness; precision; interpretability; and feasibility. Within the present study we focused on establishing appropriateness, acceptability, validity and feasibility. As with any new tool, further testing will inevitably be required and specific recommendations to establish psychometric properties of the tools are discussed within this chapter.

Content validity concerns the extent to which the choice of items included in a questionnaire, and the relative importance given to each, are viewed as appropriate by those who are well-informed in the area under investigation (McCull *et al.*, 2001). Prior to field testing, the draft tools were reviewed by the Reference Group (see Chapter 1) as one means of establishing content validity. This provided an opportunity for recognised experts in the field to see how the components of person-centred care had been translated into tools and to review the draft tools in terms of comprehensiveness and relevance to person-centred care.

This chapter describes the comparative case studies in which the tools were field tested in a range of models of respite care and short breaks. As described in Chapter 6, the tools comprised:

- structured conversational interview guide for people with dementia
- self-completion questionnaire for carers
- self-completion questionnaire for staff and volunteers
- vignettes for discussion by staff
- observation.

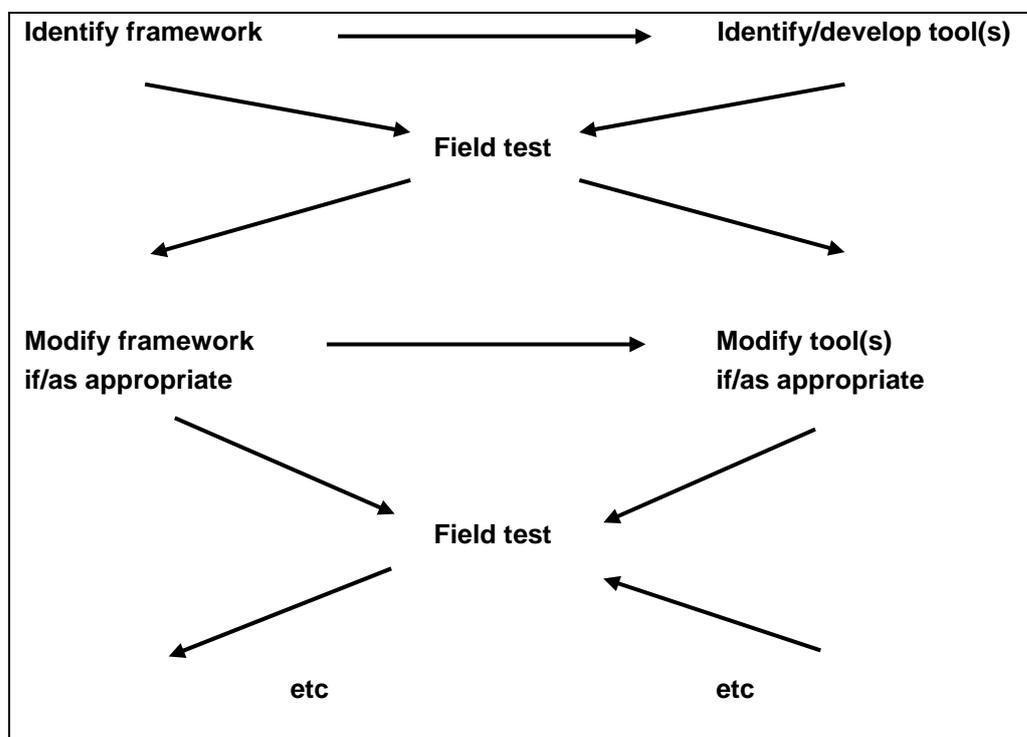
Our original intention was to conduct the case studies sequentially, but in practice this turned out not to be possible for a number of reasons. First, the low number of people using some services (for example, the specialist resource centre), meant that data collection had to take place over an extended period. Secondly, the availability of research staff for fieldwork meant that services had to be visited on several occasions over a period of time, rather than conducting an intensive period of fieldwork in each service as planned. Thirdly, the availability of staff and service users could cause delays. For example, there was a delay of nearly four weeks before a second visit to one service could be scheduled when particular members of staff were on duty.

Because the case studies could not be undertaken consecutively, the research team met periodically to review progress and to integrate findings from the cognitive interviews completed to date (Figure 24). The benefit of working in this way, was that we could use data from a range of models to

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'fine-tune' the tools rather than changing them to fit one type of respite care or short breaks only to find to that they did not fit the next model.

**Figure 24. Iterative process of field testing and refining tools**



### 7.3 Resumé of method

The methods of research are described in full in Appendix 1. In the testing and further development of the tools we used a mixed-methods approach within a comparative case study design. The six services included different models of respite care and short breaks: traditional overnight respite; home day care; day care; extended day care; one-to-one support; and holidays (Table A3, Appendix 1). Within each service we carried out structured conversational interviews with people with dementia, self-completion questionnaires and cognitive interviews with carers of people with dementia, self-completion questionnaires and cognitive interviews with staff, vignette discussion groups and observation (see Tables A4 and A5, Appendix 1). In this chapter we report data on each of the tools.

### 7.4 Conversational interviews with people with dementia

A total of nine conversational interviews were completed with people with dementia. Additional data were gathered through informal conversations and observation, during which individual questions from the interview guide were sometimes asked.

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#### 7.4.1 Acceptability

Interviews lasted between approximately two and 33 minutes, with a median duration of around 14 minutes. The shortest interview was terminated when the person with dementia being interviewed decided to go to talk to another service user. With this exception, all of the remaining participants were happy to complete the interview. While most participants seemed comfortable with the process of being interviewed, one person with dementia expressed concerns over whether he was performing adequately:

“Do you get all these daft answers all the time or is it just me?” (P301)

Opportunities to develop rapport with people with dementia were often limited due to the fieldwork schedule. However, some people with dementia appeared to be more forthcoming towards the end of site visits, suggesting that opportunities to become familiar and comfortable with the researcher conducting the interviews were important.

It was clear from our informal conversations and observations within the services that the process of seeking approval from carers prior to approaching people with dementia resulted in the exclusion of significant numbers of service users who appeared both able and willing to talk to us about their experiences of the service. Furthermore, we found that some people with dementia with whom it was not possible to obtain informed consent for a formal interview were clearly capable of expressing their views about some aspects of the service:

As far as the home day care service is concerned, P201 did tell me that:

- she enjoyed the company; they talk a lot together, as they like and understand each other. She felt, to quote, ‘we are lucky in that way’
- they can learn a lot from being together/with each other, which meant they could then help someone else
- she liked watching television; it can give you pleasure, and can make you laugh.

(Field notes, Service 2: 454-459)

#### 7.4.2 Validity

##### *Knowledge relevant to questions*

In developing the questions we tried to focus on issues which would be relatively straightforward for people with dementia to answer and which would not rely too heavily on memory. On the whole, participants seemed to be able to answer the questions, although they could not always remember certain aspects. For example, although the following person with dementia clearly understood the question, and was able to give a vague response, further probing indicated that he could not remember any specific details about the food:

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- I "What do you think of the food so far?"  
 p301 "Well I've no complaint about it, no, no complaint at all"  
 I "Can you remember it, what's it been like?"  
 p301 "I cannot mind (laughs)"

***Consistency of responses***

The numbers of participants were too small to allow formal comparison of the responses of people with dementia with those of their carers. However, where similar questions were included on the conversational interview guide and carer questionnaire it was possible to compare the direct reports of people with dementia with carer perceptions. The following extract from an interview with a person with dementia (P406) was supported by her husband's view that she was 'most times' reluctant to use the service:

- I Do you like coming here?  
 P406 well no  
 I not really  
 P406 well I like to (pause) [mmh] I like to be at home really

The observational work to explore the delivery of person-centred care in practice also provided data for comparison with responses given in the conversational interviews. The views of people with dementia about services were not necessarily easily captured by the observational work (Section 7.8). For example, one extract from the field notes relating to the above person with dementia illustrates a very positive interaction with a member of staff:

After I had interviewed P406, we walked back to the main room together. As we approached, we could see S406. P406 commented to me that S406 was nice. S406 greeted P406 very warmly and P406 seemed pleased to see her. S406 held P406's hand and they chatted about how S406 had seen P406 and her husband in the town centre at the weekend. (Field notes, Service 4: 458-461)

This does not, however, invalidate the person with dementia's previous response that she did not like coming to the service, but simply illustrates the variety of experiences within a single episode of service use. While people with dementia can be viewed as experts on their current experiences and feelings, some people with dementia may have difficulty in recalling the range of experiences at different times and providing a judgement of their overall experiences. This variety of experience was documented on a number of occasions:

When we arrived in the conservatory and there was some conflict between P103 and another service user. P103 made some much more derogatory remarks about service 1 than she had in the interview. She clearly said that she would rather be at home. (Field notes, Service 1: 396-398)

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A number of factors are likely to influence the response given at a particular time, this could include: the time of day; the setting in which the interview takes place; contextual factors (such as interactions taking place immediately prior to the interview); and issues such as social desirability of responses. In order to capture the variety of experience, it may be necessary to collect data on a number of occasions and to use different approaches to data collection.

### ***Reluctance to criticise services***

The majority of responses to the conversational interview were positive; some questions, however did elicit more muted responses. In particular, the question about whether staff took an interest in the respondent often elicited less positive responses than other questions:

- I do people here take an interest in you?  
 P504 (pause) an interest in us?  
 I an interest in you  
 P504 no not personally no [...] oh (name) she now and again she shows a bit of interest in you

It was often only on persistently probing initially positive responses that more critical views were expressed:

- I 'So what about other outings, someone was telling me you went to a farm?  
 P401 yeah they go to a farm yeah I don't know  
 I do you like that?  
 P401 yes  
 I have you been?  
 P401 yeah, we're not keen on farms, I don't like farms, I'm not an animal lover, no'

The extent to which criticisms might be expressed more readily to an external person, rather than to a known member of staff is unclear. However, the following extract indicates that some people with dementia found it difficult to raise problems with members of staff:

- I 'Do you usually sit in the same place and with the same people?  
 P406 em not all the time no because (pause) if you're having your dinner and that you know, you're  
 I you move about, don't you?  
 P406 move about and (pause) and then sometimes you wouldn't like them you know [mmh] but you wouldn't say that.'

### **7.4.3 Content**

Generally the content of the interview seemed acceptable and relevant to participants. There was no indication that any participants found the questions too sensitive or intrusive.

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A number of additional issues were raised both by people with dementia and the researchers during the interviews. The most common comments made by people with dementia were spontaneously positive remarks about particular members of staff:

'She's a smashing lass' (P504)

These comments were often prompted when the person with dementia saw a particular member of staff, and suggest that conducting the interview during respite care and short breaks is beneficial in terms of prompting recall of the service. Other issues raised by people with dementia related to the importance of the break to their partner, aspects of the physical environment (e.g. the temperature) and the extent to which other service users 'fitted in'.

Additional questions raised by the researchers related to: transport (particularly where attending the service involved a lengthy bus journey); additional services provided (e.g. bathing, hairdressing); views on staff uniforms; the mix of male and female service users and seating arrangements within day care:

I                    'So what's the bus journey like then?  
P401                sometimes it's alright, sometimes it can be a bit harassing.'

As a result of the interviews with people with dementia, additional questions relating to personal care and transport were devised. The original interview guides were organised according to the setting in which respite care or short breaks took place (in-home; someone else's home; or in a formal setting). We subsequently re-organised the guides according to whether the service was provided on a one-to-one basis or in a group. This enabled us to reduce the number of interview guides from six (direct and indirect versions for each of three settings) to four (direct and interview questions for two types of service delivery).

### 7.4.4 Evaluation of the interview questions

#### *Question wording*

We sought to evaluate the interview questions by exploring whether the person with dementia understood the questions and how we rephrased the questions to make them more meaningful. The most common requirement was to repeat the questions, suggesting that we were at risk of outpacing participants. The majority of the time, the researcher simply repeated the question without elaborating or rephrasing. This was often sufficient to enable the person with dementia to process the question and formulate a response. When rephrasing or elaborating questions, we often drew on earlier responses or our (limited) knowledge of the service or person being interviewed. This provided contextual information which seemed to help people with dementia to respond. For example, when talking about activities, the interviewer had observed a quiz taking place earlier in the day and was able to ask specifically about this:

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- I 'Oh you had a quiz, you had a  
 P401 a quiz yeah we do quizzes  
 I yeah and are those the kinds of things you like doing or  
 P401 I don't mind doing them  
 I you don't mind them, yeah you don't *like* them?  
 P401 not really no.'

In rewording the questions, there was a danger of rephrasing initially neutral questions into leading questions. Clearly this has implications for the validity of the findings and training implications for professionals responsible for the administration of the interviews. In revising the interview guide we added some probes to encourage elaboration.

The majority of the questions seemed straightforward and were readily understood by participants. Where there were difficulties, participants often seemed able to articulate their difficulties and ask for clarification:

- I 'Do you mind coming here?  
 P406 (pause) no, I don't think I like it  
 I because I know you don't like it, but do you mind coming?  
 P406 do you mind?  
 I mmh  
 P406 wouldn't that be the same thing?  
 I I think it's slightly different because sometimes people don't like it but they come because they know it gives their husband a kind of break at home. So they might not like it, but they don't mind  
 P406 yeah  
 I So that's the difference I suppose  
 P406 yeah yeah. I'm here for that, not for myself.'

Examples for specific changes to question wording are given in Table 15.

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**Table 15. Examples of changes to question wording following interviews with people with dementia**

| <b>Initial wording</b>   | <b>Comments</b>  | <b>Revised wording</b>   |
|--|--|--|
| Do people here listen to you?                                    | Although we had used 'people' rather than 'staff' deliberately (see Section 6.3.1), we found that some people with dementia responded in terms of other service users, while others focused more on staff, making responses difficult to interpret. Respondents tended to give a positive answer, so the question was reworded to try to encourage a more discursive response. | Are the staff good listeners?<br><br>This was supplemented by using photographs of staff to clarify to whom the question referred. |
| Do people here rush around?                                      | People with dementia sometimes interpreted this as 'being rushed'. In view of the importance of pacing in delivering care to people with dementia, we changed the emphasis of the question by rewording it.  | Do you ever feel rushed here?  |
| Supposing you fancied a cup of tea or coffee, what would you do? | This question often had to be elaborated since people with dementia often responded in terms of drinks being served at particular times, whereas we were interested in the availability of drinks outside these set times. Producing a single question, however, was difficult; we therefore decided to add a standard probe which could be used when necessary.               | If refreshments are at set times:<br><br>What if you are thirsty at another time?  |

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### ***Direct and indirect questions***

Indirect questions use photographs to enable participants to project their views onto the person pictured. It was only possible to explore the use of indirect questions with two participants. For one participant, it was clear that the concept of responding on behalf of an unknown person did not make sense and indirect questions were therefore not pursued. A second participant had no difficulty with describing the views of the person in the photograph and responded to a number of questions both directly (giving her own views) and indirectly (giving the views of the woman in the photograph). However, later in the interview, the person with dementia created a story about the woman in the photograph which then influenced the responses she gave:

‘I think everybody would feel a bit sorry for her because you know her husband’s out quite a lot, he’s a drinker, [mmh mmh] so she feels, she’s lonely a lot of the time.’ (P402)

Although the use of indirect questions was not helpful with these two participants, this technique has been used successfully in previous research studies (Allan, 2001; Bamford and Bruce, 2000). Clearly the acceptability and value of indirect approaches varies with individual participants and merits further investigation.

### **7.4.5 Response categories**

We had purposefully designed the questions so that they could be asked conversationally, rather than presenting participants with pre-coded response categories. We hoped that this would decrease the burden on participants and make the interview process seem more naturalistic. It is, however, essential to produce data that are easy to process and analyse. In reviewing responses, therefore, we explored the feasibility of developing pre-coded response categories (which would not be read out to the participant, but could be used for recording responses). Review of the interview transcripts, indicated that the following categories captured the majority of responses to the questions:

- positive
- positive with some reservations
- neutral
- negative with some positive aspects
- negative
- unable to answer
- unable to code response

Since these pre-coded categories were developed from responses, the feasibility of summarising responses in this way has yet to be tested.

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#### 7.4.6 Practical issues and recommendations for further testing

Overall the preliminary testing of the interview questions indicated that they were acceptable to people with dementia. The interviews highlighted a number of practical issues. The first of these concerned recruitment and response rates. The process of seeking approval from carers undoubtedly hindered recruitment. Among carers we spoke to, reluctance to give approval for researchers to approach the person with dementia stemmed from concerns that the person with dementia would be upset by being asked questions, others felt that the person they supported would have nothing to say and one carer strongly felt that people with dementia should not be involved in research at all. Although the introduction of the Mental Capacity Act (Department for Constitutional Affairs, 2007) should enable people with dementia to make their own decisions, it is clear that many carers see themselves as having a key role in decision-making.

Issues regarding recruitment were also linked to the type of respite care or short break provided. It proved easier to recruit people with dementia from day care than from the specialist resource centre or holiday service where relatively few people with dementia had capacity to consent. This is likely to reflect the different levels of cognitive impairment characterising people with dementia using different services. The potential difficulties of interviewing the majority of people with dementia using some services emphasises the need to have alternative methods of data collection, such as observation, to complement interview data. The difficulties in recruiting people with dementia using home day care and one-to-one support services were specific to this study. The nature of these services meant that it was less feasible to conduct the interviews with people with dementia during service use, for example, because of the presence of a member of staff which could have influenced responses. Arranging interviews immediately following service use was also problematic, since people with dementia were often tired. It would therefore be necessary to arrange interviews on a separate occasion, possibly using photographs of the member of staff to facilitate recall and discussion. The fieldwork constraints in the present study meant that it was difficult to schedule the additional visits required. A number of questions were tried during informal discussions with people with dementia in receipt of these services and seemed to be relevant and acceptable.

Within the context of the present study, the interviews were conducted by experienced researchers. If the interviews are to be used as part of service development, careful consideration needs to be given to identifying an appropriate interviewer. The potential difficulties of using untrained staff are evident in the following extract from an informal conversation between a researcher, a person with dementia and a member of staff:

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- I 'Did you enjoy your bath?  
 P404 A mixture  
 I A mixture?  
 P404 Yes, seemed to be too many people there and things like that  
 S408 There was only me; I'm not that many people am I?  
 P404 There seemed to be  
 S408 I'm only one  
 P404 quite a few there  
 S408 No, there was me, just me. There was only me and you in the bathroom.'

It can be seen that the member of staff (S408) focuses on establishing the 'facts' regarding the number of people present, rather than exploring the person with dementia's view (P404) that there were 'too many people there'. The tendency of some people with dementia to give an initial positive response, which was subsequently qualified and expanded upon, also highlights the importance of probing and exploring responses rather than simply administering the questions as a quick checklist.

It was clear that some knowledge of the service user and the service was beneficial in helping people with dementia to expand on their responses and to elaborate on the questions where necessary. It has been suggested that any factual information should be obtained prior to interviews with people with dementia (Murphy, 2007) and our experience confirmed the value of this additional knowledge. At the same time, however, it seems likely that people with dementia are more likely to express critical views of the service to an outsider, rather than to a known member of staff. There is clearly a degree of tension between these two requirements. The advantages and disadvantages of internal and external evaluation of services are reviewed in detail by Lechner (2007). Depending on the nature of the service and extent of day-to-day involvement of the service manager, it might be feasible for a service manager to conduct the interviews. Other possibilities might be for an independent person (for example, from a non-statutory agency, the quality assurance department of Social Services, or a manager of a similar local service) to be briefed thoroughly prior to the interviews and to spend a few days in the service to allow information to be gathered gradually.

## 7.5 Self-completion questionnaire for carers of people with dementia

### 7.5.1 Acceptability

All of the carers approached completed the questionnaire, although a few commented that they might not have got round to completing and returning the questionnaire had it not been for the presence of the researcher. Several carers commented that this was an opportunity to 'give something back'. Some carers hoped that their feedback would make

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a difference. Previous experience of completing questionnaires about services could be off-putting if carers felt that their views had been ignored. Although one carer expressed a strong preference for a face-to-face interview, rather than a postal questionnaire, this was unusual. Although interviews had the benefit of enabling elaboration and exploration of responses, the majority of carers thought a postal questionnaire was acceptable.

It was not always possible to record how long the questionnaire took to complete because some carers discussed their responses as they completed the questionnaire. However, carers who completed the questionnaire with no or little discussion took between five and 14 minutes to do so, with an average of 10 minutes. Explicit comments made by carers indicated that the length of the questionnaire was acceptable.

### 7.5.2 Validity

Three issues relating to validity were identified through the cognitive interviews. These were the extent to which: carers felt they had the necessary knowledge to respond to the questions; their responses to the questionnaire were consistent with comments they made during informal conversation or when elaborating their responses; and their willingness to express critical views. Each of these issues is discussed below.

#### ***Knowledge relevant to questions***

Valid responses require the participant to have access to the information necessary to answer the questions. Questions relating to the impact of the service on the carer clearly posed no problems. Consistent with a previous study, a small number of carers experienced some difficulties in describing the effect of service use on the person with dementia, either because the person they cared for was unable to express an opinion him or herself or had no discernible mood states (Aggarwal *et al.*, 2003). These difficulties were limited to carers of people with more advanced dementia. Carers who lived apart from the person with dementia and did not routinely see them after episodes of service use could also find it difficult to respond to these questions.

Carers had different levels of contact with, and knowledge about, services. Unsurprisingly, carers with direct contact with services (e.g. holidays or one-to-one services where the carer either accompanied the person with dementia and support worker on outings or saw the support worker at the beginning and end of each session) experienced few problems in answering items relating to staff (e.g. 'Staff have a good understanding of my relative's needs'). Similarly, carers using home day care, where the service was provided by a single person, rarely reported problems with these items. In contrast, carers with little direct contact with services found it more difficult to respond to items such as 'I have good relationships with staff providing the service'. Even carers using the same service could have very different levels of contact with staff. For example, some carers whose relative had overnight stays in the specialist resource centre visited every

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day, while others had no contact at all during the week or fortnight that their relative used the service. One carer using the specialist resource centre commented:

'Well, I don't actually talk to anybody from [service name]' (Carer 404).

Even where carers only saw staff on the doorstep at pick up and drop off times, they often spontaneously described staff as 'kind', 'caring' or 'helpful'. Carers' judgements of staff was therefore sometimes based on limited contact outside the service, rather than on direct knowledge of the service provided. Carers' often limited knowledge of services has previously been identified as a potential barrier to service evaluation (Aggarwal *et al.*, 2003; Bamford and Bruce, 2000). This confirms the importance of focusing on areas where carers have direct knowledge.

Where the person with dementia received an extensive care package involving a number of services, some carers found it difficult to focus solely on the specific service used for respite care and short breaks.

### ***Consistency of responses***

No formal assessment of test-retest reliability was planned at this stage of questionnaire development. Instead we were interested in the extent to which carers' responses to the questionnaires were consistent with spontaneous comments made during general discussion or when elaborating their responses. Overall, questionnaire responses seemed to reflect comments made by carers during general discussion or when elaborating their responses. For example, one carer's responses indicated that various aspects of his life were 'much better' as a result of using the service. This was borne out by further discussion, when he commented that: 'I couldn't manage without it, particularly with the [health] problems I've got' (C403). In a separate discussion, a member of staff spontaneously commented that the service was vital in enabling this particular carer to continue to support his wife at home, providing further evidence of the validity of his responses. In contrast, some carers who used a service for only a few hours each week took the view that a five or six hour break once a week made little fundamental difference to their lives. For these carers, the item 'Using this service helps my relative to stay at home', and also the set of items focussing on the impact of respite care or short breaks on their life, emerged as less relevant. This does, however, suggest that these questions have criterion validity, since it would be anticipated that very low levels of service use would have relatively little impact on the carer's life.

There were, however, a number of occasions on which the questionnaire responses did not seem consistent with other comments. In most cases, the questionnaire responses seemed more positive than was merited by informal comments or elaboration. This therefore seemed to be related to a reluctance to criticise services, discussed in more detail below.

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### ***Reluctance to criticise services***

Consistent with previous studies, the extent to which carers were willing to make critical comments was variable (Bamford and Bruce, 2000). A small number of carers were quite candid and recognised the importance of giving their honest opinions. However, a number of examples arose which suggested that many carers were reluctant to criticise services. For example, one carer selected the 'strongly agree' response to the item 'I feel well supported by staff'. This contrasted with comments earlier in the interview when he had expressed the view that the current volunteer looking after his wife showed little interest in his needs as a carer (C307). While these examples raise some concerns over the validity of responses, it is important to place responses in the broader context of carers' overall experiences of services. The above carer had previously been on 19 holidays with the same organisation; his current negative experience therefore has to be balanced with his positive experiences on many previous holidays.

When carers were critical, they often tried to 'depersonalize' the criticism and either follow it with a positive comment or emphasise that it probably wasn't the fault of the service. Consistent with this reluctance to criticise, seven carers were unable to identify any negative aspects of the service in relation to themselves and eight carers could not identify any negative aspects of service use for the person with dementia.

### **7.5.3 Presentation and layout**

We grouped items in sections to structure the questionnaire. Each section started with a brief introduction to help orientate participants. This structure seemed acceptable to carers and few reported difficulties in making the transition between sections. A small number of carers had vision problems and a large print version of the questionnaire will be essential for such participants. The inclusion of grids to separate adjacent questions and response categories would also help some participants.

#### ***Instructions***

The questionnaire was tailored to each of the six services by giving it the title 'Your views of <service name>'. Where appropriate, throughout the questionnaire the name of the service under review was also included. This was to make it easier for carers to remember which service they were evaluating.

Carers generally viewed the instructions on the front cover as self-explanatory. Following comments by carers, we included an example of how to complete the questionnaire.

In conducting the cognitive interviews, we noticed that carers approached the questionnaire in different ways. Some carefully and thoroughly read through the front page (sometimes more than once) before looking at the first items. In contrast, others quickly skimmed the first page before turning over and starting to complete the questionnaire. This suggests that

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carers did not feel constrained by our presence to read every word, but behaved much as they would have done had the questionnaire arrived through the post.

#### 7.5.4 Content

Our intention had been to develop a questionnaire suitable for a range of service models. The observational work highlighted some key differences between services suggesting that it may be more appropriate to identify core items relevant to all models of respite care and short breaks, and additional items which could be included as appropriate. Examples of topics that were not relevant to all services were: outings; personal care; and provision of additional hours in emergencies. Few additional issues were identified for inclusion (see Table 16).

**Table 16. Examples of changes to content following cognitive interviews with carers**

| <b>Initial content</b>  | <b>Comments</b>  | <b>Revised content</b>  |
|---|--|---|
| Questions on impact of service on the person with dementia were included for all carers.  | Carers who did not live with the person with dementia often had difficulties in responding to these questions, since they were rarely present before or after service use. | A filter question was added so that the questions in this section applied only to co-resident carers.   |
| No questions relating to meals were included since the majority of carers were not present and therefore did not have direct knowledge about meals. | Meals were identified as an important part of the service by a number of carers, particularly those using the holiday service.   | Questions on meals were included in an additional section specifically relating to holiday services. A question about the appetite of the person with dementia was added to the series of questions on the impact of the service, since this should provide information on whether the person receives adequate nourishment at the service. |
| All questions were applicable to all participants to increase ease of completion and administration.  | A number of questions were not seen as relevant to all services.   | The questionnaire was restructured to include core questions relevant to all services and additional sections for specific types of respite care and short breaks.  |

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Few issues relating to sensitivity were raised. Some carers thought that their responses would be influenced by whether the questionnaire was being returned directly to the service manager or to an independent body. Several carers were uncomfortable with the item 'I look forward to the days when my relative uses the service', for example, commenting that this looked as though they were 'glad to get rid of' the person with dementia. This item was subsequently deleted.

### 7.5.5 Evaluation of questions

#### *Question wording*

The evidence suggested that on the whole carers understood the meaning of the questions, and could answer them without asking for further clarification from the interviewer. A key element of the cognitive interviews was to test out understandings of particular words or concepts, for example, the word 'reliable' in the item 'The service provided is very reliable'. Carers supplied similar examples to illustrate reliability, including: transport arriving on time; and being notified of any potential problems in advance so they were not let down.

Although questions were sometimes interpreted in different ways depending on the service being used, this was not necessarily a problem. Carers using day care or one-to-one support thought the item 'I find it difficult to get my relative ready for the service' related to getting the person with dementia up, dressed and breakfasted in time. In contrast, carers using services where the person with dementia would be staying overnight for several days, related the same item to preparing their relative emotionally and physically for the break. Carers were therefore able to interpret the item in the way that was most relevant to the type of respite care or short break used.

Consistent with established principles of questionnaire design (McCull *et al.*, 2001; Oppenheim, 1992), we included a mixture of positively and negatively worded items. Some carers had no problems whatsoever in understanding and answering the negative items, commenting that they were used to completing similar sorts of questionnaires. In contrast, other carers struggled with negative items, occasionally even seeing such items as trying to 'see if you are on the ball' (C202). Examples of changes to question wording made as a result of the cognitive interviews are given in Table 17.

The majority of carers had few difficulties in responding to the items relating to the impacts of respite care or short breaks on their lives. One item, concerning 'my confidence in caring' was more problematic, with some carers being unable to see a link between their levels of confidence in caring and the use of respite care or short breaks. As a result, this item was dropped.

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**Table 17. Examples of changes to question wording following cognitive interviews with carers**

| <b>Initial wording</b>  | <b>Comments</b>   | <b>Revised wording</b>   |
|---|---|--|
| My relative is upset with me after using the service                                  | Carers commented that people with dementia could be distressed for a range of reasons not necessarily related to the carer. For example, one carer said that his wife was upset with herself for needing to use the service.        | Question simplified to:<br>My relative is upset after using the service.   |
| It is difficult to fit my other commitments around the hours the service is available | A number of carers inadvertently circled the wrong response because of the negative question wording.   | Question reworded:<br>The service is available at convenient hours/times   |
| It is easy to approach staff to discuss my concerns or worries about my relative      | It was clear from comments made during the interviews that although staff might be approachable, this did not necessarily result in appropriate action being taken. The question was reworded to focus on whether action was taken. | Question changed to:<br>Staff take my concerns about my relative seriously |

### 7.5.6 Response options

#### *Use of scales*

Five-point response scales were used for the majority of items in the questionnaire. Two different response scales were used: 'Strongly agree' to 'Strongly disagree' and 'Always' to 'Never'. Although carers did not always notice when the scale changed, few problems were reported in using two different scales. Carers were occasionally frustrated by the failure of response scales to capture the nuances of their experience. For example, the middle option was not thought to adequately reflect some situations where experience was variable, such as having a good relationship with some staff but not others.

#### *Not applicable responses*

Some questions were not applicable to all carers, for example the item 'The transport arrangements for my relative run smoothly' was not relevant where transport was not provided. Two possible ways of addressing this issue were identified: first, to identify core items relevant to all services and

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participants and to have additional sections relevant to particular service models; secondly, to include items but to provide a 'not applicable' response option.

In view of the problems with the first version of the questionnaire, subsequent versions included a section of questions which included a 'Not applicable' response option. Carers' use of this option was, however, inconsistent. For example, carers who had never tried to arrange additional hours did not necessarily use the 'not applicable' response to the item 'It is difficult to get extra hours in an emergency'. Instead, some carers selected the response that they thought would best represent the likely service response. In view of these continuing difficulties, a filter question was added to the final version of the questionnaire, so that the questions were only answered by carers to whom they were relevant.

### ***Open questions***

A series of open questions were included at the end of the questionnaire and carers sometimes found it difficult to complete these questions after becoming used to circling their preferred response. For example, one carer commented: 'I'm so used to ticking things, I can't compose a sentence!' (C307). There is no easy way of addressing this issue. Starting questionnaires with open questions is thought to be off-putting to some participants and is problematic in that participants do not yet know which areas are to be covered by the formal questions.

A range of issues were highlighted in the open questions (Table 18). While the majority of carers were able to identify positive aspects for themselves and the person with dementia, they experienced more difficulties in identifying negative aspects (Table 18). For some carers, the negative aspects identified related to service availability for example, 'Only once a week' and 'It's not long enough', suggesting that carers were satisfied with the service, and wanted more of it. The negative aspects identified in relation to the person with dementia tended to be individual and could not easily be coded. For example, the 'other' category includes responses such as: 'Not being in familiar surroundings'; 'She doesn't like the food'; and 'She sometimes complains about the transport' each of which were mentioned by only one carer.

The range of comments made on the open questions confirmed that the questionnaire already included most of the areas important to carers. Although the issue of activities for people with dementia was raised by a number of carers, it is difficult to justify including an item relating to this in the questionnaire in view of the lack of knowledge about the service reported by a significant number of carers. The comments suggest that items relating to the frequency and duration of respite care or short breaks should be included.

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**Table 18. Summary of carer responses to open questions**

|   | Number of carers<br>(n=30) <sup>1</sup> |
|---|---|
| <b>Best thing about the service for the carer</b>                     |   |
| Having time to myself, having a break                                 | 15                                      |
| Peace of mind, knowing that person with dementia is well looked after | 8                                       |
| Time for appointments, household chores                               | 4                                       |
| Sense of back-up, shared responsibility                               | 3                                       |
| Other   | 6                                       |
| Nothing   | 1                                       |
| <b>Worst thing about the service for the carer</b>                    |   |
| The length of time, frequency of the service                          | 5                                       |
| Getting the person with dementia ready                                | 2                                       |
| Feeling lonely  | 2                                       |
| Lack of feedback from the service                                     | 2                                       |
| Other   | 3                                       |
| Nothing   | 17                                      |
| <b>Best thing about the service for the person with dementia</b>      |   |
| Company, relationship with staff                                      | 10                                      |
| Stimulation, change of routine or surroundings                        | 8                                       |
| Well looked after, cared for  | 8                                       |
| Enjoys service, happy at service                                      | 5                                       |
| Other   | 6                                       |
| Nothing   | 2                                       |
| <b>Worst thing about the service for the person with dementia</b>     |   |
| Not enough activity   | 2                                       |
| Other   | 7                                       |
| Nothing   | 22                                      |
| <b>Suggestions for service improvement</b>                            |   |
| Increased frequency, longer days                                      | 4                                       |
| Increased activities  | 3                                       |
| Increased feedback to carer   | 2                                       |
| Other   | 3                                       |
| Nothing   | 18                                      |

<sup>1</sup> The number of responses under each heading is greater than the number of carers since some carers gave more than one response.

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### 7.5.7 Practical issues and recommendations for further testing

All of the services participating in the case studies were able to provide lists of carers using the service. They were not, however, able to produce address labels which would facilitate the process of mailing out a postal questionnaire. There are a number of practical issues relating to how the questionnaire could be personalised to the service and printed out. The change in structure from a single questionnaire to one with core questions to be supplemented with additional questions where appropriate adds to the complexity of this process. A key issue relating to the use of the carer questionnaire for service development relates to resources for processing and summarising the results. The resources required for these activities were typically not available within services. This means that it is unlikely that services will be able to conduct their own surveys without external help. Potential sources of assistance include staff responsible for quality assurance within Social Services or Primary Care Trusts or other Trusts commissioning and providing respite care and short breaks. An alternative approach would be to use online services such as Survey Monkey ([www.SurveyMonkey.com](http://www.SurveyMonkey.com)). The acceptability and accessibility of online questionnaires to carers is unknown and this is an area which would merit further investigation.

Not all of the revised questions have been tested in practice. A number of alterations, including the addition of filter questions and reorganisation of the questionnaire in core and additional sections, were made at a late stage, following the unsuccessful testing of 'not applicable' response options. The carer questionnaires have only been tested in face-to-face interviews and not piloted as postal questionnaires.

We chose to use five-point response scales since we thought it was important to include a neutral option, and many of the existing measures reviewed were based on five-point scales (see Chapter 5). There is, however, new research which suggests that seven-point scales may be more appropriate (Jones *et al.*, 2007; Netten *et al.*, 2007). In the context of services providing home care there is evidence that seven-point response scales allow service users to express concerns over service quality without appearing to complain. Comparison of levels of satisfaction expressed by service users with quality indicators show that when service users report that they are 'quite' satisfied, rather than 'extremely' or 'very' satisfied, there are likely to be real problems with the service (Jones *et al.*, 2007; Netten *et al.*, 2007). The use of a seven-point scale may be one way of addressing the reluctance of some carers to criticise services. Further testing of a seven-point scale would be needed in order to establish whether the increased complexity had an impact on the acceptability of the questionnaire to carers.

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## 7.6 Self-completion questionnaire for staff

### 7.6.1 Acceptability

The questionnaire as a whole was generally acceptable to staff. The majority of staff participants reported that they found it relatively quick and easy to complete. One person commented that receiving the questionnaire would make her feel valued since it suggested that managers were interested in her opinions (S506). None of the staff taking part in cognitive interviews suggested that alternative methods of collecting the information, such as face-to-face interviews, would be more appropriate.

Accurate information was not available on the time taken to complete all questionnaires, since some staff discussed the questions as they completed them. Staff for whom timing was available took between five and 15 minutes, with an average of 10 minutes to complete the questionnaire. Generally the length of the questionnaire was thought to be acceptable. Service managers appeared to be more concerned about the length of the questionnaire than front-line staff.

Earlier versions of the staff questionnaire were completed anonymously, and did not ask staff to identify themselves in any way. However, we subsequently added a question asking staff to identify their role from one of five pre-defined options (including an 'Other' category). This was because we thought this background information could be valuable in understanding the resulting data. This question was only tested out with two team leaders, both of whom were happy to indicate their role in the organisation.

### 7.6.2 Validity

#### *Knowledge relevant to questions*

In contrast to the carer questionnaire, there was no evidence of staff lacking the knowledge needed to respond to the questions. There were some questions to which some members of front-line staff thought there was a 'correct' answer (e.g. the question relating to the most important aspects of person-centred care). By rewording this question (see Table 19), we hoped to avoid this impression in the final version of the questionnaire.

#### *Consistency of responses*

Carers were often keen to describe the service and their experiences, providing useful data which could be compared with their responses to the questionnaire (Section 7.5.2). In contrast, the cognitive interviews with staff were more task-focused. There were, therefore, few opportunities to compare comments made during general discussion with responses to the questionnaire. The vignette discussion groups (Section 7.7) helped endorse the validity of the staff questionnaire, in the sense that staff spontaneously talked about working well as a team, supporting each other in difficult situations and the importance of good communication. This suggests there is a good 'fit' or match between the questions on the staff questionnaire and the range of issues that arise in interactions between staff.

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### ***Reluctance to criticise services***

The cognitive interviews included questions on whether participants felt that staff would be critical of their own particular service and/or answer truthfully if they thought that their own manager would see the completed questionnaires. One participant reported panicking when she first saw the questions and immediately thought 'Do we lie? Do we tell the truth?' (S203). The following items were identified by staff as potentially being at risk of insincere responses: 'I feel appreciated by my manager', and 'It is easy to approach my manager if I have a problem at work'. Views on the likelihood of responding to such questions honestly varied. There was some limited evidence to suggest that managers and team leaders held a more rosy view, being more confident that staff would express their views honestly than staff members themselves were. A number of staff emphasised that the questionnaire should state clearly who would have access to the data.

### **7.6.3 Presentation and layout**

Overall, participant views about the presentation and the layout of the questionnaire were positive. When asked, they reported that they found that it was concise; easy to read; and that the items employed unambiguous, accessible language. Several staff commented that the questions flowed well and that the sections were helpful. Exceptionally, one person exclaimed 'God!' when she saw the first page, but having completed it said that she had found it quite straight forward and she was not 'fazed by it' (S501).

There were, however, some negative comments about the front cover. For example, a handful of participants thought that its appearance was bland, not very enticing and even that it looked like an examination paper or a government document. One suggestion was to use photographs of older people and/or carers to make the questionnaire more appealing. There was also a view that the front page of the questionnaire contained too much information; this was addressed by reducing the amount of detail provided and including a single contact point.

As noted above, a number of staff highlighted the importance of providing information on who would have access to the questionnaires and how the information would be used. Such information would need to be completed for individual services since administrative arrangements will vary from place to place.

### ***Instructions***

The instructions on the front cover were described as clear and comprehensible. We had initially estimated the time required to complete the questionnaire as 20 minutes; on the basis of our experience of testing the questionnaire we reduced this to ten minutes in subsequent versions of this questionnaire.

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In common with carers, staff adopted different approaches when completing the questionnaire, with some reading the front cover/instructions thoroughly, whereas others completely ignored them and turned straight to the first page. This suggests that staff taking part in the cognitive interviews did not feel constrained to behave in a particularly diligent way.

The questionnaire was designed to capture a global view of the delivery of care within services providing respite care or short breaks. It became obvious from participants' comments, however, that quite often their answers to items depended on circumstances, such as type and numbers of service users present and staff numbers, which could change on a daily basis. We addressed issues about variability and unpredictability by emphasising in the instructions that we were interested in the overall picture, and suggesting that staff might find it helpful to think about the last four weeks as a whole when responding.

### 7.6.4 Content

Generally speaking, participants felt that the items included in the questionnaire were relevant to their particular service and that individual items were acceptable. The exception to this was in Service 2 where staff had quite a negative view of the questionnaire. These staff were not sure how the information could be used and did not feel it would be of any help in service development. This was in stark contrast to some other services where staff felt the questionnaire would form a useful starting point for discussion within the staff team. The reasons for the negative views of staff in Service 2 are unclear. Possible explanations might be that the staff team was very small and well-established; the team rarely met together and seemed to function as autonomous individuals. Due to the limited availability of staff, the cognitive interview was conducted as a group rather than as individuals and this may have influenced responses. Although group cognitive interviews were also conducted with the one-to-one support service, which similarly comprised staff who largely worked independently with people with dementia, these members of staff had weekly meetings and were more used to discussing issues as a group. While the service providing home day care clearly had some unique characteristics, it shared many features with the other case study sites. The negative views expressed could not therefore simply be explained by differences between the models of respite care or short breaks.

A number of members of staff expressed the view that participants might answer questions differently depending on their role. Two of the items that were highlighted by staff as falling into this category were: 'My opinions are considered when changes are made at work', and 'I have enough time to get to know service users'. Interestingly, only team leaders and managers selected 'Valuing the staff team' as one of the three most important aspects of providing care for people with dementia and their carers, suggesting that role may have an important influence on responses.

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The staff questionnaire went through four iterations in response to the findings of the cognitive interviews. Key changes to the content of the questionnaire are summarised in Table 19 and described below.

**Table 19. Examples of changes to content following cognitive interviews with staff**

| <b>Initial content</b>   | <b>Comments</b>   | <b>Revised content</b>   |
|--------------------------|---|--|
| Team work                | Not all staff identified as members of a team   | Reordered and modified questions<br>Introduced open question to enable staff to add comments   |
| Training and supervision | Confirmed as important areas<br>Formal and informal supervision both valued<br><br>List of training options too narrow                          | Divided into two separate sections<br>Instructions clarify that both formal and informal supervision included<br>Examples of diverse training courses identified through internet search |
| Role of staff member     | Not included in initial questionnaire due to concerns about confidentiality<br><br>Staff comments suggested that role might influence responses | Addition of question about staff role within team  |

The reorganisation of the section on teamwork did enable staff to make comments specific to the way in which their service was set up:

'We do not really work as a team as we work on a one-one basis with our clients, however I do feel supported by the rest of my colleagues and managers' (S606).

The section on supervision was expanded in response to comments by staff. We consulted relevant guidelines on supervision (Skills for Care and the Children's Workforce Development Council, 2007) and conducted an internet search to identify existing questionnaires relating to supervision. Questions relating to three aspects of supervision were included: line management; professional supervision; and continuing professional development (Skills for Care and the Children's Workforce Development Council, 2007). Comments about the additional supervision items were mainly positive. There was evidence of some confusion concerning supervision arrangements, suggesting that the inclusion of some basic questions concerning frequency and knowledge of arrangements may be merited, for example about half way through the questions in the supervision section, one member of staff asked:

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### 'Who's my supervisor then?' (S408)

A new item, 'My training needs are met', was introduced after a number of staff indicated that identified (and even agreed) training needs were not necessarily acted on because of resource issues:

'Although we identify training opportunities sometimes they cannot be acted on, e.g. for reasons of funding, staff shortages' (S606)

Finally, the main gaps that were identified by staff from two or more services related to bereavement and loss and food (from the therapeutic/social perspective rather than nutritionally). The issue of bereavement and loss arose in relation to training needs; since there was already a space for staff to identify needs not already listed, we decided not to include this in the list of items. Provision of meals was also identified as a core activity; however, the staff questionnaire was not organised around *what* the service did, but rather on *how* care was provided. We did not, therefore, think it was appropriate to add questions specifically related to certain aspects of care.

### 7.6.5 Evaluation of questions

#### *Question wording*

The majority of interviewees understood the majority of items, which meant relatively few items had to be reworded. This suggested that the questionnaire was accessible to staff with different educational/literary levels and to staff for whom English was not their first language.

However, the cognitive interviews indicated that a number of words and/or phrases were problematic, for a range of reasons (examples are given in Table 20). We drew on participants' own words as far as possible in rewording the items.

Like the carer questionnaire, the staff questionnaire contained negative items. On the whole, staff had fewer difficulties with negative items, although occasionally some staff inadvertently circled the wrong response. To help address these issues, we changed a small number from negative to positive items (see example in Table 20). Several questions required staff to select the most important items from a list of pre-specified options. We asked staff whether they would prefer to simply write in the three most important things from their perspective. The majority of staff expressed a strong preference for a pre-specified list, commenting that identifying options themselves would be 'daunting'.

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**Table 20. Examples of changes to question wording following cognitive interviews with staff**

| <b>Initial wording</b>  | <b>Comments</b>   | <b>Revised wording</b>   |
|---|---|--|
| There are few opportunities to use my initiative at work  | Some participants had difficulty reading the word 'initiative'; Concerns were expressed over the accessibility of this item to staff with lower literacy levels or staff with English as a second language<br><br>Negatively worded items were confusing for some members of staff. | There are opportunities to try out new ideas at work   |
| What do you think are the <u>three</u> most important aspects of person-centred care for people with dementia and their carers? | The term 'person-centred care' was not in common use in all services and could create anxiety, for example, where staff thought that they 'ought' to know what it meant, but were not entirely sure what 'person-centred care' actually was   | What do you think are the <u>three</u> most important aspects of providing care for people with dementia and their carers? |

### 7.6.6 Response options

#### *Response scales*

In common with the carer questionnaire, the initial version of the staff questionnaire included two different five-point response scales: 'Strongly agree' to 'Strongly disagree' and 'Always' to 'Never'. The cognitive interview indicated that staff found both response scales easy to understand and use. Staff generally liked having a neutral option, and also the graded options that a five-point scale provided, although occasionally they would have liked to be able to qualify their responses. In the process of rewording items and reorganising the questionnaire, only the 'Always' to 'Never' response scale was used. This was appropriate to all of the retained items and fitted well with the way that staff talked about the variability of their work.

#### *Prioritising items*

The first draft of the questionnaire included a ranking exercise to identify the most important (a) aims of the service and (b) components of person-centred care. These questions underwent substantial revisions in order to produce lists of mutually exclusive aims and components. Furthermore ranking was replaced by simply requesting staff to tick the three most important items (Table 21).

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**Table 21. Examples of changes to response options following cognitive interviews with staff**

| <b>Initial response options</b>  | <b>Comments</b>   | <b>Revised response options</b>   |
|--|---|---|
| Asked to rank the three most important aims of the service   | Staff were unfamiliar with ranking<br>Instructions were not clear<br>High proportion of unusable responses  | Asked to tick the three most important aims   |
| Asked to use a scale from 'strongly agree' to 'strongly disagree' to indicate need for training on each of a range of topics | Staff tended to use 'strongly agree' or 'agree' responses for all topics, reflecting their view that 'the more training the better'<br>We were concerned that the results would be of little use to managers in prioritising training needs | Asked to tick the three most important areas in which training or updating was needed |

Staff found it difficult to prioritise just three areas on all of the questions that used this format. Despite this, we decided to continue to ask them to select only three options since this would give a better sense of staff priorities (and the extent to which these were consistent within the staff team).

### ***Open questions***

A series of open questions were included at the end of the questionnaire and many staff welcomed the opportunity to express their views. The majority of staff responded to the specific items asking for ways of improving the service for people with dementia and carers; however, relatively few added any other comments and these are therefore not summarised here. Suggestions for service improvements are summarised in Table 22. Increased resources, whether in terms of staff numbers, increased hours or expansion of the service, was the most commonly identified way of improving services both for people with dementia and carers. Staff training was also highlighted in relation to people with dementia, but arose less frequently in relation to carers. Some responses were strongly linked to individual services; for example, comments relating to increased knowledge of the person with dementia and carer were made only by staff and volunteers at the holiday service, reflecting the limited information available about service users within this service. Increased community involvement for people with dementia was most frequently raised by staff in the non-statutory day centre.

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While most staff were able to identify ways of improving the service for people with dementia and carers, some staff were hesitant about committing their ideas to paper. This in part seemed to relate to whether they thought their suggestions would make any difference to the service. This confirms the importance of providing information on how the questionnaires will be used which was discussed in Section 7.6.3.

**Table 22. Summary of staff responses to open questions**

|  | <b>Number of staff<br/>(n=43)<sup>1</sup></b> |
|--|---|
| <b>How could the service to people with dementia be improved</b> |   |
| Increased resources  | 19  |
| Staff training   | 8   |
| More activities, choice of activities                            | 4   |
| More community involvement, outings                              | 4   |
| More knowledge of the individual service user                    | 3   |
| Better induction to the service                                  | 2   |
| Other  | 6   |
| Nothing  | 7   |
| <b>How could the service to carers be improved</b>               |   |
| Increased resources  | 15  |
| Opportunities to develop relationships with carers               | 4   |
| Increased recognition of carer needs                             | 4   |
| Staff training   | 3   |
| Other  | 7   |
| Nothing  | 13  |

<sup>1</sup> The number of responses under each heading is greater than the number of staff since some staff gave more than one response

### **7.6.7 Practical issues and recommendations for further testing**

We were able to recruit staff much more easily than either people with dementia or carers which provided us with more opportunities to revise the questionnaire. The staff questionnaire went through a total of four iterations, and it was possible to test out the majority of revisions to the questions and layout. However further psychometric testing would be required prior to these questionnaires being used in the evaluation of services providing respite care or short breaks.

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## 7.7 Vignettes for discussion by staff

### 7.7.1 Acceptability

#### *Willingness to participate*

Discussion groups lasted for between 24 and 49 minutes with a mean of 40 minutes. The number of participants ranged from two to six. Generating ideas for discussion could be more difficult in smaller groups, especially when thinking of solutions and ways to improve practice. A group size of around six people was preferred by some participants:

- S3 'I think it was nice to do it as a group, a small group, not the whole staff team  
 S4 big groups I wouldn't say a word  
 S3 a lot of people don't like big groups  
 S5 because sometimes you've got something to say and you just you don't want to and you just sit there and think "oh it doesn't matter"' (Service 1, vignette discussion 2)

It was not possible to organise vignette discussions in two services. The explicit barriers identified by managers were (a) the length of time required and (b) the difficulties in releasing several members of staff at a time. While other services faced similar problems with staffing and resources, it proved possible to use existing staff meetings, allocated training time, handover meetings between shifts or, in one service, to arrange a special staff meeting. In one of the services in which we were unable to organise a discussion session, our observation work suggested that there were potential opportunities for a small group of staff to meet and discuss the vignettes. The key barrier therefore appeared to be the commitment of the service manager.

On the whole staff seemed to find the experience enjoyable and useful:

'I think it makes us feel part of things as well, when we're invited in and asked what we think about things' (Service 4, vignette discussion 2)

'Some of these things we do, I think, on a daily basis without particularly thinking and things like this sometimes I find these very interesting to read, because you suddenly then think 'Oh yes, that's why we do this, that's why we don't do that'. So I think my first sort of thoughts are that it's very interesting.' (Service 6, vignette discussion 1).

It was suggested that the discussion could be used for a number of purposes: for information gathering; to find out levels of staff knowledge of different care situations; as a training exercise; or to actively seek to solve problems. One participant queried whether the activity could count towards a staff NVQ, since this would encourage participation and involvement.

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Staff working in one service, however, had a less positive view of the vignettes. Although explicit criticisms centred on the use of the term 'person-centred care', the main problem appeared to be that the vignette document required staff to be able to recognise the scope for service development and improvement. The staff in this service felt that all of the care they delivered was person-centred because it was delivered in small groups:

'Hang on; isn't all care person-centred?'

'I don't think there's ever an instance where you find difficulties providing person-centred care as a [home day care] carer. I think an institution could have difficulties in providing person-centred care on the basis that they don't have sufficient staff or facilities in order to do that.' (Service 2, vignette discussion 1)

Given that a number of participants in the telephone surveys had similar difficulties in identifying ways of improving their services since they viewed themselves as providing person-centred care (Chapter 4), it is not surprising that this issue arose in one vignette discussion. This problem highlights the importance of facilitation, discussed in more detail below.

### **Facilitation**

Clearly in the context of the present study, the research team were available to act as facilitators and to evaluate the use of the vignettes. In the longer term, an external facilitator is unlikely to be available. As part of the process of evaluating the vignettes, we explored participants' views on the need for facilitation. There was a consensus amongst participants that discussions should be facilitated. The main benefits of having a facilitator were: maintaining focus, especially if staff were discussing issues they were already familiar with; encouraging more creative solutions rather than simply focusing on (lack of) resources.

However, it was clear from the difficulties experienced by staff in one service that facilitation was also needed to help to encourage staff to explore ways in which the service could be improved. The extent to which staff have the skills necessary to facilitate discussion of the vignettes is likely to be variable. It will therefore be necessary to produce and test a guide to facilitation which highlights the main roles of the facilitator and includes additional prompts, examples and ways of rephrasing questions which could be used to encourage recognition of the scope for improvement within the service.

### **Length of vignettes**

We had originally intended to discuss more than one of the vignettes before moving on to applying the principles to practice. However, the amount of discussion generated by each vignette meant that it was only feasible to discuss one. This seems to reflect positively on the process, since it indicates that staff were engaged and interested in the discussion. The

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length of the vignettes appeared to be satisfactory, and some participants were interested in discussing the other vignettes at a later date.

### 7.7.2 Validity

#### *Authenticity of vignettes*

There was a consensus across all discussion groups that the vignettes were authentic representations, and that the situations described were familiar to practitioners. The situations were also viewed as transferable across services:

- I Tell me what you thought about that little scenario?
- S2 Well I think this happens quite a lot not only on the respite side but also the day centre. (Service 1, vignette discussion 2)

The style of the vignettes and the way in which participants were invited to respond entailed them initially taking on the perspective of different vignette characters. This approach seemed to ease people into the discussion, and they quickly responded within the context of the particular situation presented and also from their own personal viewpoint.

### 7.7.3 Content

Although the vignette document was quite long (11 sides of A4 paper), this was viewed as acceptable by staff. There were strong objections to the word 'vignette' which was not commonly known, viewed as jargon, and generally disliked. Alternatives that were preferred were 'case studies' or 'scenarios'. One group emphasised the importance of using clear, simple language since care staff may not have high levels of literacy, and/or English as their first language. As already described, there were some criticisms of the use of 'person-centred care' in the document. Alternatives such as 'personal care needs' or 'individualised care needs' were thought to be more accessible. However, neither of these terms was thought to reflect the scope of person-centred care. We decided to keep the term person-centred care but tried to reduce staff anxieties by explicitly stating that there was no agreed definition of person-centred care and that many staff were unsure what exactly it entailed.

There was considerable discussion of the level of detail provided in the vignettes. Some individuals would have preferred to have had more information included in the vignettes, as they felt they had to make too many assumptions to substitute for details that had been left out. One group suggested developing 'staged' vignettes, which would allow for additional information to be presented to participants as they worked through the questions about the vignette. In contrast, other staff felt that too much detail was unhelpful:

- 'I think it's about right in the detail and questions because there's enough there to inspire discussion.' (Service 6, vignette discussion 1)

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The level of detail of the vignettes had been discussed with the Reference Group (see Chapter 1). They were concerned that the provision of too much information could hinder discussion as the 'answer' would become obvious. Furthermore, one purpose of the vignettes was to generate discussion about additional information needed about a person with dementia in order to provide them with person-centred care; providing too much information at the outset would clearly pre-empt such discussion. In the light of staff comments, we amended the instructions for discussion of the vignettes, suggesting that where staff felt more information was needed, that they should start by producing a list of the information required and how they could find this out. The instructions then suggested that the staff should then explore how subsequent actions would be tailored to the additional information elicited.

### ***Instructions***

The style of the vignettes and the way in which participants were invited to respond entailed them initially taking on the perspective of different vignette characters. It was clear from participants' comments that they were able to consider situations from the perspective of different vignette characters. There was a view that this could be helpful, as it was all too easy to think (too) narrowly, in terms of just the person with dementia, for example, or the carer. One individual proposed that the vignette situations could be acted out in a role play, with the three key roles circulated amongst the same people; in other words, each person would take on the character of a person with dementia, their carer, and a member of staff. The participant felt this might help staff whose primary empathy was with a person with dementia to understand better what it was like to be their carer.

### ***Model answers***

The model answers were seen as useful and thought provoking, so much so that one group was keen to see something similar for the real life case study. This is because they took the view that some members of staff might be too quick to give up and simply say that that nothing more could be done. In view of the diversity of situations that might be discussed, we did not think it was feasible to develop a model answer for the discussion of a real life situation. Instead, we expanded this section and included additional questions.

### ***Applying principles to day-to-day practice***

An overall aim of the vignettes was to stimulate discussion, encourage staff to share ideas and think creatively about their own practice. There was evidence to suggest that the second activity, applying the vignette technique to day-to-day practice, was more useful than discussing the vignettes provided which did not necessarily generate any new or deeply insightful responses. From this point of view, the value of the early part of the discussion was debatable. However, participants did feel that it was a useful 'warm up' or lead in to the second part of the activity, where they

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identified a service user (or carer) for whom it had proved difficult to provide person-centred care.

Despite the increased complexities and conflict of real life situations in comparison with vignettes, staff generally found it easier to discuss familiar service users/situations. This again related to the level of detail available:

'I think because you do know more information it is easier to talk about people that you actually know, you've got a physical picture in the head, you've read their care plans, you know what kind of things they like doing, so it's more easier than that lady [in the vignette] because you know very little information about her'. (Service 1, vignette discussion 2)

The discussion groups had varying degrees of success in applying the principles to day-to-day practice. Not surprisingly, staff providing one-to-one support and/or home day care, could find it difficult to think of an individual whom they all knew well enough to discuss. Other groups found this easier, and interestingly two different discussion groups from the same service independently discussed the same service user and his wife. Difficulties had arisen in providing care for this couple, since the wife wanted her husband to have one-to-one care (ideally from a male member of staff) and did not appear to trust female staff. It was not possible to meet her preferences within the constraints of the service and female staff felt nervous about giving the service user any personal care in case his wife made a complaint against them:

'That situation made everybody, all the whole staff as a team, feel as though we were doing something wrong but we weren't.' (Service 1, vignette discussion 1)

Although staff said that they frequently had the opportunity to discuss such matters, it was clear that there had never been a formal opportunity for a detailed discussion of the problems they were individually encountering. This is consistent with the lack of opportunities for care staff to express their feelings about working with 'difficult' people with dementia reported in the literature (Packer, 2000d). Staff spontaneously commented on the value of 'debriefing' in this way:

S6 'It's the first time we've talked in a group about it  
S2 like handovers and things like that you know  
S4 but I think in this sort of situation I really feel that you know a debriefing in a sense would have been so beneficial  
S1 I think it would have made the staff feel a lot better  
S4 where we could have said what did we did wrong or what could we have done better.' (Service 1, vignette discussion 1)

The instructions for applying the principles to day-to-day practice were amended to clarify that the selected service user and/or carer did not necessarily need to be known to all staff present at the discussion. For example, in services providing one-to-one support or home day care, one

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member of staff could select a service user and/or carer and describe the issues arising in providing care. This approach was already routinely used in team meetings in the one-to-one support service as a way of joint problem-solving. Specific questions to encourage discussion of common issues that might arise in the real life situation were also added, to try to address staff concerns that some people might simply view some situations as inevitable and therefore spend little time on exploring possible solutions.

### 7.7.4 Practical issues and recommendations for further testing

The vignettes drew on data collected from the interviews and focus groups conducted early in the study (Chapter 2, 3 and 4). The observational work conducted as part of the case studies identified other possible issues that could usefully be explored in vignettes, including the delivery of personal care and the management of conflict or intolerance between people with dementia in communal services. We are also conscious that vignettes relating to specific groups will be required, including younger people with dementia and people from black and minority ethnic groups. Our limited exposure to such services (and the lack of representation in the case studies) meant that we had limited data to draw on, which made it difficult to write authentic vignettes. In particular, it was difficult to produce a sufficiently subtle vignette relating to black and minority ethnic groups. Any new vignettes will require further evaluation.

The main practical issue relating to the use of the vignettes concerns facilitation. Additional work is needed to identify the most appropriate person in services to take on the role of facilitator and to develop guidelines for facilitation. While service managers and team leaders may be an obvious choice, there is a danger that staff may feel constrained in what they can say in front of more senior staff. (Although staff in the vignette discussions we conducted thought that they would be able to be frank and honest in the presence of senior staff, this may not be the case in other services). Observation of discussions (either direct observation or analysis of recorded discussions), followed by debriefing of participants and the facilitator would be needed to evaluate the use of internal facilitators.

## 7.8 Observation

The observation component of the fieldwork was primarily included to explore the ways in which the components of person-centred care were delivered in practice and to check for any additional components which had not emerged from the focus groups and interviews (see Chapter 3). However, there is a risk of excluding the experiences of people with dementia who do not wish or are unable to participate in an interview if this is the only approach to data collection used. We were therefore interested in exploring the potential use of observation as part of the tools.

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### **7.8.1 Acceptability**

All of the people with dementia, carers and staff approached agreed to take part in observation, suggesting that this is an acceptable approach to data collection. Several carers who did not wish the person with dementia they supported to be invited to take part in an interview gave approval for observation, suggesting that, for these carers, observation was more acceptable than interviews.

### **7.8.2 Content**

The unstructured observation work allowed us to document the range of events that occurred rather than documenting the frequency of predetermined events. Analysis of the observation data (Appendix 1) indicated a number of areas for observation with particular relevance to the delivery of person-centred care. In Table 23 we highlight these areas, summarise the components of person-centred care most relevant to each area and provide an illustrative example from the field notes. Further detailed examples from the observation field notes showing how each component of person-centred care can be facilitated or undermined in relation to people with dementia, carers and staff are provided in Appendix 2. We hope the use of examples from day-to-day practice, will illustrate the components of person-centred care in a way that is accessible and meaningful to front-line staff. Furthermore, by providing detailed examples from practice we aim to highlight the potential use of observation for reviewing and developing practice.

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**Table 23. Suggested areas for observation**

| Area  | Rationale for inclusion   | Example from practice   |
|---|---|---|
| Physical location of staff and people with dementia | <ul style="list-style-type: none"> <li>• Staff need to be with people with dementia to deliver person-centred care</li> <li>• Staff ratios identified as a facilitator/barrier to person-centred care</li> <li>• People with dementia value one-to-one time with staff</li> </ul>   | <p>During the observation period, I noticed that at times there seemed to be about four members of staff in the office area in the lobby. There were clearly a lot of staff on duty, but individual service users did not seem to be benefitting from the high staff ratio. Field notes, Service 1: 109-112</p>   |
| Serving of meals                                    | <ul style="list-style-type: none"> <li>• Meal times present opportunities to observe the delivery of a range of components of person-centred care including:               <ul style="list-style-type: none"> <li>○ Respect (are dietary preferences known and acted upon?)</li> <li>○ Autonomy (what opportunities are people with dementia given to make choices?)</li> <li>○ Social relationships (to what extent are mealtimes an opportunity to talk to others?)</li> <li>○ Communication (how are options presented to people with dementia?)</li> <li>○ Physical and personal needs (how are the dietary needs of people with dementia met?)</li> </ul> </li> <li>• Meal times are often at risk of being task-focused rather than person-centred (how do routines of meal times reflect institutional needs rather than the needs of individuals?)</li> </ul> | <p>S202 produced a roast chicken lunch (with potatoes, carrots, cauliflower, broccoli), and pie and ice cream whilst still ensuring that the visitors were occupied/happy. S202 prepared an omelette for P203, who eats Kosher food. [...] S202 plated-up the meals, rather than put serving dishes etc out on the table for people to help themselves. She gave different people different sized portions, e.g. P204 had far more than the women, suggesting S202 was a reasonable judge of the size of respective appetites. No-one asked for any more and no-one left anything that they were given. Field notes, Service 2: 70-78</p> |

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|                              |  |  |
|------------------------------|--|--|
| Negotiation of personal care | <ul style="list-style-type: none"> <li>• The sensitivity with which personal care was negotiated varied in our observational work</li> <li>• Negotiation of personal care provides opportunities to observe a range of components of person-centred care including: <ul style="list-style-type: none"> <li>○ Respect (can other people with dementia or staff overhear the discussion?)</li> <li>○ Autonomy (are any requests relating to personal care made by people with dementia met promptly?)</li> <li>○ Physical and personal needs (are requests relating to personal care needs met? Do people with dementia ask for help with physical and personal needs?)</li> </ul> </li> </ul> | <p>There were some subtle episodes of helping people to the toilet. P304 was either asked by a volunteer or himself asked to go to the toilet (possibly asked first, declined and then subsequently said that he wanted to go). He seemed to have no problem with being helped to the toilet by the volunteer. P301 went to the toilet alone and I noticed two volunteers exchanging glances and one (V301) commenting that he was alright. V304 then came over and quietly approached P305 to ask whether she needed to go to the toilet. Field notes, Service 3: 395-401</p>   |
| Activity                     | <ul style="list-style-type: none"> <li>• The extent to which appropriate activities were available also varied in our observational work</li> <li>• Activities can promote several components of person-centred care including: <ul style="list-style-type: none"> <li>○ Psychological well-being (are activities enjoyable? Do they promote a sense of achievement?)</li> <li>○ Social relationships (are groups appropriately matched for abilities?)</li> <li>○ Autonomy (how much choice do people with dementia have over activities?)</li> <li>○ Respect (are activities relevant and meaningful to individual people with dementia?)</li> </ul> </li> </ul>                           | <p>When S502 came to the table, she was carrying a box of cards. On the reverse side of each card was the word 'Talk', on the other side each card started with 'Think back...' and then gave a specific topic to discuss. S502 explained that we were going to do some reminiscing. She took out a handful of about 7 or 8 cards and held these out in a fan, face down, and invited the person with dementia sitting to her left to pick a card. S502 waited to see whether the person with dementia would be able to read out the card. Reading ability in the group was varied, and in general S502 first gave people an opportunity to read out the card themselves, before reading it out. Some people seemed to be given a longer time than others before S502 read out the card. For example, S502 seemed to read out cards for P502 almost automatically, even though P502 was sitting holding discarded cards and reading them out to herself. Field notes, Service 5: 31-41</p> |

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|                      |  |  |
|----------------------|--|--|
| Physical environment | <ul style="list-style-type: none"> <li>• The importance of the physical environment in promoting the well-being of people with dementia is increasingly recognised, particularly in services located outside the home</li> <li>• Components of person-centred care which may be affected by the physical environment include:           <ul style="list-style-type: none"> <li>○ Autonomy (are the toilets clearly marked?)</li> <li>○ Psychological well-being (does information displayed help with orientation, for example, date and time are correctly displayed, decorations are appropriate to the time of year)</li> <li>○ Respect (where overnight care is provided, are names/photographs used on bedroom doors to help people with dementia to find their room?)</li> </ul> </li> </ul>                                       | <p>When we arrived, I had noticed that one clock had both hands and a digital display, but that while the hands indicated that the time was 12:02, the digital display said 12:19. I subsequently noticed that the other clock in the entrance lobby displayed the day and date; these showed Weds 15, whereas the date was Weds 19.</p> <p>While I was in a small TV lounge interviewing the manager, I noticed that one display on the wall was all about Halloween, with Christmas decorations on the windowsill. When I subsequently looked at the notices displayed in the hall, one of them was headed (something like) 'Things to look forward to', all but one of which had already taken place. Field notes, Service 1: 42-52</p> |
| Transport            | <ul style="list-style-type: none"> <li>• Transport arrangements can form a significant part of the day in some services, particularly if the route includes additional errands (e.g. picking up prescriptions or groceries)</li> <li>• Examples of components of person-centred care that may be affected by transport arrangements include:           <ul style="list-style-type: none"> <li>○ Physical and personal needs (is the temperature comfortable? In cold weather, are the bus doors left open when staff walk with service users to or from their homes?)</li> <li>○ Autonomy (do people have a choice over whether the radio is on or the types of music played?)</li> <li>○ Communication (how are people greeted in the morning? Is it possible to hold a conversation over any background music?)</li> </ul> </li> </ul> | <p>I was at P401's home when the bus came to pick her up. We had finished the interview and so I had arranged to get a lift back to [service name] on the bus. S409 came to the door to collect P401. As we walked to the bus, S410 was sitting in the driver's seat, looking pointedly at his watch, joking about how long P401 was taking and telling her to 'come on'. (She is usually ready and watches out for the bus; because I was sitting and talking to her, she wasn't as quick as usual out of the house). S410 clearly felt very easy with P401 and they seemed to enjoy having a joke about her being late. Field notes, Service 4: 5-8</p>  |

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### 7.8.3 Practical issues and recommendations for further testing

The identification of areas for observation and provision of examples from practice clearly do not constitute a formal observational tool. The development of such a tool is beyond the scope of this study. The information provided in Table 23 and Appendix 2 provide a basis for front-line staff and managers to review the care provided and identify opportunities for enhancing the delivery of person-centred care. One practical issue for staff conducting observation is their ability to focus on experiencing the situation without justifying or focusing on the rationale for what is observed. To take a simple example, there may be a good reason for staff to congregate in an office space, but the observation work initially needs to focus on the fact that staff tend to be in one place whilst people with dementia are in another. Further development work is needed to establish the extent to which staff are able to observe and document events or routines without being distracted by the underlying rationale for what they see. A preliminary testing of this relatively unstructured approach to observation is needed in order to identify any other training needs or barriers to the use of observation in practice.

Where quantitative data are required, the use of Dementia Care Mapping (see Section 5.5) will ensure that all of the components of person-centred care are addressed, although it will not be possible to disaggregate the data to examine different components of person-centred care in isolation. Although Dementia Care Mapping has a number of shortcomings, it currently represents the approach to observation that is most closely aligned to the components of person-centred care. Unstructured observation has been used successfully in one-to-one services, including home care and support services (Briggs *et al.*, 2003; Ryan *et al.*, 2002); The potential for using DCM within one-to-one services has not been explored; given the acceptability of unstructured observation, the possibility of using a more structured approach merits investigation. Even if using all three coding frames comprising DCM is not feasible, there may be scope for focusing on a simplified version or on one coding frame.

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## 7.9 Discussion and policy implications

A summary of the key findings from the comparative case studies is provided in Figure 25.

**Figure 25. Key findings from the comparative case studies**

- Field testing of the tools indicated that they were generally acceptable with good face and content validity
- Front-line staff and managers will require guidance, training and support to enable them to use and interpret the tools
- There are continuing challenges in including people with dementia in research.

### 7.9.1 Limitations of field testing

This chapter describes the process of testing and further development of the tools developed in Chapter 6 for evaluating person-centred care in services providing respite care and short breaks. The strength of our approach has been the use of a mixed-methods approach that has allowed some triangulation between methods and between data collected from different participants: people with dementia, carers and front-line staff. The tools developed in this study have been assessed in terms of their appropriateness, acceptability, validity and feasibility. Further psychometric testing will be required prior to implementation more widely within services providing respite care and short breaks. There are number of other limitations of the field testing.

A key challenge for the study was to hear the voice of people with dementia. Despite the introduction of the Mental Capacity Act 2005 (Department for Constitutional Affairs, 2007) to facilitate the inclusion of people with mental incapacities in decision making about their own lives, the process of obtaining consent and recruiting people with dementia was particularly difficult. This has resulted in an under-representation of people with dementia and potential bias in terms of the characteristics of participants with dementia recruited to the study.

A further limitation of the study is that the interviews and questionnaires have **not** been tested for use in routine practice. Commissioners and providers would have direct access to people with dementia and would not require formal informed consent from participants to participate. The different approaches that are allowable to commissioners and providers would facilitate greater involvement by key stakeholders of respite care and short breaks. The tools would be more readily acceptable to participants because they are now more streamlined and participants would not be expected to participate in methods to evaluate the quality of the tools.

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### 7.9.2 Recommendations for further testing

The comparative case studies focused on preliminary field testing of the tools. The findings suggest that the tools are generally acceptable to people with dementia, carers and staff and have face and content validity. Data from the cognitive interviews with carers suggest that the impact of the service was greater for those carers who used the service more intensively. This preliminary indication of construct validity needs further examination by using the carer questionnaire more extensively in different models of respite care and short breaks and comparing carers receiving different levels of care within the same service. Wider scale testing would allow examination of construct validity through factor analysis.

The assessment of criterion validity is problematic in the absence of existing tools or gold standard measures to evaluate person-centredness. The lack of such tools forms the rationale for the present study. There are, however, a number of generic quality of life measures which could be used alongside the tools we have developed. Dementia care mapping (DCM) is a well-established indicator of the quality of care, assuming quality of care and person-centred care are interrelated, it would be possible to compare the use of DCM with the tools developed.

Additional work is needed to establish the psychometric properties of the tools. Further testing of the conversational interview with people with dementia, and the carer and staff questionnaires could explore internal consistency, inter-rater reliability and test-retest reliability.

### 7.9.3 Conclusions

The tools developed are aligned to the key policy objective of providing person-centred care during respite care and short breaks. The tools could potentially be used for:

- formal service evaluations to contribute to the evidence base on the effectiveness of respite care and short breaks
- service review and development to identify strengths and areas for development
- studies exploring the outcomes of person-centred care to characterise the extent to which the service(s) provided are delivered in ways consistent with the components of person-centred care.

Further investment in the tools is needed prior to further use. For the purposes of the present study, members of the research team administered the tools, and analysed the data collected. Staff working in services providing respite care and short breaks and professionals with a broader responsibility for commissioning or quality assurance will require guidance and support in order to use the tools. The precise nature of the support required requires further investigation prior to developing and testing appropriate materials.

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## 8 Discussion and conclusion

The aim of this study was to develop and conduct preliminary field-testing of practical tools to evaluate the delivery of person-centred care in services providing respite care and short breaks for people with dementia. In this final chapter of the report we summarise the main findings, discuss the strengths and limitations of the study, draw out the implications for policy and practice and conclude with recommendations for further research.

### 8.1 Main findings

#### 8.1.1 Models of respite care and short breaks

A range of models of respite care and short breaks was identified (Chapter 2). These varied in terms of: location, duration, pattern of use, carer involvement, service provider, financial cost, availability, flexibility and the characteristics of service users and staff.

The need for a range of services to meet the unique needs and circumstances of people with dementia and carers, including those from black and minority ethnic groups and younger people with dementia, is well recognised. To this end, over £1 billion of financial support has been provided to Local Authorities in England since the Carers Grant was introduced in 1999 (HM Government 2008). This funding was intended to stimulate the development of new services, particularly the provision of short breaks, relevant to local populations.

Data from the focus groups and interviews with people with dementia and carers (Chapters 3 and 4), however, suggested that a limited range of services was available locally, with people being 'fitted' into available services. Little information is available about the distribution of different types of respite care and short breaks nationally. Review of Alzheimer Society websites and data from the Older People's Mental Health mapping exercise (Barnes and Lombardo, 2006) suggests a continued focus on traditional forms of respite care and short breaks. A review of services provided in Scotland similarly found evidence of restricted choice and under-provision of respite care and short breaks (Murphy and Archibald, 2004). Although some 'innovative' services have been available for more than 20 year (e.g. home day care), little progress has been made in integrating such services into the mainstream. The reasons for this are unclear, although there is some evidence that innovative models can be difficult to replicate (Archibald, 1996).

The need for additional evidence of the quality and cost-effectiveness of respite care and short breaks has been highlighted (HM Government, 2008). Structured and systematic reviews have consistently concluded that there is little evidence of the effectiveness of respite care and short breaks (Arksey *et*

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*al.*, 2004; Lee and Cameron, 2004; Mason *et al.*, 2007). A range of methodological problems have been identified, including the diversity of service aims and the lack of appropriate outcome measures. Despite varied aims, the detailed telephone interviews in the present study indicated that the delivery of person-centred care was widely accepted as being central to service provision, confirming that person-centredness could form a legitimate basis for comparative studies.

### 8.1.2 Components of person-centred care and facilitators and barriers to such care

It was clear that the term person-centred care was unfamiliar to most people with dementia and carers. Many front-line staff also had difficulties in describing person-centred care. Whilst they were aware of the concept and knew they 'ought' to be delivering it, many staff were unsure of exactly what it entailed. While managers generally appeared to have a better understanding of person-centred care, this was not universally the case.

Through focus groups and interviews with a range of stakeholders, we developed a framework of components of person-centred care (Chapter 3). This was subsequently confirmed by non-participant observation in different models of respite care and short breaks. Nine components of person-centred care were identified:

- respecting individuality and values
- enhancing psychological well-being
- promoting autonomy
- promoting a sense of shared responsibility
- fostering social context and relationships
- enhancing communication
- meeting physical and personal needs
- developing therapeutic alliance
- valuing expertise.

Although the components are described using abstract concepts, detailed examples from the focus groups and interviews with all stakeholders and from non-participant observation (Chapter 3 and Appendix 2) have been used to illustrate how the components are delivered in routine practice. By elaborating the components at both a conceptual and practical level, we hope to make the framework of person-centred care accessible to a wide range of audiences.

Current policy focuses almost exclusively on person-centredness in relation to service users. However, the components of person-centred care can also be applied to carers, front-line staff and managers. The framework can therefore contribute to a range of policy initiatives, including the Carers Strategy (HM Government, 2008), Putting People First (HM Government,

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2007) and the Adult Social Care Workforce Strategy (Department of Health, 2008a).

The lack of clarity over the meaning of person-centred care was an important barrier to the delivery of such care. For example, some staff thought that any service provided on a one-to-one or small-group basis was inevitably person-centred. These misconceptions could result in a lack of awareness of opportunities for service development and an overemphasis on staffing levels as being the key way of improving services. Poor understanding of person-centred care, coupled with waiting lists for services and lack of choice for people with dementia and carers, can also result in complacency. Consistent with previous studies, the delivery of person-centred care was perceived as dependent on a shared culture or ethos which permeated the whole organisation (Brooker, 2007b; Pool, 2006; Sheard, 2004; Zoutewelle-Morris, 2006).

### 8.1.3 Tools for evaluating person-centred care

An extensive review of measures used to evaluate respite care and short breaks indicated a poor 'fit' between existing measures and the components of person-centred care. We therefore developed new tools to evaluate person-centred care, drawing on existing measures as appropriate. Tools were developed for all stakeholders, reflecting our view that the principles of person-centred care are equally relevant to people with dementia, carers and staff. The tools comprised:

- conversational interview guide for people with dementia
- self-completion questionnaire for carers
- self-completion questionnaire for staff
- vignettes for discussion by the staff team
- observation.

Field testing indicated that the tools were acceptable and had good face validity. Some additional work is needed to identify the best way of administering the tools and analysing the data. Web-based approaches such as Survey Monkey (<http://www.surveymonkey.com>) may be useful since they can provide simple numerical summaries of responses to individual questions. However, additional data is required on the acceptability and feasibility of using web-based questionnaires for carers and staff. Further work is also needed to explore the psychometric properties of the tools. Such testing could be undertaken as part of an evaluative study of respite care and short breaks, alongside existing measures such as Dementia Care Mapping (Brooker and Surr, 2006) and quality of life measures (Albert and Logsdon, 2000; Ettema *et al.*, 2005; Ettema *et al.*, 2007a; Smith *et al.*, 2005; Trigg *et al.*, 2007). This could allow the evaluation of:

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- test-retest reliability
- concurrent validity (i.e. whether consistent with 'gold standard')
- factor analysis of tools to identify whether the components of person-centred care are reflected in the questions included.

Our review of existing observation measures indicated a poor 'fit' between the components of person-centred care and most of the measures. Whilst Dementia Care Mapping (see Section 5.5) has been used extensively in the dementia field and includes all of the components of person-centred care it is resource intensive and requires a three-day training course. We therefore explored the use of unstructured observation to supplement the data collected through interviews and questionnaires. On the basis of our observation, we have identified particular areas on which to focus observation. While this is clearly a long way from being a structured observation tool, the guidelines we have produced could usefully contribute to service review and development.

All of the tools could be used by services as a way of evaluating their service and identifying areas for improvement. The vignette discussions proved successful at highlighting different levels of understanding of person-centred care within staff teams (Chapter 7) and could be a powerful tool for service development and training.

### 8.2 Strengths and limitations of the study

The present study represents a considered attempt to explore the meanings of person-centred care and to translate this abstract concept into practical tools. While a number of indicators, or benchmarks, for person-centred care have previously been developed, these have tended to focus on the structure rather than the process of care, and have relied heavily on professional perspectives (Baker and Edwards, 2002; Reilly *et al.*, 2006). The present study included the perspectives of all stakeholders both in identifying the components of person-centred care and in evaluating the tools developed. The wide-ranging focus of the tools, which address basic personal and physical needs in addition to more aspiration aspects of care, such as developing a therapeutic alliance, should ensure that they identify areas for development in services that are already performing well as well as those with more scope for improvement.

A further strength was the interdisciplinary team with wide experience of the subject area and research methods. The different perspectives and levels of understanding of person-centred care within the research team meant that we directly experienced some of the barriers and difficulties that would be encountered in trying to evaluate person-centred care within services. The preliminary field testing took place in six very different services, in terms of the type of respite care or short break provided, staff perspectives on person-centred care and the emphasis on staff training and development.

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There were, however, a number of limitations to the study. In common with many previous studies we experienced difficulties in recruiting people with dementia (Pratt and Wilkinson, 2003). These difficulties partly reflected low expectations among carers and staff concerning the ability and willingness of people with dementia to express their views. The heterogeneity of people with dementia and carers was not fully represented in the study and further work with people from black and minority ethnic groups and younger people with dementia is needed to ensure that the framework of components of person-centred care and tools are relevant and acceptable to these groups. While the tools appeared to work well in the diverse services participating in the case studies, their relevance to other models of respite care and short breaks needs to be established.

A further limitation of the study is that the interviews and questionnaires have not yet been tested in the conditions that would characterise their use in routine practice. The self-completion questionnaires were completed in the presence of a researcher and involved reflecting on the questions and layout as well as responding to the questions. The guided conversational interview and vignette discussions with staff were facilitated by experienced researchers. All participants in the study had to be formally consented. While this would be necessary in future research studies, the consent process could be simplified significantly if the tools were used by providers or commissioners for service review and development.

### 8.3 Implications for national policy

Key implications for national policy are summarised in Figure 26. Despite considerable investment in respite care and short breaks, available evidence suggests that innovation and service development has been variable, resulting in restricted choice at a local level. The collation of innovative approaches to respite care and short breaks and dissemination of models of best practice to be undertaken as part of the new Carers Strategy (HM Government, 2008) may encourage greater replication of innovative services, particularly if attention is paid to how such models could be adapted to local contexts (Gibson, 1996; Innes *et al.*, 2005; Kelly and Williams, 2007). Clearer guidance on the scope and methods of the consultations with service users and carers may ensure that the needs of the local population are met. Together these additional resources may ensure that future investment is more successful in stimulating more flexible and innovative models of respite care and short breaks.

Rapidly moving policy can lead to cynicism among service providers, with initiatives being seen as the 'flavour of the month' and therefore not taken seriously. The use of poorly-defined terms, such as person-centred care, in policy documents can militate against the delivery of such care, since there is a tendency for services to rebrand existing practices in line with new terminology without changing the nature of their work. A lack of knowledge of person-centred care was identified as a key barrier to service development. There is therefore a need for an explicit and detailed description of concepts

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such as person-centred care as a first step to promoting the delivery of such care in practice. Recent policies have tended to emphasise personalisation and dignity rather than person-centred care. Neither of these concepts is as wide ranging as person-centred care, which may limit the potential for service development.

Both the present and previous studies have suggested that the principles or components of person-centred care apply to people with dementia, carers and staff. This has not yet been recognised in policy. The relevance of service ethos or culture to the delivery of person-centred care, suggests that policy needs to address organisational culture if person-centred care is to be successfully implemented.

Protected time for staff development is required. Too often training focuses on health and safety issues, with few resources available for other training. Improved pay and conditions could also contribute to staff development by encouraging a more diverse and appropriate range of staff.

### **Figure 26. Key implications for national policy**

- Provision of further guidance on the range of models of respite care and short breaks and on consultations with local service users and carers may encourage the development of more innovative and flexible services
- Constantly changing policy results in fatigue and can lead to a rebranding of existing practice in line with new terminology and priorities. It is therefore essential for new policies to reinforce and build on existing initiatives
- Conceptual terms, such as person-centred care, need to be carefully defined in policy documents to ensure shared understanding and facilitate implementation
- The implementation of person-centred care includes the current dignity and personalisation agendas and provides a more extensive framework for service development and evaluation
- The relevance of the components of person-centred care to service users, carers and staff needs to be explicitly recognised in policy, as does the importance of organisational culture
- Since staff are central to the delivery of person-centred care, policies need to address the recruitment, retention and development of a skilled workforce

## **8.4 Implications for local practice**

Key implications for local practice are summarised in Figure 27. At a local level, detailed information on current service provision and the needs and preferences of people with dementia and carers is needed to ensure that

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services meet the diverse needs of the local population. This should include exploration of the demand for joint breaks for the person with dementia and carer and for breaks outside the local area. Information on how people with dementia negotiate the boundaries between different services is also needed since transitions can disrupt the provision of person-centred care. The dissemination of models of best practice (HM Government, 2008) should provide commissioners and strategic managers with information on the range of innovative models of respite care and short breaks. This will be a useful resource since it can be difficult to identify approaches outside existing structures and services. The availability of an increased range of services at a local level may help in highlighting the shortcomings of existing services which are currently hidden.

The need for appropriate training for managers and front-line staff was emphasised in the present study. Staff at all levels, including managers and commissioners, need a good understanding of person-centred care. A range of approaches to training are needed to ensure that training permeates day-to-day practice. The framework of components of person-centred care, description of barriers and facilitators to such care and the vignettes developed in the present study have considerable potential as training materials. The components of person-centred care are relevant to people with dementia, carers and staff. Service level agreements, therefore, need to include details of how person-centred care is to be delivered and evaluated in relation to each of these stakeholder groups. For staff, this could include protected time for development; formal and informal supervision arrangements; opportunities for reflective practice; and collective problem solving.

Given the importance of organisational culture to the delivery of person-centred care, it is recommended that strategic and operational managers audit organisational culture (using existing tools or the staff questionnaire developed in the present study). This could highlight areas for development. Involving all stakeholders in developing a shared values base could improve consistency of service delivery and ensure that the fundamental principles underlying the service are aligned with the values important to people with dementia and carers. This could address some of the issues relating to acceptability of services highlighted in previous studies. A significant barrier to service development was the lack of awareness of the scope for improvement among some front-line staff and service managers. This highlights the need for commissioners, strategic and operational managers to facilitate a culture of continuous service development and improvement which builds on feedback from people with dementia, carers and staff.

Robust ways of evaluating services from the perspectives of people with dementia, carers and staff are required. Focusing on person-centred care provides an inclusive approach to evaluation which incorporates basic aspects of physical well being as well as more aspirational aspects of care, such as developing a therapeutic alliance. The tools developed in the present study

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require further testing; however, few other tools are available which capture the range of components of person-centred care.

### Figure 27. Key implications for local practice

- Commissioners should map the range of services providing respite care and short breaks at a local level to identify the models available
- Commissioners should explore the preferences of local people with dementia and carers for different models of respite care and short breaks
- Commissioners, strategic and operational managers should work together to develop existing services and identify ways of introducing models of respite care and short breaks that are not currently available
- Opportunities for developing an understanding of person-centred care through training, reflective practice and observation for staff at all levels are needed
- Service level agreements need to include details of how person-centred care is to be delivered and evaluated in relation to people with dementia, carers and staff
- Strategic and operational managers should audit existing organisational culture and develop a shared values base with all stakeholders
- Commissioners and strategic managers need to prioritise a culture of continuous service development and improvement which includes the collection and use of feedback from service users and carers
- Protected time is needed for staff and service development
- Robust ways of evaluating person-centred care from the perspectives of people with dementia, carers and staff are required

## 8.5 Recommendations for further research

Key recommendations for further research are provided in Figure 28. Available evidence regarding the outcomes of respite care and short breaks is inconclusive and inconsistent. This in part reflects methodological difficulties in evaluating such services and the lack of appropriate outcome measures. The lack of robust evidence is inconsistent with the policy emphasis on respite care and short breaks and the desire to move towards evidence-based policy. Further studies are required to clarify the outcomes and cost-effectiveness of respite care and short breaks.

Further development and testing of the tools developed in the present study is needed to explore their psychometric properties. Further work is also needed to explore how the tools could be administered in routine practice and contribute to ongoing service review and development, for example, by service managers or commissioners.

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In view of the paucity of information on the range of respite care and short breaks available, a national mapping exercise is recommended. This could highlight areas in which innovation and replication have been successful and contribute to the identification of models planned as part of the Carers Strategy (HM Government, 2008). Alongside a mapping exercise, we suggest further research on the preferences of people with dementia and carers for different models of respite care and short breaks. This would then provide a firm basis for the development of new services and ensure that people with dementia and carers had an appropriate range of local services to meet their needs and preferences. Although carers are to be consulted in the development of joint plans for provision of breaks (HM Government, 2008), the perspectives of people with dementia also need to be considered.

There is increasing recognition that respite care and short breaks should be a positive experience for people with dementia, yet little is currently known about the characteristics of services that contribute to a positive experience. Further study of experiences and outcomes of respite care and short breaks is merited in order to maximise the benefits of such services to people with dementia.

In view of the limited evidence of innovation following the provision of the Carers Grant (Department of Health, 1999), a study of facilitators and barriers to the development and replication of innovative models of respite care and short breaks is needed. This could draw on the mapping exercise suggested above to identify areas with high and low rates of innovation and to compare their experiences.

Studies of the facilitators and barriers to person-centred care have yielded similar findings. There is now scope for research to explore ways of maximising facilitators and overcoming barriers to person-centred care in delivering services. For example, the use of volunteers was identified as a potential facilitator to person-centred care. However, only one of the services participating in the comparative case studies used volunteers. Exploration of the facilitators and barriers to recruiting (and retaining) volunteers to work alongside staff in services providing respite care and short breaks could potentially enhance the delivery of person-centred care at relatively little financial cost.

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**Figure 28. Key recommendations for further research**

- The lack of robust evidence for the cost-effectiveness of respite care and short breaks is inconsistent with the policy emphasis on such services and on evidence-based practice
- Further development and testing of the tools developed in the present study is recommended
- A national mapping exercise is recommended to identify: the full range of models of respite care and short breaks; the availability of different models; and areas where innovative services have been successfully implemented
- Research is needed into the preferences of people with dementia and carers for different models of respite care and short breaks and the characteristics of services that contribute to a positive experience
- We recommend that research is commissioned to increase understanding of the factors associated with the successful development and replication of innovative services
- Research is needed into ways of maximising facilitators and overcoming barriers to the delivery of person-centred care in routine practice

## 8.6 Conclusion

The production of a framework of components of person-centred care represents a significant step towards a shared understanding of person-centred care in the context of respite care and short breaks. The study has also highlighted the need to extend the concept of person-centred care to carers and staff. The tools for people with dementia, carers and staff are at an early stage of development. The preliminary testing indicates that they are acceptable to stakeholders and relevant to a range of models of respite care and short breaks. Further field testing is needed to examine the psychometric properties of the tools. Delivering services that treat people with dementia, carers and staff in a person-centred way continues to be a major challenge. We hope that the increased understanding of person-centred care (and the barriers and facilitators to such care), together with the practical tools developed can contribute towards a greater alignment between service evaluation and review and the key policy objective of providing person-centred care.

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## References

- Abendstern M, Reilly S, Hughes J, Venables D and Challis D. (2006) Levels of integration and specialisation within professional community teams for people with dementia. *International Journal of Geriatric Psychiatry* 21: 77-85.
- Adams T. (1996) Kitwood's approach to dementia and dementia care: a critical but appreciative review. *Journal of Advanced Nursing* 23: 948-953.
- Adams T and Gardiner P. (2005) Communication and interaction within dementia care triads: developing a theory for relationship-centred care. *Dementia* 4: 185-205.
- Aggarwal N, Vass AA, Minardi HA, Ward R, Garfield C and Cybyk B. (2003) People with dementia and their relatives: personal experiences of Alzheimer's and of the provision of care. *Journal of Psychiatric and Mental Health Nursing* 10: 187-197.
- Albert SM, Del Castillo-Castaneda C, Sano M, Jacobs DM, Marder K, Bell K, *et al.* (1996) Quality of life in patients with Alzheimer's disease as reported by patient proxies. *Journal of the American Geriatrics Society* 44: 1342-1347.
- Albert SM and Logsdon RG. (2000) *Assessing quality of life in Alzheimer's disease*. New York: Springer Publishing Company.
- Allan K. (2001) *Communication and consultation: exploring ways for staff to involve people with dementia in developing services*. Bristol: The Policy Press and Joseph Rowntree Foundation.
- Almberg B, Graftstrom M, Krichbaum K and Winblad B. (2000) The interplay of institution and family caregiving: relations between patient hassles, nursing home hassles and caregivers' burnout. *International Journal of Geriatric Psychiatry* 15: 931-939.
- Archibald C. (1996) *A movable feast: different examples of respite care provision for people with dementia and their carers*. Stirling: Dementia Services Development Centre, University of Stirling.
- Arksey H, Jackson K, Croucher K, Weatherley H, Golder S, Hare P, *et al.* (2004) *Review of respite services and short-term breaks for carers for people with dementia*. York: University of York: Social Policy Research Unit.
- Ashworth M and Baker AH. (2000) 'Time and space': carers' views about respite care. *Health and Social Care in the Community* 8: 50-56.
- Baker CJ and Edwards P. (2002) The missing link: benchmarking person-centred care. *Journal of Dementia Care* 10: 22-23.
- Bamford C and Bruce E. (2000) Defining the outcomes of community care: the perspectives of older people with dementia and their carers. *Ageing and Society* 20: 543-570.
- Bamford C, Hughes J and Robinson L. (2007) Improving patient-centred care for people with dementia in medical encounters. *Gerontologist* 47: 158-159.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Banister R, Burman E, Parker I, Taylor M and Tindall C. (1994) *Qualitative methods in psychology*. Buckingham, UK: Open University Press.
- Barnes D and Lombardo C. (2006) *A profile of older people's mental health services: report of service mapping 2006*. Durham: Durham University.
- Barnes S. (2006) Space, choice and control, and quality of life in care settings for older people. *Environment and Behavior* 38: 589-604.
- Barter C and Renold E. (1999) The use of vignettes in qualitative research. *Social Research Update* Issue 25.
- Bate P. (1994) *Strategies for cultural change*. Oxford: Butterworth Heinemann.
- Beavis D, Simpson S and Graham I. (2002) A literature review of dementia care mapping: methodological considerations and efficacy. *Journal of Psychiatric and Mental Health Nursing* 9: 725-736.
- Bond J. (1992) The medicalization of dementia. *Journal of Aging Studies* 6: 397-403.
- Bond J. (1999) Quality of life for people with dementia: approaches to the challenge of measurement. *Ageing and Society* 19: 561-579.
- Bowes A and Wilkinson H. (2003) 'We didn't know it would get that bad': South Asian experiences of dementia and the service response. *Health and Social Care in the Community* 11: 387-396.
- Briggs K and Askham J. (1998) *The needs of older people with dementia and those who care for them*. London: Alzheimer's Disease Society.
- Briggs K, Askham J, Norman I and Redfern S. (2003) Accomplishing care at home for people with dementia: using observational methodology. *Qualitative Health Research* 13: 268-280.
- Brod M, Stewart AL and Sands L. (1999a) Conceptualization of quality of life in dementia. *Journal of Mental Health and Aging* 5: 7-19.
- Brod M, Stewart AL and Sands L. (2002) Conceptualization of quality of life in dementia, in Albert, SM and Logsdon, RG (eds) *Assessing quality of life in Alzheimer's disease*. New York: Springer Publishing Company: 3-16.
- Brod M, Stewart AL, Sands L and Walton P. (1999b) Conceptualization and measurement of quality of life in dementia: the Dementia Quality of Life Instrument (DQoL). *Gerontologist* 39: 25-35.
- Brody H. (2007) Meaning and measurement of caregiver outcomes. *International Psychogeriatrics* 19: 363-381.
- Brody H, Draper B and Low L. (2003) Nursing home staff attitudes towards residents with dementia: strain and satisfaction with work. *Journal of Advanced Nursing* 44: 583-590.
- Brooker D. (2001) Enriching lives: evaluation of the extracare activity challenge. *Journal of Dementia Care* 9: 33-37.
- Brooker D. (2004) What is person-centred care in dementia? *Reviews in Clinical Gerontology* 13: 215-222.
- Brooker D. (2005) Dementia care mapping: a review of the research literature. *The Gerontologist* 45: 11-18.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Brooker D. (2007a) *The development of SOFI Short Observation Framework for Inspection*. Commission for Social Care Inspection.
- Brooker D. (2007b) *Person-centred dementia care. Making services better*. London: Jessica Kingsley Publishers.
- 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. *Aging and Mental Health* 2: 60-70.
- Brooker DJ and Surr C. (2006) Dementia care mapping (DCM): initial validation of DCM 8 in UK field trials. *International Journal of Geriatric Psychiatry* 21: 1018-1025.
- Calvert Trust. (2004) *Calvert Trust, Kielder Activity Holidays*. Available at: [www.calvert-trust.org.uk](http://www.calvert-trust.org.uk) [Accessed: 01/05/08].
- Capstick A. (2003) The theoretical origins of dementia care mapping, in Innes, A (ed), *Dementia care mapping: applications across cultures*. Baltimore: Health Professions Press.
- Care Services Improvement Partnership. (2005) *Everybody's business. Integrated mental health services for older adults: a service development guide*. London: Department of Health.
- Care Services Improvement Partnership. (2008) *CSIP fact sheet. Creative models of short breaks (respite care) for people with dementia*. London: Department of Health.
- Carroll AM, Vetter K, Holmes S and Supiano KP. (2005) Ask the consumer: an innovative approach to dementia-related adult day service evaluation. *American Journal of Alzheimer's Disease and other Dementias* 20: 290-294.
- Carver CS, Scheier MF and Weintraub JH. (1989) Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psychology* 56: 267-283.
- Cass E, Robbins D and Richardson A. (2008) *Dignity in Care*. London: Social Care Institute for Excellence.
- Charlesworth GM, Tzimoula XM and Newman SP. (2007) Carers assessment of difficulties index (CADI): psychometric properties for use with carers of people with dementia. *Aging and Mental Health* 11: 218-225.
- Chenoweth L and Jeon Y-H. (2007) Determining the efficacy of dementia care mapping as an outcome measure and a process for change: a pilot study. *Aging and Mental Health* 11: 237-245.
- Cheston R and Bender M. (1999) *Understanding dementia: the man with worried eyes*. London: Jessica Kingsley Publishers.
- Coffey A. (1999) *The ethnographic self*. London: SAGE publications.
- Cohen J. (1960) A coefficient of agreement for nominal scales. *Educational and Psychological Measurement* 20: 37-46.
- Cohen J. (1968) Weighted Kappa: nominal scale agreement with provision for scaled disagreement or partial credit. *Psychological Bulletin* 70: 213-220.
- Commission for Social Care Inspection. (2008) *The state of social care in England 2006-07*. London: CSC1.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Corner L. (2003) *Assessing quality of life from the perspective of people with dementia and their carers [Final report Alzheimer's Society Fellowship]*. University of Newcastle upon Tyne: Alzheimer's Society and Centre for Health Services Research.
- Cotrell V. (1996) Respite use by dementia caregivers: preferences and reasons for initial use. *Journal of Gerontological Social Work* 26: 35-55.
- Cotrell V and Schulz R. (1993) The perspective of the patient with Alzheimer's disease: a neglected dimension of dementia research. *Gerontologist* 33: 205-211.
- Cottrell V and Engel RJ. (1998) The role of secondary supports in mediating formal services to dementia caregivers. *Journal of Gerontological Social Work* 30: 117-32.
- Crandall LG, White DL, Schuldheis S and Talerico KA. (2007) Initiating person-centred care practices in long-term care facilities. *Journal of Gerontological Nursing* 33: 47-56.
- Cresswell JW. (2003) *Research design: qualitative, quantitative and mixed methods approaches*. Thousand Oaks, CA: Sage.
- Cronbach LJ. (1951) Coefficient alpha and the internal structure of tests. *Psychometrika* 16: 297-334.
- Daker-White G, Beattie AM, Gilliard J and Means R. (2002) Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice. *Aging and Mental Health* 6: 101-108.
- DeJong R, Osterlund OW and Roy GW. (1989) Measurement of quality-of-life changes in patients with Alzheimer's disease. *Clinical Therapeutics* 11: 545-554.
- Denzin NK. (1970) *Sociological Methods: A Sourcebook. Part XII: Triangulation; a case for methodological evaluation and combination*. London: Butterworth.
- Department for Constitutional Affairs. (2007) *Mental Capacity Act 2005. Code of Practice*. London: The Stationery Office.
- Department of Health. (1999) *Caring about carers: a national strategy for carers*. London: Department of Health.
- Department of Health. (2000) *Extension of direct payments scheme to pensioners* Available at: [http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT\\_ID=4002473&chk=51BnAN](http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4002473&chk=51BnAN) [Accessed: 16/05/05].
- Department of Health. (2001a) *National Service Framework for Older People*. London: NHS Executive.
- Department of Health. (2001b) *A practitioner's guide to assessment under the carers and disabled children act 2000*. London: Department of Health.
- Department of Health. (2005a) *Independence, well-being and choice. Our vision for the future of social care for adults in England*. London: The Stationery Office.
- Department of Health. (2005b) *The national service framework for long-term conditions*. London: Department of Health.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Department of Health. (2005c) *Give carers a break* Available at: [http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT\\_ID=4104029&chk=o4YyAt](http://www.dh.gov.uk/PublicationsAndStatistics/PressReleases/PressReleasesNotices/fs/en?CONTENT_ID=4104029&chk=o4YyAt) [Accessed: 17/05/05].
- Department of Health. (2006) *Our health, our care, our say: a new direction for community services*. London: Department of Health.
- Department of Health. (2008a) *Putting people first - working to make it happen: Adult social care workforce strategy - interim statement*. London: Department of Health.
- Department of Health. (2008b) *Transforming the quality of dementia care: Consultation on a national dementia strategy* Available at: [www.dh.gov.uk/dementia](http://www.dh.gov.uk/dementia) [Accessed: 23/09/08].
- Department of Health and Department of Education and Skills. (2005) *Carers and Disabled Children Act 2000 & Carers (Equal Opportunities) Act 2004. Carers and people with parental responsibility for disabled children. Combined Draft Policy Guidance*. Leeds: Department of Health.
- Derence K. (2005) Dementia-specific respite. *North Carolina Medical Journal* 66: 50-54.
- Dillman DA. (1978) *Mail and telephone surveys: the total design method*. New York: John Wiley and Sons.
- Donabedian A. (1980) *The definition of quality and approaches to its assessment. Explorations in quality assessment and monitoring*. Ann Arbor, Michigan: Health Administration.
- Donaldson C and Gregson B. (1989) Prolonging life at home: what is the cost. *Community Medicine* 11 (3): 200-209.
- Dowling S, Manthorpe J, Cowley S, King S, Raymond V, Perez W, *et al.* (2006) *Person-centred planning in social care. A scoping review*. York: Joseph Rowntree Foundation.
- Downs M, Small N and Froggatt K. (2006) Explanatory models of dementia: links to end-of-life care. *International Journal of Palliative Nursing* 12: 209-13.
- Dröes R-M, Breebaart E, Meiland FJM, Van Tilberg W and Mellenbergh GJ. (2004a) Effect of meeting centres support program on feelings of competence of family carers and delay of institutionalization of people with dementia. *Aging and Mental Health* 8: 201-211.
- Dröes R-M, Meiland F, Schmitz M and van Tilburg W. (2004b) Effect of combined support for people with dementia and carers versus regular day care on behaviour and mood of persons with dementia: results from a multi-centre implementation study. *International Journal of Geriatric Psychiatry* 19: 673-684.
- Edelman P, Fulton BR, Kuhn D and Chang CH. (2005) A comparison of three methods of measuring dementia-specific quality of life: perspectives of residents, staff and observers. *The Gerontologist* 45: 27-36.
- Edelman P, Guihan M, Bryant FB and Munroe DJ. (2006) Measuring resident and family member determinants of satisfaction with assisted living. *The Gerontologist* 46: 599-608.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Edelman P, Kuhn D and Fulton BR. (2004) Influence of cognitive impairment, functional impairment and care setting on dementia care mapping results. *Aging and Mental Health* 8: 514-23.
- Edvardsson D, Winblad B and Sandman PO. (2008) Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurology* 7: 362-67.
- Ettema TP, Dröes R-M, de Lange J, Mellenbergh GJ and Ribbe MW. (2005) A review of quality of life instruments used in dementia. *Quality of Life Research* 14: 675-686.
- Ettema TP, Dröes R-M, de Lange J, Mellenbergh GJ and Ribbe MW. (2007a) QUALIDEM: development and evaluation of a dementia specific quality of life instrument-validation. *International Journal of Geriatric Psychiatry* 22: 424-430.
- Ettema TP, Dröes R-M, de Lange J, Mellenbergh GJ and Ribbe MW. (2007b) QUALIDEM: Development and evaluation of a dementia specific quality of life instrument. Scalability, reliability and internal structure. *International Journal of Geriatric Psychiatry* 22: 549-556.
- Faulkner M, Davies S, Nolan M and Brown-Wilson C. (2006) Development of the combined assessment of residential environments (CARE) profiles. *Journal of Advanced Nursing* 55: 664-677.
- Finch J. (1987) The vignette technique in survey research. *Sociology* 21: 105-14.
- Fitzpatrick R, Davey C, Buxton MJ and Jones DR. (1998a) Patient-assessed outcome measures, in Black, N, Brazier, J, Fitzpatrick, R and Reeves, B (eds) *Health Services Research Methods. A guide to best practice*. London: BMJ Books: 13-22.
- Fitzpatrick R, Davey C, Buxton MJ and Jones DR. (1998b) Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment* 2(14).
- Folstein MF, Folstein SE and McHugh PR. (1975) Mini-mental state: a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research* 12: 189-198.
- Fossey J, Lee L and Ballard C. (2002) Dementia Care Mapping as a research tool for measuring quality of life in care settings: psychometric properties. *International Journal of Geriatric Psychiatry* 17: 1064-1070.
- Francis J and Netten A. (2004) Raising the quality of home care: a study of service users' views. *Social Policy and Administration* 38: 290-305.
- Frost P. (1990) *Short-term care in East Sussex: a study of the experience and needs of carers for the East Sussex Care for Carers Council*. Brighton: Community Studies Department, Brighton Polytechnic.
- Fulton BR, Edelman P and Kuhn D. (2006) Streamlined models of dementia care mapping. *Aging and Mental Health* 10: 343-351.
- Gendron M and Adam E. (2005) An innovative respite and support service\* in the home of the family caregiver of a person with Alzheimer's. *Alzheimer's Care Quarterly*: 249-261.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Geron SM, Smith K, Tennstedt S, Jette A, Chassler D and Kasten L. (2000) The home care satisfaction measure: a client-centred approach to assessing the satisfaction of frail older adults with home care services. *Journal of Gerontology* 55b: S259-S270.
- Gerritsen DL, Ettema TP, Boelens E, Bos J, Hoogeveen F, de Lange J, *et al.* (2007) Quality of life in dementia: do professional caregivers focus on the significant domains? *American Journal of Alzheimer's Disease and other Dementias* 22: 176-183.
- Gibson F. (1996) *Dementia day care innovation in rural areas*. Stirling: Dementia Services Development Centre, University of Stirling.
- Gill TM and Feinstein AR. (1994) A critical appraisal of the quality of quality of life measurements. *Journal of the American Medical Association* 272: 619-626.
- 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: 233-248.
- Gilmour JA. (2002) Dis/integrated care: family caregivers and in-hospital respite care. *Journal of Advanced Nursing* 39: 546-553.
- Glynn M, Beresford P, Bewley C, Branfield F, Butt J, Croft S, *et al.* (2008) *Person-centred support. What service users and practitioners say*. York: Joseph Rowntree Foundation.
- Godfrey A. (2000) What impact does training have on the care received by older people in residential homes? *Social Work Education* 19: 55-65.
- Grant LA. (1996) Assessing environments in Alzheimer special care units - nursing unit rating scale. *Research on Aging* 18: 275-291.
- Graytoft P and Anderson JG. (1981) The nursing stress scale - development of an instrument. *Journal of Behavioral Assessment* 3: 11-23.
- Gwyther LP. (1997) The perspective of the person with Alzheimer disease: which outcomes matter in early to middle stages of dementia? *Alzheimer Disease and Associated Disorders* 11: 18-24.
- Hallberg IR and Norberg A. (1995) Nurses' experiences of strain and their reactions in the care of severely demented patients. *International Journal of Geriatric Psychiatry* 10: 757-766.
- Harding N and Palfrey C. (1997) *The social construction of dementia. Confused Professionals?* London and Philadelphia: Jessica Kingsley Publishers.
- Healthcare Commission, Commission for Social Care Inspection and Audit Commission. (2006) *Living well in later life*. London: Healthcare Commission.
- Hepworth D. (2001) Beyond caring? *Community Care* 30 August-5 September: p20.
- HM Government. (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*. London: HM Government.
- HM Government. (2008) *Carers at the heart of 21st-century families and communities - "A caring system on your side. A life of your own."* London: HM Government.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Hughes J, Bamford C and May C. (2008) Types of centredness in health care: themes and concepts. *Medicine Health Care and Philosophy* 11: 455-463.
- Hughes JC. (2001) Views of the person with dementia. *Journal of Medical Ethics* 27: 86-91.
- Hughes R. (1998) Considering the vignette technique and its application to a study of drug injecting and HIV risk and safer behaviour. *Sociology of Health and Illness* 20: 381-400.
- Hulko W. (2002) Making the links: social theories, experiences of people with dementia, and intersectionality, in Leibing, A and Scheinkman, L (eds) *The diversity of Alzheimer's disease: different approaches and contexts*. Rio de Janeiro, Brazil: CUCA-IPUB: 231-264.
- Husband HJ. (1999) The psychological consequences of learning a diagnosis of dementia: three case examples. *Aging and Mental Health* 3: 179-183.
- Illife S and Manthorpe J. (2004) The debate on ethnicity and dementia: from category fallacy to person-centred care? *Aging and Mental Health* 8: 283-292.
- Innes A, Blackstock K, Mason A, Smith A and Cox S. (2005) Dementia care provision in rural Scotland: service users' and carers' experiences. *Health and Social Care in the Community* 13: 354-365.
- Innes A and Kelly F. (2007) Evaluating long stay settings: reflections on the process with particular reference to dementia care mapping, in Innes, A and McCabe, L (eds) *Evaluation in dementia care*. London: Jessica Kingsley Publishers: 144-160.
- Innes A, Macpherson S and McCabe L. (2006) *Promoting person-centred care at the front line*. York: Joseph Rowntree Foundation.
- James IA. (2007) Person-centred care: the holy grail or a muddled and misguided goal. *PSIGE Newsletter* 99: 9-13.
- Jarrott SE, Zarit SH, Parris-Stephens MA, Townsend A and Greene R. (1999) Caregiver satisfaction with adult day service programs. *American Journal of Alzheimer's Disease* 14: 233-244.
- Jeon Y-H, Brodaty H and Chesterson J. (2005) Respite care for caregivers and people with severe mental illness: literature review. *Journal of Advanced Nursing* 49: 297-306.
- Jewson N, Jeffers S and Kalra V. (2003) *Family care, respite services and Asian communities in Leicester*. Leicester: Ethnicity Research Centre, University of Leicester.
- Jones K, Netten A, Francis J and Bebbington A. (2007) Using older home care user experiences in performance monitoring. *Health and Social Care in the Community* 15: 322-332.
- Kane RL. (1997) Which outcomes matter in Alzheimer Disease and who should define them? *Alzheimer Disease and Associated Disorders* 11: 12-17.
- Katbamna S, Bhakta P and Parker G. (1998) *Experiences and needs of carers from the South Asian communities*. Leicester: Nuffield Community Care Studies Unit, University of Leicester.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Keady J and Gilliard J. (2002) Testing times: the experience of neuropsychological assessment for people with suspected Alzheimer's disease, in Harris, PB (ed), *The person with Alzheimer's disease: pathways to understanding the experience*. Baltimore & London: The Johns Hopkins University Press: 3-28.
- Kelly CM and Williams IC. (2007) Providing dementia-specific services to family caregivers: North Carolina's project C.A.R.E. program. *Journal of Applied Gerontology* 26: 399-412.
- Keywood K, Fovargue S and Flynn M. (1999) *Adults with learning difficulties' involvement in health care decision making*. York: Joseph Rowntree Foundation.
- King's Fund. (2001) *More breaks for carers*. London: King's Fund.
- Kitwood T. (1997) *Dementia reconsidered: the person comes first*. Buckingham: Open University Press.
- Kitwood T and Benson S. (1995) *The new culture of dementia care*. London: Hawker Publications.
- Kitwood T and Bredin K. (1992) A new approach to the evaluation of dementia care. *Journal of Advances in Health and Nursing Care* 1: 41-60.
- Knapp M, Prince M, Albanese E, Banerjee S, Dhanasiri S, Fernandez J-L, *et al.* (2007) *Dementia UK: the full report*. London: Alzheimer's Society.
- Kosberg JI, Kaufman AV, Burgio LD, Leeper JD and Sun F. (2007) Family caregiving to those with dementia in rural Alabama. *Journal of Aging and Health* 19: 3-21.
- Kuhn D, Edelman P and Fulton BR. (2005) Daytime sleep and the threat to well-being of persons with dementia. *Dementia* 4: 233-247.
- Kuhn D, Kasayka RE and Lechner C. (2002) Behavioral observations and quality of life among persons with dementia in 10 assisted living facilities. *American Journal of Alzheimer's Disease and other Dementias* 17: 291-298.
- Kwok C. (2003) Government policy and medical traditions in Honk Kong, in Innes, A (ed), *Dementia care mapping: applications across cultures*. Baltimore: Health Professions Press.
- La Fontaine J. (2004) Providing person-centred care for younger people with dementia. *Journal of Dementia Care* Jan/Feb 2004: 18-20.
- Lai JM, Hawkins KA, Gross CP and Karlawish JH. (2008) Self-reported distress after cognitive testing in patients with Alzheimer's disease. *Journal of Gerontology: Medical Sciences* 63A: 855-859.
- Lawley D, Bell J and Rudd M. (2005) Modernising a psychiatric day hospital service for older people. *Psychiatry* April: 25-31.
- Lechner C. (2007) Internal versus external evaluation, in Innes, A and McCabe, L (eds) *Evaluation in dementia care*. London: Jessica Kingsley Publishers: 46-65.
- Lee H and Cameron M. (2004) Respite care for people with dementia and their carers *Cochrane Database of Systematic Reviews Library, Issue 1. Art No.: CD004396. DOI: 10.1002/14651858.CD004396.pub2*.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Lees K. (2006) 'Gentleman who lunch': developing self-help groups for people with early diagnosis of dementia. *PSIGE Newsletter*: 33-38.
- Leplege A, Gzil F, Cammelli M, Lefevre C, Pachoud B and Ville I. (2007) Person-centredness: conceptual and historical perspectives. *Disability and Rehabilitation* 29: 1555-1565.
- Levin E, Moriarty J and Gorbach P. (1994) *Better for the break*. London: HMSO.
- Loewenstein DA, Argüelles S, Bravo M, Freeman RQ, Argüelles T, Acevedo A, *et al.* (2001) Caregivers' judgments of the functional abilities of the Alzheimer's disease patient: a comparison of proxy reports and objective measures. *Journal of Gerontology* 56B: P78-84.
- Logsdon RG, Gibbons LE, McCurry SM and Teri L. (1999) Quality of life in Alzheimer's disease: patient and caregiver reports. *Journal of Mental Health and Aging* 5: 21-32.
- Lund DA, Hill RD, Caserta MS and Wright SD. (1995) Video respite: an innovative resource for family, professional caregivers, and persons with dementia. *Gerontologist* 35: 683-687.
- MacGregor G. (2000) *Give us a break: a study of the impact of the carers special grant in the north of England*. London: Carers National Association.
- Malfullul YM. (2002) Informal carers of mentally infirm elderly in Lancashire. *East African Medical Journal* 79: 284-290.
- Maslach C and Jackson SE. (1981) *Maslach burnout inventory*. Palo Alto, CA: Consulting Psychologists Press.
- Mason A, Weatherly H, Spilsbury K, Arksey H, Golder S, Adamson J, *et al.* (2007) A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers. *Health Technology Assessment* 11: 1-151.
- Mason P, Slatter G and Sincock C. (2006) Psychoeducational support groups for clients with early-stage dementia and their carers. *PSIGE Newsletter* 93: 19-25.
- McCallion P, McCarron M and Nickle T. (2006) Dementia and carer burnout: usefulness of the Maslach Burnout Inventory. *Journal of Applied Research in Intellectual Disabilities* 19: 230.
- McCull E, Jacoby A, Thomas L, Soutter J, Bamford C, Steen N, *et al.* (2001) Designing and using patient and staff questionnaires: a review of best practice applicable to surveys of health service staff and patients. *Health Technology Assessment* 5(31).
- McCormack B. (2004) Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing* 13: 31-38.
- McKee KJ, Philp I, Lamura G, Prouskas C, Oberg B, Krevers B, *et al.* (2003) The COPE index-a first stage assessment of negative impact, positive value and quality of support of caregiving in informal carers of older people. *Aging and Mental Health* 7: 39-52.
- McNally S, Ben-Shlomo Y and Newman S. (1999) The effects of respite care on informal carers' well-being: a systematic review. *Disability and Rehabilitation* 21: 1-14.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Mead N and Bower P. (2000) Patient-centredness: a conceptual framework and review of the empirical literature. *Social Science and Medicine* 51: 1087-1110.
- Miles MB and Huberman AM. (1984) *Qualitative data analysis: a sourcebook of new methods*. California: Sage.
- Mitchell R. (1999) Home from home: a model of daycare for people with dementia. *Generations*: 78-81.
- Moise P, Schwarzingler M, Um M-Y and Dementia Experts' Group. (2004) *Dementia care in 9 OECD Countries*. Paris: OECD.
- Morgan DG, Stewart NJ, D'Arcy KC and Werezak LJ. (2004) Evaluating rural nursing home environments: dementia special care units versus integrated facilities. *Aging and Mental Health* 8: 256-265.
- Moriarty J. (1999) Use of community and long-term care by people with dementia in the UK: a review of some issues in service provision and carer and user preferences. *Ageing and Mental Health* 3: 311-19.
- Moriarty J. (2001) Day care for older adults: developing services for diversity, in Clark, C (ed), *Adult day services and social inclusion: better days*. London: Jessica Kingsley: 109-32.
- Moriarty J and Levin E. (1993) Interventions to assist caregivers. *Reviews in Clinical Gerontology* 3: 301-308.
- Morris RG, Morris LW and Britton PG. (1988) Factors affecting the emotional wellbeing of the caregivers of dementia sufferers. *British Journal of Psychiatry* 153: 147-156.
- Mountain G and Godfrey M. (1995) *Respite care provision for older people with dementia: a review of the literature*. Leeds: Community Care Division, Nuffield Institute for Health.
- Mozley CG, Huxley P, Sutcliffe C, Bagley H, Burns A, Challis D, *et al.* (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: 776-783.
- Mulhall A. (2003) In the field: notes on observation in qualitative research. *Methodological Issues in Nursing Research* 41: 306-13.
- Murphy C. (2007) User involvement in evaluations, in Innes, A and McCabe, L (eds) *Evaluation in dementia care*. London: Jessica Kingsley Publishers: 214-229.
- Murphy C and Archibald C. (2004) *Overnight respite and short break provision in Scotland*. Stirling: Dementia Services Development Centre, University of Stirling.
- Murphy J, Gray CM and Cox S. (2007) *Communication and dementia - How talking mats can help people with dementia to express themselves*. York: Joseph Rowntree Foundation.
- National Audit Office. (2007) *Improving services and support for people with dementia*. London: The Stationery Office.
- Netten A, Jones K, Malley J, Sandhu S and Francis J. (2007) What do older people want? Lessons for home care services. *The Gerontologist* 47: p736.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Neumann PJ, Araki SS and Gutterman EM. (2000) The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. *Journal of the American Geriatrics Society* 48: 1646-1654.
- Neville CC and Byrne GJA. (2002) Behaviour of older people admitted for residential respite care. *Australian Journal of Advanced Nursing* 20: 8-12.
- Nicholas E and Patmore C. (1999) *Outcomes of social care for older people and their carers*. York: Social Policy Research Unit, University of York.
- Nolan M and Grant G. (1992) *Regular Respite. An Evaluation of a Hospital Rota Bed Scheme for Elderly People*. London: Age Concern Institute of Gerontology.
- Nolan M, Ingram P and Watson R. (2002) Working with family carers of people with dementia. *Dementia* 1: 75-93.
- Nolan MR, Davies S, Brown J, Keady J and Nolan J. (2004) Beyond 'person-centred' care: a new vision for gerontological nursing. *Journal of Clinical Nursing* 13: 45-53.
- Nolan MR, Davies S and Grant G (eds.) (2001) *Working with older people and their families: Key issues in policy and practice*. Buckingham: Open University Press.
- Novella JL, Ankri J, Morrone I, Guillemin F, Jolly D, Jochum C, et al. (2001) Evaluation of the quality of life in dementia with a generic quality of life questionnaire: The Duke Health Profile. *Dementia and Geriatric Cognitive Disorders* 12: 158-166.
- Oppenheim AN. (1992) *Questionnaire design, interviewing and attitude measurement*. London and New York: Pinter Publishers.
- Packer T. (2000a) A person-centred approach to the people who care. *Journal of Dementia Care* 8: 28-30.
- Packer T. (2000b) Pass the hot potato - is this person-centred teamwork? *Journal of Dementia Care* 8: 17-19.
- Packer T. (2000c) Does person-centred care exist? *Journal of Dementia Care* 8: 19-21.
- Packer T. (2000d) Facing up to the bills. *Journal of Dementia Care* 8: 30-33.
- Packer T. (2001) 'Everyone wants something': recognising your own needs. *Journal of Dementia Care* 9: 26-28.
- Parahoo K, Campbell A and Scoltock C. (2002) An evaluation of a domiciliary respite service for younger people with dementia. *Journal of Evaluation in Clinical Practice* 8: 377-385.
- Parker C, Barnes S, McKee K, Morgan K and Torrington J. (2004) Quality of life and building design in residential and nursing homes for older people. *Ageing and Society* 24: 941-962.
- Parse RR. (1996) Quality of life for persons living with Alzheimer's disease: the human becoming perspective. *Nursing Science Quarterly* 9: 126-133.
- Patton MQ. (2002) *Qualitative research and evaluation methods*. London: Sage.
- Pearlin LI, Mullan JT, Semple SJ and Skaff MM. (1990) Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 30: 583-594.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Perks A, Nolan M, Ryan T, Enderby P, Hemmings I and Robinson K. (2001) Breaking the mould: developing a new service for people with dementia and their carers. *Quality in Ageing - Policy, practice and research* 2: 3-11.
- Perry J and Bontinen K. (2001) Evaluation of a weekend respite program for persons with Alzheimer disease. *Canadian Journal of Nursing Research* 33: 81-95.
- Pickard L. (2004) *The effectiveness and cost-effectiveness of support and services to informal carers of older people. A review of the literature prepared for the Audit Commission*. London: Personal Social Services Research Unit.
- Pickard S. (1999) Coordinated care for older people with dementia. *Journal of Interprofessional Care* 13: 345-54.
- Pool J. (2006) Best practice in dementia care - improving the health and wellbeing of older people with mental health needs. *Journal of Care Services Management* 1: 16-23.
- Pratt R and Wilkinson H. (2003) A psychosocial model of understanding the experience of receiving a diagnosis of dementia. *Dementia* 2: 181-191.
- Qureshi H. (2001) *Outcomes in social care practice* York: Social Policy Research Unit, University of York.
- Rabins PV, Kasper JD, Kleinman L, Black BS and Patrick DL. (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: 33-48.
- Ray M. (1999) Developing person-centred standards for care homes. *Journal of Dementia Care* 7: 16-8.
- Reid D, Ryan T and Enderby P. (2001) What does it mean to listen to people with dementia? *Disability and Society* 16: 377-392.
- Reilly S, Venables D, Hughes J, Challis D and Abendstern M. (2006) Standards of care in day hospitals and day centres: a comparison of services for older people with dementia. *International Journal of Geriatric Psychiatry* 21: 460-468.
- Revell AJ, Caskie GIL, Willis SL and Schaie W. (2002) Quality of life in Alzheimer's disease (QoL-AD) Scale: factor solutions in non-demented elders. *Gerontologist* 42: 147.
- RIS MRC CFAS. (2000) Psychological morbidity among informal caregivers of older people: a 2-year follow-up study. *Psychological Medicine* 30: 943-955.
- RIS MRC CFAS Resource Implications Study Group of the Medical Research Council Cognitive Function and Ageing Study. (1997) Psychological distress among informal supporters of frail older people at home and in institutions. *International Journal of Geriatric Psychiatry* 12: 737-744.
- RIS MRC CFAS Resource Implications Study Group of the Medical Research Council Cognitive Function and Ageing Study. (1999) Informal caregiving for frail older people at home and in long-term care institutions: who are the key supporters? *Health and Social Care in the Community* 7: 434-444.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Robertson JM. (2002) *Assessing the impact of short breaks for couples in dementia care. MSc dissertation.* University of Stirling: Department of Applied Social Science.
- Rudin DJ. (1994) Caregiver attitudes regarding utilisation and usefulness of respite services for people with Alzheimer's disease. *Journal of Gerontological Social Work* 23: 85-107.
- Ryan T, Nolan M, Enderby P and Reid D. (2004) 'Part of the family': sources of job satisfaction amongst a group of community-based dementia care workers. *Health and Social Care in the Community* 12: 111-118.
- Ryan T, Nolan M, Reid D and Enderby P. (2002) *'You fetch me to all the right places': an evaluation of the Community Dementia Support Service.* Sheffield: University of Sheffield.
- Ryan T, Nolan M, Reid D and Enderby P. (2008) Using the Senses Framework to achieve relationship-centred dementia care services: a case example. *Dementia* 7: 71-93.
- Ryden MB, Gross CR, Savik K, Snyder M, Oh HL, Jang Y-P, *et al.* (2000) Development of a measure of resident satisfaction with the nursing home. *Research in Nursing and Health* 23: 237-245.
- Sabat SR. (2001) *The experience of Alzheimer's disease: life through a tangled veil.* Oxford: Blackwell.
- Schneider J, Murray J, Banerjee S and Mann A. (1999) Eurocare: a cross-national study of co-resident spouse carers for people with Alzheimer's disease: I-factors associated with carer burden. *International Journal of Geriatric Psychiatry* 14: 651-661.
- Schols JMGA and van der Schriek-van Meel C. (2006) Day care for demented elderly in a dairy farm setting: positive first impressions. *Journal of the American Medical Directors Association* 7: 456-459.
- Scottish Executive. (2005) *National care standards: short breaks and respite care services for adults.* Edinburgh: Scottish Executive.
- Searson R, Hendry AM, Ramachandran R, Burns A and Purandare N. (2008) Activities enjoyed by patients with dementia together with their spouses and psychological morbidity in carers. *Aging and Mental Health* 12: 276-282.
- Selai C and Trimble MR. (1999) Assessing quality of life in dementia. *Aging and Mental Health* 3: 101-111.
- Selai CE, Trimble MR, Rossor MN and Harvey RJ. (2000) The Quality of Life Assessment Schedule (QOLAS) - a new method for assessing quality of life in dementia, in Albert, SM and Logsdon, RG (eds) *Assessing Quality of Life in Alzheimer's Disease.* New York: Springer Publishing Company: 31-48.
- Seppänen R. (1998) Day care: old and young together. *Journal of Dementia Care* 6: 18-19.
- Shah A and Dickenson D. (1999) The capacity to make decisions in dementia: some contemporary issues. *International Journal of Geriatric Psychiatry* 14: 803-806.
- Sheard D. (2004) Bringing relationships into the heart of dementia care. *Journal of Dementia Care* 12: 22-24.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Silberfeld M, Grundstein-Amado R, Stephens D and Deber R. (1996) Family and physicians' views of surrogate decision-making: the roles and how to choose. *International Psychogeriatrics* 8: 589-596.
- Skills for Care and the Children's Workforce Development Council. (2007) *Providing effective supervision: a workforce development tool, including a unit of competence and supporting guidance*. Leeds: Skills for Care and the Children's Workforce Development Council.
- Sloane PD, Zimmerman S, Williams CS, Reed PS, Gill KS and Preisser JS. (2005) Evaluating the quality of life of long-term care residents with dementia. *Gerontologist* 45: 37-49.
- Smith SC, Lamping DL, Banerjee S, Harwood R, Foley B, Smith P, *et al.* (2005) Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment* 9 (10).
- Snyder L, Jenkins C and Joosten L. (2007) Effectiveness of support groups for people with mild to moderate Alzheimer's disease: an evaluative survey. *American Journal of Alzheimer's Disease and other Dementias* 22: 14-19.
- Social Care Institute for Excellence and National Institute for Health and Clinical Excellence. (2007) *Dementia: A NICE-SCIE guideline on supporting people with dementia and their carers in health and social care - National clinical practice guideline number 42*. Leicester: National Collaborating Centre for Mental Health.
- Social Services Inspectorate. (1999) *Care in the country: inspection of community care in rural communities*. London: Department of Health.
- Social Services Inspectorate. (2000) *Getting the right break. Inspection of short-term breaks for people with physical disabilities and older people*. London: Department of Health Publications.
- Sörensen S, Pinquart M, Habi D and Duberstein P. (2002) How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist* 42: 356-372.
- Stephens MAP, Ogrocki PK and Kinney JM. (1991) Sources of stress for family caregivers of institutionalized dementia patients. *Journal of Applied Gerontology* 10: 328-342.
- Strang VR and Haughey M. (1998) Factors influencing the caregivers' ability to experience respite. *Journal of Family Nursing* 4: 231-254.
- Strauss A and Corbin J. (1998) *Basics of qualitative research: techniques and procedures for developing grounded theory*. Thousand Oaks: Sage Publications.
- Surr C and Bonde Neilson E. (2003) Inter-rater reliability in dementia care mapping. *Journal of Dementia Care* Nov/Dec: 33-35.
- Tashakkari A and Teddlie C. (2002) *Handbook of mixed methods in social and behavioural research*. London: Sage.
- Teno JM, Landrum K and Lynn J. (1997) Defining and measuring outcomes in end-stage dementia. *Alzheimer Disease and Associated Disorders* 11: 25-29.

Person- and carer-centred respite care for people with dementia: developing methods of evaluating the effectiveness of different models

- Thorne C (2008) *Facilitators and barriers to person-centred respite care for people with dementia*. Belfast. Dementia Services Development Centre Conference, Embracing the Challenge: Citizenship and Dementia.
- Thornton A, Hatton C and Tatham A. (2004) Dementia care mapping reconsidered: exploring the reliability and validity of the observational tool. *International Journal of Geriatric Psychiatry* 19: 718-726.
- Trigg R, Skevington SM and Jones RW. (2007) How can we best assess the quality of life of people with dementia? The Bath assessment of subjective quality of life in dementia (BASQID). *The Gerontologist* 47: 789-797.
- Vitalise. (2008) *Annual review 2007-2008*. London: Vitalise.
- Walker E, Dewar B, Dewing J and Pritchard E. (2001) *An evaluation of day care services for people with dementia from the perspective of major stakeholders*. Edinburgh: Queen Margaret University College.
- Weightman G. (1999) *A guidebook for good practice in the provision of short-term breaks as a support for care in the community*. London: Department of Health.
- Willis GB. (2005) *Cognitive interviewing: a tool for improving questionnaire design*. Thousand Oaks: Sage Publications.
- Wilson K. (2008) *The changing face of day hospitals for older people with mental illness: consensual development of functions and standards*. London: Faculty of Old Age Psychiatry, Royal College of Psychiatrists.
- Wind G. (2008) Negotiated interactive observation: doing fieldwork in hospital settings. *Anthropology & Medicine* 15: 79-89.
- Woods B and Pratt C. (2005) Awareness in dementia: ethical and legal issues in relation to people with dementia. *Aging and Mental Health* 9: 423-429.
- Yin RK. (1984) *Case study research. Design and methods*. Sage Publications.
- Zarit SH, Femia EE, Watson J, Rice-Oeschger L and Kakos B. (2004) Memory club: a group intervention for people with early-stage dementia and their care partners. *Gerontologist* 44: 262-269.
- Zoutewelle-Morris S. (2006) Making person-centred care happen: a view from Holland. *Journal of Dementia Care* 14: 26-27.

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**Addendum:**

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