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## How to evaluate quality of care from the perspective of people with dementia

van Baalen, A.; Vingerhoets, A.J.J.M.; Sixma, H.J.; de Lange, J.

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# How to evaluate quality of care from the perspective of people with dementia: An overview of the literature

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**Angela van Baalen**

Reinier van Arkel groep, 's-Hertogenbosch, The Netherlands

**Ad J.J.M. Vingerhoets**

Tilburg University, Tilburg, The Netherlands

**Herman J. Sixma**

NIVEL, Utrecht, The Netherlands

**Jacomine de Lange**

Trimbos Institute, Utrecht, The Netherlands

## Abstract

This article reviews the literature on the inclusion of the perspective of people with dementia when evaluating quality of care. The few identified relevant studies suggest that there is consensus that people with mild to moderate dementia are able to talk about their experiences with care with clarity and insight. A minimum level of orientation to place, attention and language skills in the person with dementia are important for a successful subjective evaluation. On the basis of the relevant literature, we additionally formulated practical guidelines useful when one aims to collect information with interviewing, self-administered questionnaires, or focus groups from people with dementia to assess quality of care. In people with mild to moderate dementia, assessment of quality of care can best be done by individual interviewing and focus groups. Further research is needed to ascertain what people with dementia find important in relation to quality of care.

## Keywords

assessment, dementia, methods, patient perspective, quality of healthcare

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## Corresponding author:

Angela van Baalen, Reinier van Arkel groep, 's-Hertogenbosch, The Netherlands, P.O. Box 70058, 5201 DZ, 's-Hertogenbosch

Email: a.van.baalen@RvAGroep.nl

## Introduction

The quality of care delivered by health care institutions greatly depends on the responsiveness to patients' needs and expectations about health care (Lewin, Skea, Entwistle, Zwarenstein, & Dick, 2001; Rijckmans, 2005). In an attempt to improve the quality of provided care, health care institutions try to match their care to these needs and expectations. For the supply and organization of optimal health care, insight into these needs and expectations is becoming increasingly important. If health care organizations succeed in making these needs and expectations more explicit, they are more able to take into account the patients' perspective in their health care policy. Several instruments to measure the patients' perspective on quality of care have been developed for specific patient groups, such as people with asthma and COPD, rheumatic disorders, HIV and older people living at home (Groenewegen, Kerssens, Sixma, Eijk van der, & Boerma, 2005; Hekkink et al., 2003; Rupp et al., 2005; Sixma, Campen van, Kerssens, & Peters, 2000; Van Campen, Sixma, Kerssens, & Peters, 1997; Van Campen, Sixma, Kerssens, Peters, & Rasker, 1998). However, to date, relatively little is known about the experiences of people with dementia in relation to quality of care. Studies which include the perspective of people with dementia are few; particularly those with a focus on issues such as quality of care (Aggarwal et al., 2003). Most dementia research is based on proxy reports, observations and judgments by informal and professional caregivers (Van der Roest et al., 2007). Various authors, however, agree that it is possible for most people with mild to moderate dementia to talk about their experiences with care with clarity and insight (Hellström, Nolan, Nordenfeldt, & Lundh, 2007; Phinney, 1998). This is important, because the input of these patients could offer an important new perspective which allows greater understanding of the experience of quality of care. Through consulting people with dementia about the services they receive, it is possible to obtain first-hand evaluation of these services (Robinson, 2002). This may facilitate the development of services which better fit the needs of people with dementia (Keady, Nolan, & Gilliard, 1995).

This article aims to provide an overview of the international research literature on present knowledge on how to include the perspective of people with dementia when evaluating quality of care. The focus is on the following research questions: (1) what information can be derived from the literature on the inclusion of the perspective of people with dementia regarding provided care?; (2) what can we learn from the literature on methods taking into account the perspective of people with dementia?; (3) which conclusions can be drawn from studies that included the perspective of people with dementia to measure quality of care?; (4) what does the above mean for measuring quality of care including the perspective of people with dementia?

## Method

### *Search procedure and selection criteria*

Relevant literature for this article was identified in the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Ovid MEDLINE, PsycINFO, and PubMed. The search was limited to material published in English between January 1985 and December 2007. Information derived from these databases was supplemented with the results of checks of references listed in the identified papers. Studies were included when they reported on: (1) the inclusion of the perspective of people with dementia regarding provided care, and/or (2) the methods used to assess this perspective. Studies addressing the views on quality of care of (in)formal carers only were excluded.

(People with) Dementia	Health care quality assessment	Method
<i>MeSH &amp; free text:</i>	<i>MeSH:</i>	<i>MeSH:</i>
dementia, Alzheimer disease, Alzheimer's disease	health care quality, quality of healthcare, healthcare quality, health care quality assurance, quality	methods, interview [Publication Type], interviews, interview, psychological, focus groups,
<i>Free text:</i>	assurance, healthcare, health care	questionnaires, data collection,
person with dementia, people with dementia, elderly with dementia, elderly person with dementia, elderly persons with dementia, elderly	quality assessment, health care quality, access, and evaluation, health care delivery, health services research	health care survey, proxy, observation, communication, research
people with dementia, patient with dementia, client with dementia, individual with dementia, elder with dementia		<i>Free text:</i> patient perceptions, patient experience, patient reports, self report, proxy reports

**Figure 1.** Domains of keywords used in the search of the perspective on quality of care of people with dementia

Initially, a preliminary search was done to have an overview of the research issues with the combination of the search terms ‘dementia’ or ‘Alzheimer’s disease’, and ‘health care quality’. This yielded 267 publications, but only a small minority met the inclusion criteria. The keywords appeared to be too generic. For example, the keyword ‘health care quality’ yields many publications on a wide variety of topics. In order to find more specific keywords, the ‘Medical Subject Headings Thesaurus’ (<http://www.nlm.nih.gov/mesh/MBrowser.html>) was used and attention was paid to keywords displayed in traced articles that met the inclusion criteria. This resulted in a number of relevant and more specific keywords in three domains: ‘dementia’, ‘health care quality assessment’, and ‘method’ (Figure 1). A combination of the domains of ‘dementia’, ‘health care quality assessment’, and ‘method’ led to a second search. This search resulted in 737 publications. Applying our inclusion criteria finally resulted in a total of 82 papers selected for further analysis.

## Analysis

Hard copies were obtained from all 82 selected papers. When multiple findings were reported, only the findings relevant to the current study were considered. The articles were reviewed for applicability in contributing to the aim and research questions of this study.

## Results

### Using the perspective of individuals with dementia when assessing care quality: Is it feasible?

Quality of care is an individual experience which is considered to be influenced by one’s own general experiences throughout the care process as well as by specific expectations and perceptions of living with a certain disease or handicap. When assessing care quality it is

therefore necessary to take into account the patients' perspective. There is a growing interest in the idea that people with dementia could have a more important role than they used to have in shaping care practice (Bond, 1999; Karel, Moye, Bank, & Azar, 2007; Reid, Ryan, & Enderby, 2001). There is, however, little or no evidence on how to reflect optimally on the views and experiences of people with dementia when planning or evaluating services (Biernacki, 2000; Karel et al., 2007).

In recent years, clinical and research interest in dementia has increased, including attempts to understand how a person with dementia experiences and perceives the onset of the illness and how they evaluate their quality of life (Mason, Clare, & Pistrang, 2005; see for example Clare, 2002a, 2002b, 2003; Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2005; Frank et al., 2006; Keady et al., 1995; Pearce, Clare, & Pistrang, 2002). The assessment of experience with care is regarded as a highly complex procedure of introspection and evaluation, involving several components of cognition including implicit and explicit memory (Thorgrimsen et al., 2003). Ettema et al. (2005) therefore asserted that in the field of dementia self report of quality of life is not possible at all stages of the disease, as dementia affects the cognitive abilities, raising doubts about the capacity of persons with dementia to serve as valid and reliable informants on their life quality. However, the notion that all people with dementia lack the capacity to report reliably on what they find important for their quality of life seems to have been taken mainly at face value and is lacking empirical support (Thorgrimsen et al., 2003). The validity of information given by individuals with dementia concerning their own state of well-being is increasingly supported by recent research (e.g., Acton, Mayhew, Hopkins, & Yauk, 1999; Cotrell & Schultz, 1993; Frank et al., 2006; Friss Feinberg & Whitlach, 2001; Nygård, 2006; Reid et al., 2001; Sands, Ferreira, Stewart, Brod, & Yaffe, 2004). Individuals with early-stage dementia have been demonstrated to be able to participate in focus groups, to report feelings, and to express concerns regarding their disease. These individuals are also able to provide information that could be interpreted meaningfully by others (Silberfeld, Rueda, Krahn, & Naglie, 2002). Their reports may offer an important perspective which allows greater understanding of the experience of quality of care (Phinney, 1998).

Studies which include the perspectives of individuals with dementia are, however, few and relatively small scale, particularly those which focus on issues such as quality of care (Aggarwal et al., 2003; Friss Feinberg & Whitlach, 2001; Moriarty, 1999). It nevertheless can be concluded that it is possible to use the perspective of a person with dementia when assessing care quality, but apparently a variety of difficulties may be encountered by doing so.

## **Using the perspective of individuals with dementia when assessing care quality: Difficulties and challenges**

When attempting to improve the care using the perspective of people with dementia, one may encounter a number of possible difficulties and face many challenges. Below, we will address the main issues.

### *The cognitive limitations of individuals with dementia*

Subjective assessment in cognitively impaired populations has long been ignored because of the presumed logistical and methodological issues, specifically regarding comprehension and

reliability (Stewart, Sherbourne, & Brod, 1996). These kinds of assessments comprise a highly complex procedure of introspection and evaluation, involving several aspects of cognition including implicit and explicit memory (Thorgrimsen et al., 2003). Cognitive impairment, a diagnostic criterion for dementia (DSM IV), increases in severity as dementia progresses. Factors that can affect the credibility of qualitative accounts given by individuals with dementia include poor or inconsistent memory for events and lack of insight or awareness (Hubbard, Downs, & Tester 2003; Keady, 1996). Self report in dementia thus raises a number of complex methodological issues (Rabins, 2000; Whitehouse, Patterson, & Sami, 2003). Since several cognitive abilities including implicit and explicit memory are required, it follows that, at a certain stage of cognitive decline, there will come a point where self assessment will no longer be possible (Selai & Trimble, 1999; Selai, Trimble, Rossor, & Harvey, 2000). In addition, the patients' ability to evaluate and communicate issues related to quality of care will be determined by a wide variety of clinical features such as the decline of cognitive skills, insight, denial, anosognosia, and a range of neuropsychiatric symptoms such as delusions, agitation, anxiety, and personality changes (Selai et al., 2000). An important question therefore is how to establish at what stage of the disease self-report is no longer possible (Fletcher, Dickinson, & Philp, 1992). A few studies have examined the relation between interviewability and the score on the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). Mozley et al. (1999) found that 77.5% of 213 individuals with dementia having a MMSE score and >10 appeared to be 'interviewable' on the subject of quality of life. Interviewability was significantly associated with two of the MMSE domains – orientation to place and attention. These findings support the view that a minimum level of orientation to place, language skills and attention are essential for interviewability and, in combination, these three domains appear to offer a way of isolating the cognitive skills required for successful quality of life interviewing. Moreover, Friss Feinberg and Whitlach (2001) showed that individuals with mild to moderate cognitive impairment (i.e., MMSE scores 13–26) are able to respond consistently to questions about preferences, choices, and their own involvement in decisions about daily living, and can provide accurate and reliable responses to questions about their own demographics. Finally, Logsdon, Gibbons, McCurry, and Teri (2002) demonstrated that it is possible for individuals with mild to moderate dementia (i.e., MMSE scores 11–29) to reliably and validly rate their own quality of life.

In conclusion, dementia related progressive decrease in cognitive abilities should not be regarded as a criterion for exclusion from studies on quality of care and quality of life (Wilkinson, 2001). The most important requirement for obtaining reliable data from elderly individuals with cognitive impairment may not be the overall level of cognitive impairment but, more specifically, a minimum level of orientation to place, attention, and language skills (Mozley et al., 1999). In combination, these three cognitive skills are required for successful subjective assessment in individuals with dementia.

### *Communicating with individuals with dementia*

When assessing the perspective of individuals with dementia, almost inevitably language has to be used, which might pose a problem for individuals with dementia as language impairment is a common symptom. Factors that may affect the credibility of qualitative accounts given by individuals with dementia include confabulated or meaningless responses.

Dementia is often characterized by vague and empty speech, dwindling vocabulary, and disordered speech patterns. These characteristics might compromise the ability to respond with fluency to open questioning (Lloyd, Gatherer, & Kalsy, 2006). In addition to the deterioration of language and memory, dementia has an influence on perceptual skills and functioning. The ability to recognize visual and other stimuli can be distorted leading to disorientation and misperception. Dementia can also affect visual acuity and narrow the visual field, and it may lead to delusions and hallucinations (Aalten, de Vugt, Jaspers, Jolles, & Verhey, 2005). All of these have a direct impact upon communication (Vass et al., 2003). There can be little doubt that individuals with dementia can have considerable difficulties when communicating their experiences. However, their ability to express and discuss experiences, perceptions, feelings, and thoughts, and to provide us with a comprehensive account of these, may be supported in several ways: by the context, by simultaneously showing by doing, and by adapting the interview (Nygård, 2006). In his plea for more research into the subjective experience of dementia, Cohen (1995) has emphasized that attempting to hear a person's 'voice' rather than obtaining his or her narrative is a more suitable approach. According to this author, the lack of knowledge on the subjective experience of dementia in the general population might be partly attributed to researchers' inability to listen rather than to the incapacity to communicate of those affected.

In the early stages of dementia, the form and structure of the language may remain intact but the content of speech often changes (Haak, 2002). This means that a significant amount of time may be spent on searching for particular words, with specific words being replaced by, for example, 'stuff' and 'thing' indicating that the active vocabulary of those with dementia seems to be shrinking (Haak, 2002). While difficulties may be apparent in lengthy conversations, individuals with dementia can be very competent in shorter interactions (Gillies, 2000). If interviews are conducted more than once, they need to be spaced close together to benefit memory (Clarke & Keady, 2002).

Reid et al. (2001) interviewed 19 individuals with dementia who attended day-care and they concluded that these service-users have important things to say if appropriate strategies for listening are employed. According to Goldsmith (1996) communication with people with dementia is possible, providing the will to communicate is there, as well as the relevant skills and techniques. Ways in which the views and feelings of people with dementia can be validly assessed include adapting to their pace and timescale, taking account of environmental factors, and studying non-verbal communication (Goldsmith, 1996). The challenge in applying the patient perspective in dementia care lies in finding new ways to communicate in order to explore their views and ensure that these views are incorporated into service planning and evaluation (Biernacki, 2000).

### *Denial and loss of insight in individuals with dementia*

Another challenge when eliciting information from individuals with dementia lies in the fact that there is often an initial denial over the reality of events in the early stages of dementia (Weinstein, Friedland, & Wagner, 1994), and an accompanying feeling of fear and uncertainty (Keady & Gilliard, 1999). This denial makes it difficult to confront individuals with the first signs of dementia with questions about how they perceive care services.

Loss of insight into and awareness of one's own condition is common in dementia, and this fact raises concerns about the validity of data provided by individuals

diagnosed with dementia. However, there is evidence showing that awareness of impairments varies across modalities in dementia (Green, Goldstein, Sirochman, & Green, 1993). Brod, Stewart, & Sands (1999a) argue that awareness of cognitive impairment may be distinct from awareness of one's own feeling status. Thus, patients may be able to report reliably on quality of care, even when they have poor insight into the severity of their dementia.

It is advisable when including individuals with dementia in research not to mention the term dementia or Alzheimer's disease unless they are first mentioned by the participants (Pearce et al., 2003).

### *Informed consent*

Informed consent refers to the fact that information has been provided to the potential participant together with the request to take part, under the assumption that the information is understood and any decision taken is on a voluntary basis (Bartlett & Martin, 2002). Informed consent is a fundamental principle of ethical research, and this becomes more pertinent when the participants involved have cognitive or expressive language difficulties that might impair their ability to express their concerns or reservations fully. The lack of competence to provide full and informed consent has been described as a dilemma for research conducted with individuals with dementia (Hubbard, Downs, & Tester, 2002; Reid et al., 2001). Cheston, Bender, & Byatt (2000) argued that the factors that made it important to examine the views of these individuals, also made them vulnerable to abuse regarding consent. Not only do procedures to obtain informed consent give rise to feelings of anxiety and insecurity, especially if written consent is required, but questions about the feasibility of actually obtaining informed consent with participants suffering from dementia have also been raised (Bartlett & Martin, 2002).

An important starting point with regard to informed consent is the recognition that individuals with dementia, despite having a common diagnosis, are not a homogeneous group (Morris, 1999). Levels of ability in retaining information and/or subsequently making informed decisions vary greatly between persons with dementia, and for some will fluctuate considerably over time (Fellows, 1998). Also, the capacity to consent should be judged primarily in terms of what the person is asked to do (Hubbard et al., 2002). For people with dementia, their capacity to understand is far greater when the focus is on feelings and experiences rather than on the recollection or manipulation of facts (Pratt, 2002). The basic precept is that a person should be regarded as competent until demonstrated otherwise, and that incompetence in one area of life does not mean incompetence in others (Holm, 2001). Researchers should be very sensitive to any verbal and non-verbal signs which might signal distress resulting from participation in the research project (Hubbard et al., 2002; Lloyd et al., 2006). When this is the case, the participant must be withdrawn immediately from the research protocol (Berghmans & Ter Meulen, 1995).

For people with dementia, consent should be regarded as a continuous process rather than as a discrete *a priori* fact. This implies a periodical rechecking of the individual's willingness to remain involved (Usher & Arthur, 1998), particularly if initial consent is obtained on a separate occasion before the research itself, or if a series of research contacts are planned (Lloyd et al., 2006). Those involved in assessing people with dementia about the services that they receive need to ensure that their respondents are able to give their consent in a meaningful way and they have to be sensitive to the withdrawal of that consent. It is important to present the rationale for evaluation and to



ensure that individuals are aware that there will be no negative consequences if they choose not to take part, or do not want to answer all questions (Cheston et al., 2000).

When involving individuals with dementia in the evaluation of the services that they receive, the initial approach to them should be through a professional who they already know (Cheston et al., 2000).

The current best practice is to obtain informed consent from both the potential dementia participant and his or her proxy (Sachs et al., 1994). Pratt (2002) suggests that gatekeepers, especially family members/carers, should be actively included and their contribution valued because they may provide additional insights into the experiences of persons with dementia.

It is better not to ask for written consent from persons with dementia, because that might create unwanted and unnecessary anxiety. Instead, one can rely on verbal and behavioural consent, and stress that participants are free to withdraw at any point during the research (Bamford & Bruce, 2002). This verbal consent should be documented by the researcher.

### *Further ethical issues*

Research involving individuals with dementia inevitably is associated with diverse complex ethical issues (Clarke & Keady, 2002; Vass et al., 2003). These ethical issues have often been considered as valid reasons not to include people with dementia in research (Hellström et al., 2007). Potential ethical problems when including individuals with dementia in research include (a) the risk of intruding unwanted in people's lives; (b) the risk of raising expectations of continuing friendship which may not be realized; (c) the issue of confidentiality; and (d) the need to give people something in return for the data they have provided (Stalker, Gilliard, & Downs, 1999). In dementia research, one may state that there is only seldom direct benefit to the individual, although the primary aim might be the increase of knowledge and improvement of care in the future (Berghmans & Ter Meulen, 1995). However, several authors have proposed that inclusion of persons with dementia, despite the ethical issues, is likely to yield beneficial effects for them such as feeling valued with a consequent boost to self-esteem (Barnett, 2003), being afforded the opportunity to validate one's feelings and experiences (Barnett, 2003; Clarke & Keady, 2002; Keady & Gilliard, 1999), and perceiving oneself as being taken seriously (Dewing, 2002). In conclusion, the benefits of including people with dementia when evaluating quality of care probably outweigh the risks of causing harm. The most important question remaining to be answered is, however, 'How can we?'

## **Using the perspective of individuals with dementia when assessing care quality: Methods**

At present, experiences with the involvement of individuals with dementia as informants in scientific research remain limited and fragmented (Clarke & Keady, 2002; Cowdell, 2006; Hellström et al., 2007; Moore & Hollett, 2003; Wilkinson, 2001). Reid, Ryan, & Enderby (2001) argue that there is still a serious lack of methodological guidance available when wanting to take into account the judgments of individuals with dementia as 'users' of services.

There are several methodological approaches to obtain knowledge about the perception that patients with dementia have of quality of care, such as interviewing, using self-administered questionnaires, observation, focus groups and proxy reports. Selection of an appropriate method of administration that will provide data of the highest quality requires an understanding of the advantages and comparability of each method.

### *Interviewing, self-administered questionnaires and observation*

Interviewing (open-ended or semi-structured), self-administered questionnaires and observation are methods that can be applied in a one-on-one situation and all these three methods are theoretically suitable for measuring quality of care from the perspective of a person with dementia. Based on the limited available information, we have identified evaluation dimensions and aspects allowing a meaningful comparison of these methods (Table 1). Some aspects are specifically important when doing research to assess the perspective of a person with dementia to measure quality of care. A self-administered questionnaire is the least expensive method and offers respondents the most privacy and anonymity. However, it may be problematic for people with dementia to complete due to their cognitive problems and possible vision, reading or language problems as evidenced by the considerable number of missing data when self-administration is used (Stewart et al., 1996). A face-to-face interview enhances the possibility to access meanings, perspectives, interpretations and embrace individual differences. The interviewer can be sensitive to diverse forms of expression, has a possibility to clarify the meaning of questions and to check the comprehension of questions and to make spontaneous reflections. These aspects are particularly important when doing research with people with dementia for they allow the assurance of a complete assessment of data. An interview is more time-consuming than self-administration, both in terms of staff and respondent burden, but the savings of time needed to follow up on missing data and non-returned self-administered forms may somewhat offset these higher costs (Stewart et al., 1996). When talking about the perspective of a person with dementia, we want to take into account his or her subjective experiences, and place value on the perspective of the person who has the most to gain or lose from treatment. This respect for the autonomy of the individual is very important from a clinical and ethical standpoint (Logsdon et al., 2002) and the interview seems the best method possible to achieve this. In Table 2 we have summarized practical guidelines when wanting to use interviews and self-administered questionnaires in people with dementia to measure quality of care.

Observation is a method that is appropriate for use in mild, moderate and severe dementia (Ready & Ott, 2003). An important limitation of this method, however, is the uncertainty as to whether what is being observed is what the individual considers to be important for quality of care.

### *Focus groups*

Group work has long been established as an important way of working with people with dementia (Bamford & Bruce, 2002; Cheston et al., 2000) and it has demonstrated the ability of people with dementia to work together meaningfully in groups (Bamford & Bruce, 2002). The defining characteristic of focus groups is the use of group processes and interactions between participants to generate data. By prompting an exchange of views and opportunities

**Table 1.** Evaluation dimensions found in the literature using interviewing, self-administered questionnaires and observation to assess care quality from the perspective of a person with dementia

Evaluation dimensions	Interview - open-ended - semi-structured	Self-administered questionnaire	Observation
<u>Applicability</u>			
• mild dementia	Carroll et al., 2005; Cheston et al., 2000; Keady & Gilliard, 1999; Train et al., 2005; Whitlach et al., 2005		Ready & Ott, 2003
• moderate dementia	Carroll et al., 2005; Train et al., 2005		Ready & Ott, 2003
• severe dementia			Ready & Ott, 2003
<u>Quality of the data</u>			
• clarify the meaning of questions	Stalker et al., 1999		
• make spontaneous reflections	Nygård, 2006		Nygård, 2006
• gain rich and in-depth data	Aggarwal et al., 2003		Stalker et al., 1999
• check the comprehension of questions and response options	Logsdon et al., 2002		
• adapt questions or prompts to priorities and communication style	Stalker et al., 1999		
• ensure complete assessment of data	Stewart et al., 1996		
• ensure confidentiality/ anonymity		Stewart et al., 1996	
• ensure reliability		Stalker et al., 1999	
<u>Possible threats to internal/ external validity</u>			
• dependency on reading capabilities		Stewart et al., 1996	
• risk of social desirable information	Stewart et al., 1996		
• risk of interviewer bias	Cowdell, 2006		
• being too demanding or distressing	Stewart et al., 1996	Aggarwal et al., 2003	
<u>Practical issues</u>			
• high time and cost investment (collecting and analysing data)	Stewart et al., 1996		Stalker et al., 1999; Stewart et al., 1996
• high personell investment (collecting and analysing data)	Stewart et al., 1996		

**Table 2.** Practical guidelines identified in the literature using an interview and a self-administered questionnaire to assess the perspective of a person with dementia in relation to quality of care

Practical guidelines	Open interview	(Semi-)structured interview	Self-administered questionnaire
<i>Communication:</i>			
• Begin with relatively straightforward questions (Flynn, 1986).	X	X	
• Avoid abstract notions, and questions relating to time and frequency (Flynn, 1986).	X	X	X
• Use stimulus materials to discuss abstractions (Bamford, 1998).	X	X	X
• Third-party approach: asking person with dementia how they would describe the care offered to a third person, such as a friend (Allan, 2000).	X	X	
• Attending to non-verbal cues and accepting the emotional reality of the words of the person with dementia (Allan, 2000).	X	X	
• Show person with dementia a picture of a person who they do not know, but with whom they might be able to identify in some way. Then say: 'Let's imagine that this lady is coming to live here. What do you think she might feel about that?' Other questions might be 'What would she want to know about living here? What sorts of concerns might she have?' (Allan, 2000).	X	X	
• Use the term 'memory problems' rather than 'dementia' as a more sensitive way to explore issues relating to the participants' dementia (Beattie, Daker-White, Gilliard, & Means, 2004).	X	X	X
• Allow time for person with dementia to understand what is being said (it can take five times longer to process information even with moderate dementia) and make sure that people understand before moving the conversation on (Goldsmith, 1996).	X	X	
• Persons with dementia often speak metaphorically (Goldsmith, 1996).	X	X	
• Use short sentences and do not carry double messages in them (Goldsmith, 1996).	X	X	X
• Carry out a pilot study to ascertain respondents' communication skills and decide whether alternative format questions are required (Flynn, 1986).	X	X	
• Before assessing the interview, use test questions to serve as the primary method of assessing the respondent's ability to comprehend a structured answer form (Brod et al., 1999a).		X	
• Use the schedule flexibly, modifying the order and content of questions as appropriate (Flynn, 1986).		X	

(continued)

Table 2. Continued

Practical guidelines	Open interview	(Semi-)structured interview	Self-administered questionnaire
<ul style="list-style-type: none"> <li>Comprehension of questions and selection of appropriate responses can be facilitated by the use of explicit instructions, face-to-face administration by a trained interviewer, and use of visual cues to remind the respondent of the response options (Ettema, Hensen, Dröes, de Lange, Mellenbergh, &amp; Ribbe, 2007; Logsdon et al., 2002).</li> </ul>		X	X
<ul style="list-style-type: none"> <li>Use clear language, focused questions and visual aids such as photographs (Bamford, 1998).</li> </ul>	X	X	X
<ul style="list-style-type: none"> <li>Keep questions short, use familiar words, avoid compound sentences, and avoid double negatives (Kohout, 1992).</li> </ul>	X	X	X
<ul style="list-style-type: none"> <li>Questionnaires need to be readable by those who have vision problems, so allow sufficient space on the page and use a large print size (font size 14) (Stewart et al., 1996).</li> </ul>			X
<i>Guaranteeing comfort of person with dementia:</i>			
<ul style="list-style-type: none"> <li>Try to establish a good relationship, based on trust, warmth and empathy (Hellström et al., 2007).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Interview on more than one occasion for this allows effects of anxiety which may be present during a first interview to recede and enables the researcher to assess the consistency of the views of the people who have dementia across time (Cheston et al., 2000).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Short interviews are recommended for patients with dementia since patients tire easily (Selai &amp; Trimble, 1999).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Adapt the length of each interview to the person with dementia's capacity to concentrate (Nygård, 2006).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>When possible or preferable to conduct longer interviews, include pauses and relaxed small talk to allow the person with dementia to rest (Nygård, 2006).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Use open questions regarding what person with dementia usually does and what they think about particular issues in their daily life (Nygård, 2006).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Questions that contain a time frame may need to be modified to a very short time frame (Stewart et al., 1996).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Leave the person with dementia with a sense of achievement, and find a positive subject on which to conclude (Barnett, 2003; McKillop &amp; Wilkinson, 2004).</li> </ul>	X	X	

(continued)

Table 2. Continued

Practical guidelines	Open interview	(Semi-)structured interview	Self-administered questionnaire
<ul style="list-style-type: none"> <li>Continue to show interest in the person with dementia after the more formal part of the interview has finished if a lasting positive impression is to be created, and a 'hit and run' approach should be avoided at all costs (Clarke &amp; Keady, 2002).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Give people a choice of time (McKillop &amp; Wilkinson, 2004). Preferable is to conduct interviews before lunch, when people with dementia are often likely to be more alert (Carroll et al., 2005).</li> </ul>	X	X	
<i>Guaranteeing validity:</i>			
<ul style="list-style-type: none"> <li>Use an individualized approach: different methods depending on individual preferences and on severity of dementia (Aggarwal et al., 2003).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Follow-up interviews can enrich and validate findings (Phinney, 1998; Pratt, 2002).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Vary the direction of item wording so that high scores do not always have the same meaning (Stewart et al., 1996)</li> </ul>			X
<i>Practical:</i>			
<ul style="list-style-type: none"> <li>The interview should be held in a familiar surrounding (Bamford, 1998) with minimal background noise (Goldsmith, 1996).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Time schedule for data collection must be very flexible (Nygård, 2006).</li> </ul>	X	X	
<ul style="list-style-type: none"> <li>Involve gatekeepers as a resource to the research process and in supporting persons with dementia into research (Pratt, 2002).</li> </ul>	X	X	X

to hear and react to the views and experiences of other participants, focus groups can provide insight into both how and why people think as they do. It is considered to be a non-threatening approach to gathering information from people with dementia (Bamford & Bruce, 2002). The interaction among participants may lead to shared views that transcend individual experiences and might trigger recall of similar events or feelings (Bamford & Bruce, 2002). In conclusion, focus groups could be useful when attempting to derive issues that people with dementia consider to be important in relation to quality of care. Some practical guidelines using this method identified in the literature are summarized in Table 3.

### Proxy report

Use of a proxy in measuring quality of care from the perspective of a person with dementia can be legalized when the person with dementia, due to severe cognitive deficits, cannot reliably report on internal states and lacks 'insight' (Cheston & Bender, 1999). However,

**Table 3.** Practical guidelines identified in the literature using focus groups to assess the perspective of a person with dementia in relation to quality of care

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- Requires a skilled facilitator to ensure that those people with verbal competence are not heard at the expense of others who have less ability to express their needs (Cheston et al., 2000).
  - Use small, pre-existing groups to reassure that people are with familiar faces (Bamford & Bruce, 2002; Heiser, 2002).
  - Have some basic props to orientate people to the subject being discussed such as photographs and posters (Heiser, 2002).
  - The facilitators should ideally be known to the group and be skilled in communicating with people with dementia (Heiser, 2002).
  - If any of the participants are hard of hearing, make sure one of the facilitators sits beside the person to guarantee the questions are heard (Heiser, 2002).
  - Ideally the facilitators should have some knowledge of the personal circumstances of the participants, as this information can be used to frame questions more pertinently (Heiser, 2002).
  - Allow time for views to be expressed – meet for a second or third time, if necessary (Heiser, 2002).
  - Do not overload the session with a variety of different concepts – keep to one or two themes (Heiser, 2002).
- 

proxies also may lack information about and insight into experiences (Stalker et al., 1999) and feelings about different aspects of care of persons with dementia (Aggarwal et al., 2003). They may have difficulty separating what they themselves want and need from what the person with dementia requires (Biernacki, 2000; Cheston et al., 2000; Stalker et al., 1999). So there can be discrepancy in responses between people with dementia and their proxies (Aggarwal et al., 2003). The degree of correspondence between the accounts of the proxy and the person with dementia may be influenced by characteristics of the proxy such as the nature of the relationship, time spent with the person with dementia and their own sense of well-being and mood, the degree of objectiveness of the questions, and the level of impairment (Brod, Stewart, Sands, & Walton, 1999b; Stalker et al., 1999; Thorgrimsen et al., 2003; Zimmerman & Magaziner, 1994). A professional proxy cannot be considered to be an independent source of service evaluation as there is always possible conflict of interest (Cheston et al., 2000).

In conclusion, the more concrete the issue in question and the more objective the question, proxy report could be used to measure quality of care from the perspective of a person with dementia. However, researchers should carefully document the use of proxies and be aware of the potential errors and biases this use may introduce.

### **Studies that included the perspective of people with dementia to measure quality of care**

The literature search yielded nine core articles reporting on empirical research regarding measurement of quality of care from the perspective of people with dementia (Table 4), all having been published after 1997. Although the literature search in this article spans a period of 22 years, all of the identified articles have been published after 1997. In the 1990s people with dementia were still only sporadically involved in research (Van der Roest et al., 2007). Most of the publications which feature the subjective experience of people with dementia date from 1999 or later.

Respondents in the studies received day care (respite services), residential care, or homecare. In one-third of the studies the severity of dementia is not mentioned (Aggarwal

**Table 4.** Literature overview of perspectives of people with dementia in relation to quality of care, 1985–2007

Author	Setting and sample	Age (range) and severity of dementia (range)	Aim of the study	Method of data collection and analysis	Findings
Gwyther (1997)	United States Single case of Tommy Thompson and review of literature   male	Age 59	Highlight subjective perceptions of people with early to middle stage AD about meaningful goals and outcomes for Alzheimer disease research	Individual interviews and literature review Analysis of the interview and transcripts of people with dementia in literature	Range of relevant outcomes: – a sense of control – inclusion – reciprocity – meaningful activities – feeling safe and secure – maintaining self-esteem – maximising physical wellbeing through effective health care Important in process of service delivery: – being treated 'normally' – having services which match perceived needs
Keady & Gilliard (1999)	United Kingdom 15 people with dementia recruited from one memory disorders clinic 12 female; 3 male	Age range 67–86 (Very mild) Alzheimer's disease	Exploring how resources are viewed by people with early dementia	Interview Grounded theory design with constant comparative analysis	Information needs of people with dementia: – central reference point – technical information about what happens in the brain – information about what to expect during diagnostic assessment – reassurance about the cause of Alzheimer's disease – practical information about services and supports – information about adjusting to dependency in the caring relationship – accessible information in forms such as audio cassette, video cassette or large print writing (allow for repeated access)



Bamford & Bruce (2000)	United Kingdom 15 persons with dementia using day and respite care and/or receiving home care   male; 14 female	60 – 69 (n = 1) 70 – 79 (n = 2) 80 – 89 (n = 9) > 90 (n = 3)	Identifying the desired outcomes of community care in people with dementia	Formal and informal group discussions, individual interviews, informal conversations Search and retrieval procedures to explore emerging themes	Overall desired outcome: – having access to normal activities and patterns of life in ways that maximize choice and control Service-process outcomes: – having a say in services – feeling valued and respected – being treated as an individual – being able to relate to other service users Specific quality-of-life outcomes: – access to social contact and company – having a sense of social integration – access to meaningful activity and stimulation – maximizing a sense of autonomy – maintaining a sense of personal identity – feeling safe and secure – feeling financially secure – being personally clean and comfortable – living in a clean and comfortable environment
Reid et al. (2001)	United Kingdom 19 people with dementia, attendees of three different day care services		Exploring the question of unmet needs in relation to people with dementia receiving respite services and considering their status as service users	Semi-structured interviews and group discussions Analysis for emerging themes	– staff at day care services should try to establish a person with dementia's understanding of why they are in the setting and seek to explore what any person might want from these visits – group context is valued for the company offered, the possibility for developing friendships, and the support people could both offer others and receive from care staff

(continued)

**Table 4.** Continued

Author	Setting and sample	Age (range) and severity of dementia (range)	Aim of the study	Method of data collection and analysis	Findings
Heiser (2002)	United Kingdom 6 people with dementia receiving homecare services	Varying levels of dementia	Soliciting the views of homecare service users with dementia	Group discussion (begin question 'Do you have some help at home?')	<ul style="list-style-type: none"> <li>- have the same 'home help' to come most of the time</li> <li>- clear (written) information, handed on repeatedly</li> <li>- enable the person with dementia to still do things for themselves, with support</li> <li>- feeling of being able to trust the 'home help'</li> <li>- sense of companionship with the 'home help' is valued</li> <li>- 'home help' should have good manners</li> <li>- good domestic skills are important</li> </ul>
Aggarwal et al. (2003)	United Kingdom 10 persons with dementia in day care 17 persons with dementia in residential care	Various stages of dementia	Eliciting the views and feelings of people with dementia on care services and on experiences of dementia	Semi-structured interviews, examination of care plans, files and diaries, observation and filming Non-participant time sampling observations and qualitative analysis	<p>Methodological:</p> <ul style="list-style-type: none"> <li>- effective was the use of different methods, depending on individual preferences and on the severity of the dementia</li> <li>- effective was using open-ended broad questions (elicited more information and were less distressing than closed-ended, specific questions)</li> </ul> <p>Residential homes:</p> <ul style="list-style-type: none"> <li>- satisfactory levels of privacy and aspects of the physical environment</li> <li>- lack of choice, independence and social aspects</li> <li>- power imbalance between staff and residents in homes need addressing</li> </ul>

Carroll et al. (2005)	United States 15 persons with dementia attending an adult day service 9 female; 6 male	Mean age 80.0 (66–91) Mild to severe dementia	Evaluating the experiences of people with dementia who use respite services	Interview using a single-group, onetime, cross-sectional administration of a consumer satisfaction survey	Overall satisfaction scores: – environment 94% – food 93% – safety 93% – activities 84 % – help and guidance 89% – autonomy/respect 96% – communication 85% – socializing 78%
Train et al. (2005)	United Kingdom 21 residents with dementia living in 24-hour care settings 9 female; 12 male	Mean age 81.0 (64–99) Mean MMSE (Mini-Mental State Examination) 9.8 (1–23)	Exploring the positive and negative aspects of the experience of people with dementia living in 24-hour long-term care settings	Qualitative interviews using open semi-structured questions	Four main themes identified were: – privacy, dignity and choice (including the sub-themes of personal possessions, food and money) – relationships in the care environment (including the sub-themes of vulnerability, abuse, complaints and protection) – activities – the physical environment
Whitlatch et al. (2005)	United States 111 persons with mild to moderate cognitive impairment (59 persons diagnosed with dementia) 60 female; 51 male	Mean age 77.0 (39–94) Mean MMSE 20.7 (13–26)	Describing the development and psychometric properties of a 24-item scale to be used in both research and practice settings that assesses the everyday care values and preferences of individuals with cognitive impairment in community settings	Interview with the Values and Preference Scale (37 items, 3 response options: 'very important', 'somewhat important', 'not important', 'at all important')	Results of a factor analysis resulted in that the Values and Preference Scale can be divided into two domains or subscales for persons with cognitive impairment (i.e. Environment-Social Network and Personal Autonomy) with good internal consistency (Cronbach's alphas .81 and .70)

et al., 2003; Gwyther, 1997; Heiser, 2002), and only two studies that reported the severity of the illness indicated that it was determined by the score on the Mini-Mental State Examination (MMSE) (Train, Nurock, Manela, Kitchen, & Livingston, 2005; Whitlach, Friss Feinberg, & Tucke, 2005). The type of dementia was only mentioned in two studies (Gwyther, 1997; Keady & Gilliard, 1999). The nature of the articles was generally explorative: eliciting the views, feelings and experiences of people with dementia on received care or unmet needs in relation to care. Only one study (Carroll, Vector, Holmes, & Supiano, 2005) evaluated the experiences of people with dementia who use respite services. The article of Whitlach et al. (2005) is the first in which the development of an instrument to assess the everyday care values and preferences has been described. This instrument, however, was designed for people with mild to moderate cognitive impairment in community settings and not for people with dementia exclusively. In the majority of the studies a semi-structured or group interview was conducted to collect the data (Aggarwal et al., 2003; Bamford & Bruce, 2000; Heiser, 2002; Keady & Gilliard, 1999; Reid et al., 2001; Train et al., 2005). Only in the study of Carroll et al. (2005) was a satisfaction survey used and Whitlach et al. (2005) applied an interview with structured response options. Aggarwal et al. (2003), in addition to semi-structured interviews, also conducted document analyses, observation and filming to elicit views and feelings and argued that the use of these different methods was effective depending on individual preferences and on severity of dementia.

On the basis of these nine articles some quality indicators and specific aspects important in relation to quality of care can be specified:

- (1) Courtesy: being treated normally, feeling valued and respected, feeling safe and secure and being treated as an individual;
- (2) Autonomy: having a sense of control, maintaining self-esteem, maximal choice and control, having a say in services, maximising a sense of autonomy and maintaining a sense of personal identity;
- (3) Information: accessible and clear (written) information, repeated access to information, central reference point, information about what happens in the brain, about what to expect, about services and supports, about changes in the relationship, and reassurance about the cause of the disease;
- (4) Organization: meaningful activities and stimulation;
- (5) Safety: feeling safe and secure.

Since individual interviews and focus groups were applied in most of the studies, it may be concluded that these methods are probably most suitable for assessment of quality of care in people with mild to moderate dementia.

## Conclusions and discussion

The aim of this overview was to summarize present knowledge about how to include the perspective of people with dementia when evaluating quality of care. It can be concluded that measurement of quality of care from the perspective of people with dementia is in its early days. Whilst this topic raises a number of challenging methodological problems, preliminary research has shown that the assessment of quality of care in patients with mild to moderate dementia is feasible. Reliable and valid assessment of patient views is

necessary when it comes to shaping health policies aimed at improving the quality of health care for patients suffering from dementia. Including the perspective of people with dementia in both research and practice also has the potential to enhance their autonomy, to improve their quality of life, and to shape services that better adapt the needs of people with dementia.

After reviewing the literature on methods suitable to measure quality of care from the perspective of a person with dementia we concluded that the willingness to adapt methods appropriately and to modify expectations in order to hear the voice of respondents is prerequisite. Many of the strengths and weaknesses of the specific methods found in the literature are generalizable to all kind of respondents participating in research applying that method. However, when comparing the methods for use in research where the perspective of a person with dementia in relation to quality of care is the central theme, some issues are of specific importance. We have concluded that it is possible to elicit valid information from people with mild to moderate dementia, if one applies adequate methods such as interviewing or focus groups. These methods are expected to provoke the least anxiety and confusion because the interviewer has the opportunity to adapt to the person's communication style and to build trust, warmth and empathy during the encounter. For people with early dementia these methods offer an opportunity to discuss their experiences, while letting them feel valued for their knowledge. In the later stages of dementia, when self-report is no longer possible, observation or proxy reports are possible alternative methods to elicit perspectives on quality of care although they are likely to provide additional biased information.

We identified only nine studies that focused on measuring the views, feelings, experiences and unmet needs in relation to care. A generalization based on these studies as to what people with dementia find important in the provision of care is not possible because the type of care settings was different and the severity of dementia was not clear in all studies. Future studies should document carefully the characteristics such as age, gender, severity and type of dementia, as well as the living situation, social contacts, and the use of professional care services of the people with dementia involved. These characteristics might affect the perception of quality of care and should be documented in order to increase our understanding about the subject. Further research with varied and large populations of people with dementia should clarify if the quality indicators found in the nine studies (courtesy, autonomy, information, organization, and safety) are generalizable.

Research is further especially needed to ascertain until what stage of the disease patient self-report is possible. As Van der Roest et al. (2007) in their review on subjective needs of people with dementia stated, it is important to incorporate in future research meanings of young people with dementia, as well as older people with dementia. It is likely that young people with dementia have a different perspective on quality of care than older people, because they often have a job and younger children, and are at a stage in their lives where dementia does not fit at all.

When quality indicators, important to people with dementia, have been identified, the development of a standardized instrument to evaluate quality of care should be considered. With such an instrument, the provision of care could be evaluated regularly, and with that information care providers can develop services that better fit and are more responsive to the needs of people with dementia.

The need for organizations to assess quality of care in people with dementia will increase with the predicted increase in dementia prevalence rates, and with trying to be responsive to the needs of these people. Authors do agree that measuring quality of care from the perspective of persons with dementia will remain a highly complex challenging area of scientific investigation, but it is a challenge that has to be taken up.

### **Conflict of interest declaration**

The authors do not have a conflict of interest.

### **Description of authors' roles**

A. van Baalen undertook the study design, performed the data collection and data analysis, and is the primary author of the paper. A.J.J.M. Vingerhoets supervised the data collection, assisted with and supervised the analysis and contributed significantly to the preparation of the manuscript. H.J. Sixma, and J. de Lange commented on versions of the manuscript.

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**Angela van Baalen**, MSc, RN (corresponding author) is Researcher at the Reinier van Arkel groep, an institute for mental health care in The Netherlands, and is performing a PhD research on person-centred care for people with dementia. She also works clinically as a nurse practitioner in training in the screening, diagnosing and treatment of people with psychiatric and physical problems. [email: a.van.baalen@RvAGroep.nl]

**Ad J.J.M. Vingerhoets**, PhD, is Professor in Clinical Psychology at Tilburg University, Tilburg, The Netherlands. His main expertise is in the areas of stress, emotions, and quality of life. His special interest topics are (adult) crying, homesickness, and stress and leisure, as well as the development of new assessment tools. [email: Vingerhoets@uvt.nl]

**Herman J. Sixma**, PhD, is affiliated as Senior Researcher to the Netherlands Institute for Health Services Research (NIVEL), Utrecht, The Netherlands. His main expertise is in the field of measuring patient satisfaction and quality of care from the patient's perspective. [email: h.sixma@nivel.nl]

**Jacomine de Lange**, PhD, is Senior Researcher at the Trimbos-institute, Netherlands Institute of Mental Health and Addiction, and Professor of Transitions in Care at the Institute for Health Care of the Rotterdam University of Applied Sciences. Her main expertise is in the area of care for people with dementia and their caregivers. [email: jlange@trimbos.nl]