Living with early-stage dementia: a review of qualitative studies

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Aim. This paper presents a literature review whose aim was to provide better understanding of living with early-stage dementia.

Background. Even in the early stages, dementia may challenge quality of life. Research on early-stage dementia is mainly in the domain of biomedical aetiology and pathology, providing little understanding of what it means to live with dementia. Knowledge of the lived experience of having dementia is important in order to focus pro-active care towards enhancing quality of life. Qualitative research is fundamentally well suited to obtaining an insider's view of living with early-stage dementia.

Method. We performed a meta-synthesis of qualitative research findings. We searched MEDLINE, CINAHL, and PsycINFO and reviewed the papers cited in the references of pertinent articles, the references cited in a recently published book on the subjective experience of dementia, one thesis, and the journal *Dementia*. Thirty-three pertinent articles were identified, representing 28 separate studies and 21 different research samples. Findings were coded, grouped, compared and integrated.

Findings. Living with dementia is described from the stage a person discovers the memory impairment, through the stage of being diagnosed with dementia, to that of the person's attempts to integrate the impairment into everyday life. Memory loss often threatens perceptions of security, autonomy and being a meaningful member of society. At early stages of memory loss, individuals use self-protecting and self-adjusting strategies to deal with perceived changes and threats. However, the memory impairment itself may make it difficult for an individual to deal with these changes, thereby causing frustration, uncertainty and fear.

Conclusions. Our analysis supports the integration of proactive care into the diagnostic process, because even early-stage dementia may challenge quality of life. Moreover, this care should actively involve both the individual with dementia and their family so that both parties can adjust positively to living with dementia.

Keywords: early-stage dementia, human experience, life change events, literature review, meta-synthesis, nursing, qualitative research

Introduction

Although dementia can present in relatively young people, it is primarily a health problem of older people. With no cure in sight, dementia continues to be an invalidating chronic illness, affecting both the person with dementia and their immediate family. Because pharmacological treatment in the early stages can delay disease progression, more people are being diagnosed at earlier stages and are able to function better for longer periods before entering end-stage dementia.

In early-stage dementia, independent living is still possible but memory loss interferes with more complex activities of daily life (such as cooking, housekeeping, shopping and handling money), and especially with work and social activities (American Psychiatric Association 1987, World Health Organization 1993). As with any other chronic disease, early-stage dementia may affect quality of life for the individual with dementia and their family. Therefore, proactive care should begin early in the diagnostic process, with the aim of reducing excessive disability, dependency and suffering.

Given the reasonableness of such an approach, it is surprising that the research base for developing proactive care for these patients is limited. Research on early-stage dementia is mainly in the domain of biomedical aetiology and pathology. According to Kitwood (1990), however, dementia should be considered as a socially-embedded phenomenon, composed of interactions between the neurological impairment and life history, health status, personality and malignant social psychology. Gaining knowledge of the lived experience of having dementia, as a socially-embedded phenomenon, is important in order to focus care towards enhancing quality of life for the individual with dementia, instead of towards treating the disease (Grypdonck 1996).

Aim

The aim of this review was to advance understanding of what a person experiences when trying to live with early-stage dementia. More specifically, we sought to advance understanding of the ways in which people with early-stage dementia come to understand, account for, take action, and otherwise manage their daily life with the condition (Miles & Huberman 1994), and the ways in which social interaction is involved in this process.

Search methods

Quantitative research gives an outsider perspective on the phenomenon under study and explains by identifying determinants, while qualitative research explains by discovering and reconstructing processes from an insider perspective. Qualitative research is fundamentally well-suited to studying the meanings people place on events in their lives and how these meanings are connected to the social world around them (Miles & Huberman 1994). To obtain an insider's view of living with early-stage dementia, we carried out a meta-synthesis of qualitative studies of people with dementia. While a systematic review gives an overview of related studies, a meta-synthesis aims at an integrative interpretation of findings from single, related, qualitative studies to synthesize a more substantive description of the phenomenon (Sherwood 1999, Evans 2003, Fingeld 2003).

We searched MEDLINE, CINAHL and PsycINFO using the terms 'dement*' or 'Alzheimer*' and 'lived experience' or 'subjective experience'. Nesbit's CINAHL evidence-based filter for qualitative research was also used (Nesbit s.a.). We restricted the search to refereed publications in which the researchers interviewed people with early-stage dementia. Articles written in English or Dutch published between January 1990 and October 2004 were considered. 1990 was chosen as in the late 1980s a call was made to include the perspective of people with dementia in research and care (e.g. Lyman 1989), and this was expected to result in a rise in related research. To ensure an extensive search, we also manually searched the reference lists of all included articles, a recently published book on the subjective experience of dementia (Harris 2002), one thesis on early-stage dementia

(Robinson 2000), and performed a focused search in the journal *Dementia* (Keady *et al.* 2002).

Studies meeting the inclusion criteria were appraised using Sandelowski and Barosso's (2002) guide for qualitative research. This guide helps to dissect and organize information in research reports in 13 categories: research problem, research purpose, literature review, orientation to the target phenomenon, method, sampling, sample, data collection, data management, validity, findings, discussion and ethics. It also facilitates appraisal of the physical format and reporting style. Appraisal parameters are offered to help judge how well or badly a category of information has been addressed and how relevant this is for the credibility of findings. The guide helped us to evaluate more systematically the informational adequacy, methodological rigour and flexibility, procedural and interpretative appropriateness, theoretical connectedness, heuristic relevance and descriptive vividness of the studies (Burns 1989, Popay *et al.* 1998, Sandelowski & Barosso 2002, Eakin & Mykhalovskiy 2003).

Of the 44 articles that met the inclusion criteria, 11 were deemed inappropriate according to our appraisal criteria. The studies of Keady *et al.* (1999a, 1999b), Husband (2000) and Marzanski (2000) were excluded because of methodological limitations. Keady *et al.* (1999a, 1999b) had no way of knowing how many of their telephone helpline callers really had dementia, which may have affected reliability of the findings. Husband's (2000) content analysis and frequency counts limited the amount of in-depth information on the lived experience, as did Marzanski's (2000) questionnaire study of patients' opinions of received and desired information about dementia. The study by Dabbs (1999) was excluded because of informational inadequacy regarding methodology. In Parse's study (Parse 1996) it was unclear if the Human Becoming Theory fit or was imposed on the data. In the papers by Aggarwal *et al.* (2003) and Beattie *et al.* (2004), findings on the experience of living with dementia were not well elaborated (limitations concerned heuristic relevance and theoretical connectedness). Norman *et al.* (2004) included people with moderate to severe dementia, whose perspective was scarcely represented in the study, and Proctor's (2001) and Reid *et al.*'s (2001) studies focused mainly on service evaluation from the perspective of people with dementia.

Thirty-three relevant articles were included, representing 28 separate studies and 21 different research samples. Table 1 summarizes the characteristics of the included studies. The majority of study participants were recruited through memory clinics and had a diagnosis of dementia, except for those in one sample in which people in the prediagnostic phase were included (Robinson *et al.* 1997, 1998, 2000b) and one person in another sample who had a diagnosis of cognitive impairment without dementia (Menne *et al.* 2002). Sample sizes ranged from 1 to 84 (median = 12, IQR: 6–22), totalling 414 people with dementia. Some of these had cognitive impairment without dementia. However, because they might eventually develop dementia, they were included here. Both sexes were included, except for one study, which included only men (Pearce *et al.* 2002). The majority of studies included people younger than and older than 65 years of age. Three samples included only older people (Keady *et al.* 1995, Phinney 1998, 2002b, Keady & Gilliard 2002, Keady & Nolan 2003, Svanstrom & Dahlberg 2004), and two samples included only younger people (Nygard & Borell 1998, Robinson *et al.* 2000a). In 11 samples, the experiences of family caregivers were also surveyed. Table 1 summarizes the characteristics of the participants in all the studies we considered.

Geographically, nine samples were drawn from the United States of America, seven from the United Kingdom (UK), four from Sweden and one from Canada. The studies used descriptive, explorative, phenomenological, or grounded theory designs. While all generally explored the experience of living with dementia, some focused on specific aspects, such as the prediagnostic phase (Robinson *et al.* 1997, Keady & Gilliard 2001), the assessment process (Keady & Gilliard 2002), receiving a diagnosis (Robinson *et al.* 1998, 2000b, Pratt & Wilkinson 2001), coping and adaptation (Clare 2002, Harris & Durkin 2002, Pearce *et al.* 2002), identity (Harris & Sterin 1999), occupational self (Nygard *et al.* 1995, Nygard & Borell 1998), awareness of memory problems (Hutchinson *et al.* 1997, Robinson *et al.* 2000a, Phinney 2002a, Clare 2003), social interaction (Hutchinson *et al.* 1997, Snyder 2002, Keady & Nolan 2003, Clare & Shakespeare 2004, Svanstrom & Dahlberg 2004) and the lived body (Phinney & Chesla 2003).

Most studies were cross-sectional, with the exception of two three-year longitudinal case studies (Nygard & Borell 1998, Robinson *et al.* 2000a).

We read the included publications several times, coded, grouped, compared the findings and integrated them along dimensions of time (prediagnostic, diagnostic, or postdiagnostic phase), experiences and meanings of memory loss, feelings related to memory loss, coping strategies and experiences of interactions with others.

Findings

All findings were sorted chronologically, from the prediagnostic phase through the diagnostic to the postdiagnostic phase. These three phases represent the transitional process.

Table 1 Studies included in the literature review

Author, year and country of study	Type of qualitative study Aim of the study	Participants	Data collection Data analysis
Burgener and Dickerson-Putman (1999) USA	Qualitative study* Understanding what are the relevant aspects of the perspective of people with dementia of the impact of the disease on their functioning, changes in meaningful relationships, and values and perceptions of self	84 pairs of participants with a recent diagnosis of AD, multi-infarct, or mixed dementia and their caregiver Participants with dementia: 51 women and 33 men Caregivers: 62 women and 22 men	Interviews with the participant with dementia (it could not be derived if the caregiver was included in these interviews): within 12 months of the diagnosis and 6 months later Matrix approach to qualitative data structures and analysis
Clare (2002, 2003), UK	Phenomenological study Clare (2002): identifying and conceptualizing the coping strategies used by people with early-stage Alzheimer's Disease (AD) Clare (2003): exploring the way in which awareness is expressed in the accounts of personal experience given by people with early-stage AD	12 participants – 3 women and 9 men – with diagnosis of probable Alzheimer's disease and their spouses	Separate in-depth interviews with participants and spouses, on two occasions, approximately 3 months apart Interpretative phenomenological analysis
Clare and Shakespeare (2004) UK	Exploratory qualitative study Exploring how couples where one partner has a diagnosis of early-stage AD use talk in conversation to negotiate and co-construct an account of their experience and situation	10 married couples of which one partner was recently assigned a diagnosis of early-stage AD. Participants with dementia: 2 women and 8 men	Each couple was asked to hold a conversation, up to 5 minutes in length, with the aim of coming up with a sentence or brief statement about their present situation. Voice relational analysis supplemented with concepts from conversational analysis
Gillies (2000) UK	Qualitative study* Seeking to expand our knowledge of the perspective of people with dementia	20 individuals with dementia, 11 men and 9 women. 10 individuals have a diagnosis of probable AD, 10 individuals have either multi-infarct or unclassified dementia	Semi-structured interviews with the person with dementia.Re-interviews with 6 subjects. Analytical process involving a line by line thematic coding scheme
Harris and Sterin (1999) USA	Qualitative study* Gaining an in-depth understanding of the concept of self of a person diagnosed with early-stage AD	17 participants diagnosed with early-stage AD: 12 women and 5 men 15 caregivers, among which 10 spouses	Interviews in three consecutive sessions: the participant with AD and the caregiver interviewed by the researcher with dementia and the researcher without dementia; the participant with dementia interviewed by the researcher with dementia; the caregiver interviewed by the researcher without dementia Analysis by use of analytical strategy suggested by Glaser and Strauss (1967)
Harris and Durkin (2002) USA	Descriptive qualitative research Seeking out what the positive coping behaviours are that people in the early stage of dementia use and how these coping behaviours play a role in successful adaptation to living with AD	Same sample as for Harris and Sterin (1999), but with participants added to a total of 22 persons with early-stage AD: 15 women and 7 men 19 family members: 11 women and 8 men	Same data collection as in Harris and Sterin (1999) + 5 additional interviews by only the researcher without dementia Analysis by use of analytical strategy suggested by Glaser and Strauss (1967)

Table 1 (*Continued*)

Author, year and country of study	Type of qualitative study Aim of the study	Participants	Data collection Data analysis
Holst and Hallberg (2003) Sweden	Biographical study with an oral history approach Exploring the meaning of the everyday life of those having dementia as expressed by themselves	11 persons with diagnosis of AD, moderate level of dementia.	Interviews with the participant with dementia (alone or in the presence of next of kin) Biographical method
Hutchinson *et al.* (1997) USA	Emergent fit study Exploring the explanatory value of Awareness Context Theory (Glaser and Strauss, 1965) for social interactional issues in early AD	4 participants with probable AD attending a daycare centre (3 women and 1 man) + 10 persons with early AD on videotape (6 women and 4 men) + one autobiographical account + one fictional account + 14 family caregivers + 1 focus group of 3 family caregivers + excerpts from two years of field notes taken during participant observation at the specialized daycare centre and caregiver support groups	Participant observation (field notes and videotaping), interviews with the person with dementia and caregivers, document analysis. Initial focus of analysis on the experience of early AD. After preliminary analysis focus was placed on emergent fit with Awareness Context Theory
Keady *et al.* (1995), Keady and Nolan (1995)UK	Grounded Theory Exploring the experience of dementia and personal coping behaviour	10 persons with dementia (7 very mild AD, 2 vascular dementia, 1 frontal lobe dementia) and their family caregiver (9 spouses and 1 daughter)	Joint and separate interviews with the person with dementia and his family caregiver Constant comparative analysis
Keady and Gilliard (2001) UK Keady and Gilliard (2002) UK	Grounded Theory Keady and Gilliard (2001): exploring the experience of dementia and personal coping behaviour; when and how decisions are made to seek professional help; stresses and coping behaviours of family supporters; how resources are viewed by people with early dementia and their family supporters Keady and Gilliard (2002): construction of the meaning of psychological assessment as experienced by the participants	15 people with very mild AD [including data from 6 people with AD from the study of Keady and Nolan (1995)], 12 women and 3 men	Joint and separate interviews with the person and family caregivers Constant comparative analysis
Keady and Nolan (2003) UK	Grounded Theory Mapping out the ways in which the person with dementia and his family supporter interact and help to shape the nature of caregiving	58 family caregivers in a first phase of the study 10 persons with dementia (7 very mild AD, 2 vascular dementia, 1 frontal lobe dementia) and their family caregiver (9 spouses and 1 daughter) (=same sample as Keady *et al.* (1995) 6 family caregivers in a third phase of the study	Semi-structured interviews with family caregivers in the first and third phase of the study. 10 joint interviews with the person with dementia and his family caregiver, 3 interviews with the person with dementia and 1 interview with the family caregiver in the second phase of the study Constant comparative analysis

Table 1 (*Continued*)

Author, year and country of study	Type of qualitative study Aim of the study	Participants	Data collection Data analysis
Menne *et al.* (2002) USA	Qualitative study* Exploring the experience of dementia from the perspective of the person with the diagnosis	6 participants – 3 women and 3 men –5 with early stage dementia – 1 frontotemporal dementia and 4 AD – and 1 with cognitive impairment without dementia	One-on-one interviews with individuals with dementia.Coding process developed by Strauss (1987) Based on Atchley's continuity theory and Park and Folkman's model of meaning making
Nygard *et al.* (1995), Nygard and Borell (1998) Sweden	Longitudinal phenomenological case study Describing from a phenomenological, occupational therapy perspective, the structure and unfolding process of the illness experience over a 3-year period, as expressed in the every day lives of two persons with early-onset dementia	2 women with mild dementia: 1 with unspecified dementia and 1 with AD	Informal, conversational interviews and participant observation during home visits. Data were collected over 3 years, at intervals with a major, 6- to 8-month data collection period each year, totalling 58 home visits and 123 telephone calls Empirical, phenomenological, psychological method, but with an occupational perspective replacing the psychological perspective
Ostwald *et al.* (2002) USA	Descriptive, exploratory, qualitative design Exploring and describing the experiences of persons with dementia	56 individuals with dementia, varying from mild to severe dementia, 26 women and 30 men. Six of these individuals (Mini Mentale State Score <15) could not initiate or maintain a conversation and were excluded from the study.	Five-minute speech samples: invitation to respond in 5 minutes to the question: 'How have things been for you lately?', while being videotaped Thematic analysis
Pearce *et al.* (2002) UK	Phenomenological study Exploring the appraisals and coping processes of men who have early-stage AD	20 men with early-stage dementia and their wives	Separate interviews with the men and their wives. Interpretative Phenomenological Analysis
Phinney (1998) USA	Phenomenological study Seeking to understand how people with early AD experience and interpret symptoms; the meaning of AD for people who have been diagnosed with the disease; their concerns in living with AD	5 people with diagnosis of probable AD, 4 women and 1 man 3 spouses	Two interviews with each person with dementia over a 2-week period. One interview with the spouses. Observation of 3 participants and their families for a total of 6 hours. Thematic analysis
Phinney (2002a) USA, Phinney and Chesla (2003) USA	Naturalistic study using interpretive phenomenological methods Phinney (2002a): seeking to highlight the different ways that dementia symptoms are revealed to people as their awareness fluctuates and seeking to explore the significance of these fluctuating experiences for their illness narrativesPhinney and Chesla (2003): Trying to understand the meaning of dementia symptoms in terms of how breakdown is embodied in everyday habits and practices	9 people with mild to moderate AD, 5 women and 4 men. 9 family members	Three in-depth conversational interviews with each participant over a period of 2–6 months. Interviews with family-members on three occasions. 4–6 hours of participant observation with each family, conducted over three sessions. Data analysis following techniques for developing an interpretive account as described by Benner (1994) and Benner *et al.* (1996)

Table 1 (*Continued*)

Author, year and country of study	Type of qualitative study Aim of the study	Participants	Data collection Data analysis
Phinney (2002b) USA	Phenomenological study Seeking to understand how people with early AD experience and interpret symptoms; the meaning of AD for people who have been diagnosed with the disease; how they cope and adapt to changes in their lives	Data from two previous studies (Phinney 1998, 2002a) resulting in a total of 13 persons with early AD, 8 women and 5 men, and their family	Two or three interviews with each person with dementia. One or three interviews with the family member. Participant observation Thematic analysis (van Manen 1990)
Pratt and Wilkinson (2001) UK	Qualitative study* Exploring how people with dementia feel about the way in which they are told the diagnosis; and gaining insight into the opportunities and limitations offered by an early diagnosis for the person with dementia	24 participants with a diagnosis of dementia, 13 women and 11 men.Of the 19 people who knew their diagnosis, 10 had AD, 4 had unspecified dementia, 3 had vascular type dementia, 1 had Picks dementia and 1 had frontal lobe dementia	Unstructured interviews, guided by a number of themes.12 of the 24 participants were interviewed twice. Combined inductive and deductive approach in looking for key themes together with case study analysis
Robinson *et al.* (1997) Sweden	Phenomenological study Describing the experience of early memory loss and the transition towards seeking professional help among patients who requested treatment because of a perceived gradual loss of memory	8 participants, 5 women and 3 women4 subjective memory loss without objective evidence, 2 objective memory loss without dementia, 2 AD	Personal interviews at one of the first days of their memory investigation. Use of an semistructured interview guide. Phenomenological-hermeneutic analysis
Robinson *et al.* (1998), Robinson *et al.* (2000b) Sweden	Phenomenological study Robinson *et al.* (1998): understanding what it means for a person who is evaluated clinically due to suspected dementia to be provided with the results of this evaluation Robinson *et al.* (2000): exploring eight person's reactions upon receiving a clinical diagnosis following an extensive memory evaluation	same sample as Robinson *et al.* (1997)	Interviews approximately one month later than the first interview (Robinson *et al.* 1997) immediately after the participant had been informed about the diagnosis Phenomenological-hermeneutical analysis
Robinson *et al.* (2000a) Sweden	Longitudinal phenomenological case study Exploring how one person experienced the early years of dementia as she was living through the preclinical and early clinical stages of AD	One female participant of the eight participants included in Robinson *et al.* (1997), at first diagnosed with objective memory loss without dementia and one year later a diagnosis of AD	Interviews on 4 occasions over a 3-year period (one in the memory investigation period, one immediately after diagnosis, and the last two with 1-year interval) Analysis following phenomenological method developed by Giorgi
Snyder (2001) USA	Qualitative study* Discovering common themes in feelings and experiences of persons with early-stage AD	Transcriptions of the author's individual and group sessions with persons with AD over a decade, verbatim quotes garnered from other clinicians and documented in written literature and in videos, and writings of persons with the disease	Identification of themes

Table 1 (*Continued*)

Author, year and country of study	Type of qualitative study Aim of the study	Participants	Data collection Data analysis
Snyder (2002) USA	Qualitative study* Exploring the significance of social and familial relationships through the direct written and verbal testimonies of persons with AD	Within the sample of Snyder (2001) quotations pertaining to social or family relationships were extracted, yielding a total of 112 authentic verbalizations from 60 individuals with AD. 26 are women and 27 men, and for 7 gender is not provided	Identification of themes
Svanstrom and Dahlberg (2004) Sweden	Phenomenological study Investigating the lived experience of dementia for spouses where one of them is diagnosed with dementia	Five couples, of which 2 women and 3 men have dementia	Unstructured interviews, mainly based on reflections on a one week kept diary by the spouses (=method of reflective lifeworld research). Analysis based on principles described by Dahlberg *et al.* (2001)
Werezak and Stewart (2002) Canada	Grounded Theory Exploring and conceptualizing the process of learning to live with memory loss in older adults with early-stage dementia	6 participants, 3 women and 3 men with early-stage dementia, 5 AD and 1 vascular dementia	Semi-structured interview. Second more unstructured and open-ended interview 1–3 months later with the purpose to verify and clarify the emerging theory. Constant comparative analysis
Young (2002) USA	Qualitative study* Investigation of the medical experiences and concerns of persons with early-stage AD	Four focus groups held over a 6-week period. Three focus groups including 24 persons with AD and 3 caregivers. One focus group including 10 family caregivers. Men and women were represented almost equally.	Focus group interviews. Thematic analysis

AD, Alzheimer's disease; USA, United States of America; UK, United Kingdom.
*No further detail about the type of qualitative study was provided.

The transitional process

Prediagnostic phase

In general, the experience of living with dementia is presented in the literature as a highly individualized and complex process consisting of several progressive stages, starting long before diagnosis is or can be given. It is during this prediagnostic phase that affected people gradually become aware that they have a problem (Keady & Nolan 1995, Robinson *et al.* 1997, Pratt & Wilkinson 2001, Werezak & Stewart 2002, Clare 2003, Keady & Nolan 2003), initially passing off memory problems as part of normal ageing or as stress-related. As memory problems become more severe, they slowly suspect that something is very wrong (Keady & Nolan 1995, Robinson *et al.* 1997, Clare 2003, Keady & Nolan 2003). On the other hand, others may experience dramatic 'wake-up calls' when critical events happen, such as being banned from driving (Hutchinson *et al.* 1997). This typically forces them to admit that something is abnormal. Others may be unaware of their memory problems, yet are vaguely aware that something is wrong as other people repeatedly accuse them of forgetfulness (Robinson *et al.* 2000a, Phinney 2002a). In this latter case, discrepancy between accusations of forgetfulness and personal experience results in incomprehension, which is the basis of sensing that something is wrong (Robinson *et al.* 2000a).

Becoming aware that something is wrong produces frustration, uncertainty, and fear, which in turn puts stress on interpersonal relationships (Pratt & Wilkinson 2001). These feelings stem from inability to understand the perceived changes and their unpredictability, lack of self-assurance and feelings of being out of control (Keady & Nolan 1995, Keady *et al.* 1995, Robinson *et al.* 1997, 2000a, Pratt & Wilkinson 2001).

Being aware that something is wrong also causes individuals with dementia to form strategies of watching and analysing themselves and others for signs of deterioration that eventually lead them to the stage of searching for meaning (Keady & Nolan 1995, Robinson *et al.* 1997, Keady & Nolan 2003). Meanwhile, to maintain control and conceal growing memory problems, they develop strategies of vigilance and avoidance (Keady & Nolan 1995, Robinson *et al.* 1997, 2000a).

Attempts to keep the problems hidden and to maintain the veneer of normality become increasingly difficult and cause psychological strain (Hutchinson *et al.* 1997, Robinson *et al.* 2000a, Keady & Nolan 2003). Eventually, these strategies fail and close friends and family begin to notice the cognitive decline and may express their concern (Keady & Nolan 2003). In many cases, family members initiate the stage of sharing awareness (i.e. acknowledging the memory impairment), whereas in others the person with dementia does this (Keady & Nolan 2003). The individual's desire to acknowledge the problem may be triggered by several needs: the need for an explanation (Robinson *et al.* 1997), the need to relieve the pressure of maintaining a normal appearance, and the need to feel supported (Keady & Nolan 1995, Robinson *et al.* 2000a, Keady & Gilliard 2001).

Sharing awareness may be limited to close family and friends (Hutchinson *et al.* 1997, Keady & Nolan 2003). However, sharing awareness cannot be taken for granted. While disclosure of memory problems may relieve an individual with dementia, family members may not always be willing to acknowledge that their loved one has a problem (Keady & Nolan 1995, Keady & Gilliard 2001, Keady & Nolan 2003). If this occurs, the individual may become frustrated, being uncertain as to what to do next (Keady & Nolan 1995, Keady & Gilliard 2001). Alternatively, people with dementia may not necessarily communicate the problem to their families (Clare 2003). This does not necessarily mean that they are unaware of having memory problems, nor that, by acknowledging the problem, they are fully aware of having memory problems. Alternately denying and acknowledging memory loss, or acknowledging memory loss without being able to describe it or without expressing concern or understanding may occur (Hutchinson *et al.* 1997). Awareness may eventually lead to the stage of seeking professional help.

Diagnostic phase

During the diagnostic phase, people who suspect that they have dementia seek help, have a neuropsychological assessment, and be diagnosed. It is important that professional caregivers take these individuals and their families seriously and respond with the necessary knowledge and skills to meet their needs (Keady & Gilliard 2002). Being taken seriously may bring relief but also fear. Referral for neuropsychological testing may reinforce for these people the seriousness of their condition (Keady & Gilliard 2002). From the time when they first seek help until the time when they receive the diagnosis, they may envisage or ponder over the diagnosis, their reaction to this, possible causes of their memory impairment, future losses resulting from the impairment, and the reactions of others (Werezak & Stewart 2002). Fear and uncertainty may prompt them to plan how to manage the future (Keady & Gilliard 2002). Neuropsychological testing may trigger or heighten feelings of threat, uncertainty, and anxiety (Burgener & Dickerson-Putman 1999). This is especially the case if people receive little or no information about the testing or its consequences, forcing them to interpret these tests on their own (Keady & Gilliard 2002). During the testing period, people may adopt several strategies to cope with perceived threats, such as taking time out, challenging the validity of a question, making excuses, avoiding awkward questions, relying on others for clarification and resisting. These strategies permit them to reflect on the test and the consequence of poor performance (Keady & Gilliard 2002).

A diagnosis is made at the end of the diagnostic phase. In part, the diagnosis of dementia may be validating for the person, because it provides an explanation for their experiences and legitimizes the need to feel supported (Robinson *et al.* 1998, 2000a, 2000b, Pratt & Wilkinson 2001). Withholding a diagnosis one wants to know causes distress (Pratt & Wilkinson 2001). People unaware of their memory problems may become distressed when diagnosed with dementia, because the diagnosis forces them to acknowledge that their self-image does not match reality (Robinson *et al.* 2000a). Although the diagnosis may cause these people to re-evaluate their condition, they are often left with a vague and incomprehensible self-image, because the re-evaluation was prompted by others rather than themselves (Robinson *et al.* 2000a).

Despite providing validation, the diagnosis may threaten the person's sense of existence, resulting in fear of losing the ability to retain their personal identity in the future (Robinson *et al.* 1998). The diagnosis may cause shock, anger, fear, horror, depression and disbelief (Pratt & Wilkinson 2001, Werezak & Stewart 2002, Young 2002). Also, an early diagnosis may heighten awareness of personal limitations, which may restrict daily activities and reduce self-confidence (Pratt & Wilkinson 2001).

Individuals experience some ambivalence when they receive their diagnosis, and this requires time to process (Snyder 2001). This processing time may explain in part a denial of the diagnosis; this type of denial is, of course, separate from that originating from organic cognitive impairment. Denial may provide enough time gradually to accept the painful truth; alternatively, it may indicate having difficulty in reconciling self-image with the devastating image of dementia (Snyder 2001). In addition, denial may arise from fear that acknowledging the disease will result in loss of autonomy (Snyder 2001). Difficulty in accepting the diagnosis also results when family members cover up the problems, either by denying that problems exist or by avoiding confrontation (Snyder 2001).

Postdiagnostic phase

Loss. Present or future losses may be considered by the individual after being diagnosed. Usually after an initial crisis period, they may also seek opportunities to move on with life in spite of the dementia (Robinson *et al.* 1998, Pratt & Wilkinson 2001, Werezak & Stewart 2002).

After accepting the prospect of living with dementia, people need to address several losses they experience, impaired cognition being one of the biggest. Table 2 lists several interrelated aspects of cognitive impairment that may be experienced. The meaning of these impairments becomes more apparent when considering their consequences. Loss of control is one prominent consequence that can affect many aspects of life, such as ability to act, which leads to feelings of incompetency (Harris & Sterin 1999, Pearce *et al.* 2002, Young 2002, Clare 2003). Feeling incompetent may hinder a person in further engaging in meaningful tasks or taking on certain roles (Burgener & Dickerson-Putman 1999, Pearce *et al.* 2002, Phinney 2002b, Young 2002, Clare 2003, Holst & Hallberg 2003).

Loss of meaningful activity may occur, along with loss of meaningful relationships, as opportunities to reach out to others are lost or others to retreat as incompetence develops (Nygard & Borell 1998, Burgener & Dickerson-Putman 1999, Harris & Sterin 1999, Pearce *et al.* 2002, Holst & Hallberg 2003). Loss of intimacy with the spouse (Burgener & Dickerson-Putman 1999) or role changes in family relationships may be experienced, usually with a shift from

Table 2 Experiences commonly encountered with cognitive loss

Loss of thinking ability (Ostwald *et al.* 2002)
Decision-making difficulties (Pearce *et al.* 2002)
Problem-solving difficulties (Keady *et al.* 1995)
Loss of practical skills (Snyder 2001)
Needing more time to think to accomplish tasks (Phinney 2002b, Phinney & Chesla 2003)
Difficulty using objects or devices (Phinney 2002b, Phinney & Chesla 2003)
Unable to perform or finish taken-for-granted tasks (without difficulty) (Keady *et al.* 1995, Nygard & Borell 1998, Snyder 2001, Pearce *et al.* 2002, Phinney & Chesla 2003)
Difficulties with new situations and activities (Nygard & Borell 1998)
Forgetting/unable to recall names and events (Keady *et al.* 1995, Phinney 2002b)
Getting lost (Nygard *et al.* 1995, Phinney 1998, 2002b, Phinney & Chesla 2003)
Losing things and spending time searching for them (Snyder 2001, Phinney 2002b)
Misperception or doubts about date or time that results in difficulty in keeping appointments (Nygard & Borell 1998, Phinney 1998)
Losing track of conversations and having problems expressing oneself coherently (Phinney 1998, Burgener & Dickerson-Putman 1999, Ostwald *et al.* 2002, Snyder 2002, Holst & Hallberg 2003, Phinney & Chesla 2003)

an independent, equal standing to a dependent one (Snyder 2002, Svanstrom & Dahlberg 2004).

As well as others taking control over their lives, dementia sufferers may also perceive a loss of control over reality (Keady *et al.* 1995, Nygard & Borell 1998, Burgener & Dickerson-Putman 1999, Ostwald *et al.* 2002). This can be due to auditory and visual hallucinations (Ostwald *et al.* 2002) but also to cognitive loss, which causes unpredictable 'gaps in the flow of their day-to-day lives' (Phinney 1998, p. 11) and a fluctuating awareness of symptoms (Phinney 1998, 2002a). Indeed, the person's world becomes an unpredictable and unfamiliar terrain (Phinney 1998, 2002b, Phinney & Chesla 2003, Svanstrom & Dahlberg 2004). Compounding this distorted reality is the discrepancy between personal perceptions and what others observe (Phinney 1998, 2002b, Ostwald *et al.* 2002). For those who are unaware of their memory problems, an additional burden can be difficulty in comprehending the disease, which may produce doubts about how to adjust and prepare for the future (Robinson *et al.* 2000a). Further difficulties with recalling parts of previous life may leave people with dementia with a sense of becoming a stranger in their own lives (Holst & Hallberg 2003).

Losing control may result in loss of self-esteem and a changing sense of self (Harris & Sterin 1999, Young 2002, Clare 2003, Holst & Hallberg 2003). Core values associated with the self-identity are meaningful productivity, autonomy, comfort and security (Harris & Sterin 1999). As a result of cognitive loss, these values are threatened in people with dementia, as is apparent in the experience of 'being slow' (Phinney & Chesla 2003), 'being a blank' (Phinney & Chesla 2003, Svanstrom & Dahlberg 2004) and 'being lost' (Phinney & Chesla 2003, Svanstrom & Dahlberg 2004).

Feelings. Different feelings commonly accompany memory loss: irritation, frustration, uncertainty, or fear are frequently mentioned (Hutchinson *et al.* 1997, Burgener & Dickerson-Putman 1999, Harris & Sterin 1999, Ostwald *et al.* 2002, Phinney 2002b, Clare 2003, Holst & Hallberg 2003). Even when people are well aware of their diagnosis, they commonly feel stressed, odd, confused, uncertain and insecure because of the incomprehensibility and unpredictability of their disease and its related changes (Robinson *et al.* 2000a, Pratt & Wilkinson 2001, Ostwald *et al.* 2002, Phinney 2002b, Svanstrom & Dahlberg 2004). They also fear embarrassing themselves and being humiliated (Gillies 2000, Phinney 2002b). A deflated sense of self-esteem becomes manifest through shame, guilt, uselessness, worthlessness, or stupidity (Nygard & Borell 1998, Burgener & Dickerson-Putman 1999, Harris & Sterin 1999, Gillies 2000, Snyder 2001, Ostwald *et al.* 2002, Phinney 2002b, Clare 2003, Svanstrom & Dahlberg 2004). These feelings may also be related to the stigma surrounding dementia (Hutchinson *et al.* 1997, Pratt & Wilkinson 2001, Snyder 2001, 2002, Werezak & Stewart 2002).

Feeling misunderstood, unsupported, unaccepted, or ignored by others (Werezak & Stewart 2002, Clare 2003) may lead to feelings of alienation (Snyder 2002) and loneliness. Sadness and despair are also reported (Ostwald *et al.* 2002, Young 2002, Holst & Hallberg 2003). Anger may arise from feelings of devaluation and being out of control (Keady *et al.* 1995, Hutchinson *et al.* 1997, Harris & Sterin 1999, Snyder 2002, Holst & Hallberg 2003). Anger and aggression may be displaced or focused on the self or others (Harris & Sterin 1999, Young 2002, Holst & Hallberg 2003).

These various feelings represent responses to both present and anticipated losses. Many worry about disease progression and a hopeless future (Pearce *et al.* 2002). As they anticipate the deterioration characteristic of dementia, sufferers fear losing the intellectual and social capacity that enables them to remain valued members of society; they fear becoming burdensome (Robinson *et al.* 2000a, Ostwald *et al.* 2002, Pearce *et al.* 2002, Snyder 2002, Werezak & Stewart 2002, Clare 2003, Holst & Hallberg 2003, Clare & Shakespeare 2004); and they fear being abandoned (Gillies 2000, Robinson *et al.* 2000a, Clare 2003). The fear of becoming a burden is very difficult to handle, because it creates much guilt in those with dementia, since they feel responsible for the suffering and disappointment of their caregivers (Gillies 2000, Robinson *et al.* 2000a).

Forgetfulness, however, is not always frightening (Phinney 2002b). Similarly, being a burden (Snyder 2002) or fearing stigma (Snyder 2001) is not always a matter of concern. Positive and negative feelings may occur simultaneously. For example, past experiences can cause the person to feel quite competent; at the same time, new problems may cause them to feel incompetent (Nygard *et al.* 1995). After living through a negative crisis, a person with dementia may acquire a more positive attitude (Harris & Durkin 2002, Werezak & Stewart 2002, Young 2002).

Moving on: alternating between self-maintenance and self-adjustment. In living with dementia, moving on means coping with the changes and threats that accompany the disease. People with dementia struggle to hold on to their identity; simultaneously, they try to adjust to the changes dementia produces (Nygard & Borell 1998, Gillies 2000, Robinson *et al.* 2000a, Keady & Gilliard 2001, Menne *et al.* 2002, Pearce *et al.* 2002, Werezak & Stewart 2002, Young 2002, Holst & Hallberg 2003). The self-mainte-

Table 3 Examples of self-protective and integrative strategies

Self-protective strategies	Integrative strategies
Expressing uncertainty about the possible severe nature of registered memory difficulties (Clare 2002)	Adopting an attitude of making the best of a bad situation (Keady *et al.* 1995, Harris & Sterin 1999, Clare 2002, Clare 2003)
Denial of problems (Gillies 2000, Ostwald *et al.* 2002)	Finding out more about dementia (Nygard & Borell 1998, Clare 2002, Werezak & Stewart 2002, Young 2002)
Minimizing problems (Phinney 1998, Clare 2002, Pearce *et al.* 2002, Clare & Shakespeare 2004)	Talking about one's memory deficits (Clare 2002, Harris & Durkin 2002, Ostwald *et al.* 2002, Werezak & Stewart 2002)
Normalizing perceived changes (Gillies 2000, Clare 2002, Pearce *et al.* 2002, Clare & Shakespeare 2004)	Being useful in society (Clare 2002, Harris & Durkin 2002, Menne *et al.* 2002, Ostwald *et al.* 2002)
Focusing on continued ability to cope and lead a normal life (Nygard *et al.* 1995, Nygard & Borell 1998, Pearce *et al.* 2002, Clare 2003)	Relinquishing unable-to-perform roles and replacing them with new or adapted roles (Harris & Durkin 2002)
Not pondering about one's memory deficits (Pearce *et al.* 2002, Young 2002, Clare 2003)	Focusing on good things (Clare 2002)
Focusing on contentment with the way life was going (Clare 2003, Clare & Shakespeare 2004)	Attending support groups (Keady *et al.* 1995, Harris & Sterin 1999, Snyder 2002, Young 2002)
Adopting a fatalistic attitude (Clare 2003)	Comparing oneself to others who are worse off (Clare 2002)
Becoming argumentative and defensive (Snyder 2002)	Using humour (Harris & Sterin 1999, Werezak & Stewart 2002)
Trying harder to work or to perform at previous standard (Clare 2002, Pearce *et al.* 2002)	Engaging in holistic practices and spiritual activities (Harris & Durkin 2002)
Staying engaged and keeping an active mind (Keady *et al.* 1995, Phinney 1998, Ostwald *et al.* 2002, Phinney 2002b)	Using innovative techniques and technology (Harris & Durkin 2002)
Sticking to or setting up a routine (Keady *et al.* 1995, Keady & Nolan 1995, Clare 2002, Pearce *et al.* 2002)	Taking a proactive stance (Harris & Durkin 2002)
Maintaining hope (Clare 2002, Werezak & Stewart 2002)	Anticipating and preparing for future needs (Harris & Durkin 2002)
Using medication (Clare 2002, Pearce *et al.* 2002, Young 2002)	
Self-monitoring (Phinney 1998)	
Relying on partner or seeking support (Harris & Sterin 1999, Gillies 2000, Robinson *et al.* 2000a, Ostwald *et al.* 2002, Pearce *et al.* 2002, Phinney 2002b, Werezak & Stewart 2002, Clare 2003)	
Using external memory aids such as calendars, lists, notes, etc. (Keady *et al.* 1995, Harris & Sterin 1999, Gillies 2000, Clare 2002)	
Avoiding activities (Burgener & Dickerson-Putman 1999, Gillies 2000, Snyder 2002)	
Isolating oneself from others (Ostwald *et al.* 2002, Snyder 2002, Werezak & Stewart 2002)	
Use of humour to mask inability to remember or respond appropriately (Burgener & Dickerson-Putman 1999)	

nance stance includes self-protective strategies, while the self-adjusting stance includes integrative strategies (Clare 2002).

Self-protective strategies (Table 3) aim to protect an individual's identity and to maintain normality and continuity in line with their identity before the onset of dementia (Phinney 1998, Clare 2003). As with the prediagnostic phase, protective strategies may be insufficient, forcing adoption of a self-adjustment stance to face difficulties, either by fighting or accepting them (Pearce *et al.* 2002). In this stance, integrative strategies are used (Table 3). When people openly confront the threats of dementia with the aim of dealing with them, sometimes despair results. Therefore, to come to terms with living with dementia, it is important for them to balance despair with hope and struggle with acceptance (Clare 2002).

Although adjusting is difficult for most people, especially soon after diagnosis, some are able to adjust successfully (Harris & Sterin 1999, Pratt & Wilkinson 2001, Werezak & Stewart 2002, Young 2002). However, others keep struggling, predisposing them to severe depression (Werezak & Stewart 2002, Young 2002). Harris and Sterin (1999) identified five reaction patterns that are characterized by (1) a strong and positive fighting spirit; (2) acquiescence without much struggle; (3) denial because of unacceptability; (4) an arduous and hardly successful struggle and (5) giving up the fight and thus losing a sense of continuity.

Acceptance may stem from a positive attitude (Harris & Durkin 2002) or from resignation (Harris & Sterin 1999, Gillies 2000, Robinson *et al.* 2000a). Accepting loss may relieve pressure (Snyder 2002, Holst & Hallberg 2003) and permit an individual to focus on enjoying the remainder of life (Keady *et al.* 1995, Robinson *et al.* 2000a, Werezak & Stewart 2002). By accepting their condition, these people 'reprioritize' the dementia so that it comprises only a part of their identity (Pratt & Wilkinson 2001). However, acceptance is not always accomplished; nor is it always permanent once accomplished. Assimilation or 'fitting the dementia into one's life' (Werezak & Stewart 2002 p. 77) is a cyclical and continuous process (Pratt & Wilkinson 2001, Pearce *et al.* 2002, Werezak & Stewart 2002, Clare 2003).

Importance of social interaction

Throughout the transitional process involved in coping with the diagnosis of dementia, the important role of social interaction in supporting or obstructing the quest to cope positively is evident. People commonly view the following as supportive: having a sense of belonging and being loved (Robinson *et al.* 2000a); of being understood, accepted and valued as an individual (Keady *et al.* 1995, Burgener & Dickerson-Putman 1999, Robinson *et al.* 2000a, Snyder 2002, Werezak & Stewart 2002, Holst & Hallberg 2003); of being included in enjoyable and meaningful activities (Burgener & Dickerson-Putman 1999, Robinson *et al.* 2000a, Snyder 2002, Werezak & Stewart 2002) and of feeling supported (Robinson *et al.* 2000a, Pratt & Wilkinson 2001, Werezak & Stewart 2002). Because people experiencing early-stage dementia have an increased need to be comforted and to feel secure and valued, empathetic caregivers are needed to fulfil this burgeoning need. Caregivers are also needed because these people require added help in daily living; however, in having to rely on others, they may be forced to face their memory loss (Robinson *et al.* 2000a, Pearce *et al.* 2002, Phinney 2002b). In response, they may retreat from others, physically or mentally, thus 'suffering in silence' (Robinson *et al.* 1997, p. 107).

Suffering in silence may serve different purposes. People may need time to adjust to their memory loss, to regroup and build up inner strength to endure, and to conceal problems and maintain an appearance of normality (Keady & Gilliard 2001). They may also retreat to bolster their self-confidence and so as not to be reminded of their disease (Phinney 2002b). Alternatively, some may choose to suffer in silence to protect themselves from the accusations of those who point to their forgetfulness; this mode of protection prevents such individuals from seeking help to understand their plight better or to move forward (Robinson *et al.* 2000a). Sufferers may also hide their problems out of a sense of responsibility for the consequences of their forgetfulness and to protect others (Keady *et al.* 1995, Hutchinson *et al.* 1997, Robinson *et al.* 2000a).

Hiding memory problems may strain relationships with family caregivers. These are already strained because all parties involved are adjusting to living with dementia (Snyder 2002, Svanstrom & Dahlberg 2004). Sharing awareness before and after receiving the diagnosis of dementia and working together during the transitional period of adjustment may strengthen relationships (Young 2002, Keady & Nolan 2003). Denial of the diagnosis by one or both parties in order to protect all involved causes the person with dementia and the caregiver to work independently, may eventually damage the relationship (Hutchinson *et al.* 1997, Young 2002, Clare 2003, Keady & Nolan 2003, Clare & Shakespeare 2004). Family members may refuse to participate in concealing the problems, or they may prevent the person from voicing their concerns (Clare & Shakespeare 2004). In this way, the person may be silenced.

Interactions with professional caregivers may also silence the person with dementia and sometimes also family members (Young 2002). This is especially true if sufferers perceive that they are not taken seriously or are ignored or treated like children (Pratt & Wilkinson 2001, Young 2002, Holst & Hallberg 2003, Keady & Nolan 2003), which may leave them with the feeling that they must deal with the dementia on their own. On the other hand, receiving appropriate concern and care from professional caregivers may encourage all parties, strengthening their resolve to work together (Keady & Nolan 2003).

Being taken seriously and supported also plays a central role in enabling people with dementia to describe their impressions of living with dementia. However, fluctuating disease symptoms and varying awareness of these symptoms makes it difficult for the person with dementia to fully comprehend and relate their story. Because of this difficulty, both family and professional caregivers should look for ways beyond words to learn about the experience and to help tell the story (Phinney 2002a).

Discussion

In this review, we integrated findings from various studies to give an overview of the transitional processes experienced by those with early-stage dementia. However, the review was mainly based on cross-sectional studies that collected information retrospectively or focused on only one aspect of dementia or one time period. Only two studies had a longitudinal design (Nygard & Borell 1998, Robinson *et al.* 2000a), of which only one covered the pre- and postdiagnostic phases (Robinson *et al.* 2000a). More longitudinal research is necessary to explore important changes that are experienced during early-stage dementia and to examine the triggers and consequences of these changes.

Our review is limited to a meta-synthesis of qualitative studies. A synthesis of quantitative research findings concerning quality of life issues for people with early-stage dementia might provide valuable complementary information to enhance our understanding of important aspects of life with dementia.

As reflected by our assessment, living with early-stage dementia is a highly individualized experience wrought with diverse feelings and reactions. Although our findings contribute to formulating supportive care for these people, studying patient experiences can give us insight only into the possible course of dementia over time and do not allow us to predict what will happen in individual cases.

In line with Kitwood's (1990) concept of dementia as a socially-embedded phenomenon, we found several factors that influence the experience of living with dementia, two of which (unawareness and interaction with family and professional caregivers) were clearly apparent in our review. The influence of other factors, such as gender, age, personality, type of dementia, type of relationship with family caregivers, and educational level, remain unclear. In future research, people with diverse backgrounds should be examined to determine the influences of these factors on the experiences of living with dementia.

We identified certain features that corresponded across the 21 samples we examined, indicating that our review is, to some extent, generalizable to a larger population of people with dementia. These features include the experience of uncertainty; the importance of autonomy, meaningfulness, and security; and the struggle between self-protection and self-adjustment. All of these samples represent individuals willing to communicate their experiences. Whether these individuals also represent the voices of those unable or unwilling to relate their experiences remains to be determined.

The goal of this integrative review was to provide a better understanding of what it means to live with early-stage dementia. After a thorough literature search, we compared pertinent findings from different studies and formulated a description of living with early-stage dementia. This included a transitional process, starting with the prediagnostic phase, then the diagnostic phase and finally ending with the postdiagnostic phase. In general, the person with dementia is actively involved in this transitional process, noticing changes, searching for meaning, figuring out how to deal with current and future changes, and dealing with them. Integration of dementia into daily life is often carried out in silence, giving sufferers the time to think things through, to conceal problems, and to prevent losing face.

Memory decline often causes loss in many domains of life, including one's identity. Being a meaningful member of society, feeling secure, and having autonomy are threatened. The threat stems not only from the cognitive loss, but foremost from being accused, restricted, ignored, or patronized by others. For those unaware of their memory loss, the hard-to-comprehend reactions of others represent the forefront of their experience.

Family members also must adjust to the cognitive loss of their loved ones. How they cope may either help or hinder the affected person to deal successfully with dementia. The way in which professional caregivers interact with people with dementia and their families also can help or hinder efforts to deal with dementia. At present, the importance of this interaction during early stages of the disease has only been superficially touched on. Nurses and other professional caregivers should be made more aware of their potential to positively support those with dementia and their families. Additional research is needed to determine effective ways for professional caregivers to become skilled companions, so that all involved can work effectively to live with this disorder.

The efforts of professional and family caregivers to empathize with people with dementia can be hampered by various factors, such as denial. Memory difficulties, and especially varying awareness of these difficulties, may make it difficult for those with dementia to cope effectively, causing them to become frustrated, uncertain and fearful. Rather than counterbalancing despair with hope, many purposefully use denial to deal with perceived threats. In order for caregivers to provide the best possible care, they must listen carefully to these individuals, help them to understand the disease and its consequences, and look for ways to help them face threats positively.

Although at first a diagnosis of dementia may be devastating, in time it may become, for some, more of a challenge than a threat. With a varying degree of success, dementia can be integrated into the life of the person with dementia and their family and can be dealt with more positively. Yet, integration is a cyclical process. Due to the progressive nature of dementia, new difficulties may arise that cause all involved to reassess the situation (e.g. noticing changes, searching for their meaning and reacting accordingly). These setbacks commonly experienced by those with early-stage dementia support the need to develop proactive care with regular follow-up.

This review was founded on the belief that accurate knowledge of the lived experiences of people with early-stage

What is already known about this topic

- Even in an early stage, dementia is disabling and may affect quality of life.
- Dementia is lived as a socially-embedded phenomenon, and knowledge of this lived experience is important in order to focus proactive care towards enhancing quality of life.
- Most studies on the experience of living with dementia at an early-stage are cross-sectional in nature.

What this paper adds

- Individuals with early-stage dementia experience a transitional process that starts with the sensation that something is wrong and extends to the integration of the disorder into their lives.
- Common features in the experience of living with early-stage dementia are feelings of uncertainty; the importance of autonomy, meaningfulness and security; and the struggle between self-protection and self-adjustment.
- Nurses have an important role in positively supporting people with dementia and their families from early on in the disease course.

dementia is central to developing effective proactive care for them. Successful proactive care programmes must acknowledge the importance of involving them as active and dignified participants in their own care. In addition, because both dementia sufferers and their families must adjust together to cope, professional caregivers must consider their concerns seriously. This means that proactive care should ensure that the diagnostic phase is performed respectfully, in a way that is tailored to how the parties involved are adjusting to the disorder, and with the aim of supporting them as they continue to adapt to their ever-changing circumstances. This may include boosting their self-esteem without disguising problems and providing hope, as appropriate.

Conclusion

This integrative review represents a synthesis of current qualitative research studies on the experience of living with dementia from the first-hand perspective of those with this disorder. These combined data reveal that people with early-stage dementia experience a transitional process, which starts with the sensation that something is wrong and extends to the integration of the disorder into their lives. During the latter, they develop strategies to preserve their self-identity and to adjust to their situation. Although more research is needed to refine and deepen our present understanding of living with dementia, this review emphasizes the need to develop proactive supportive care for these people and their families.

Author contributions

ES, BD, JG and MG were responsible for the study conception and design and drafting of the manuscript. ES performed the data collection and data analysis. BD, JG and MG made critical revisions to the paper. BD, JG and MG supervised the study.

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