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Transitioning into the caregiver role following a diagnosis of Alzheimer's disease or related dementia: A scoping review

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ABSTRACT

Objectives: To identify experiences, needs, interventions and outcomes for caregivers of persons with Alzheimer's disease or related dementia as they transition into this new role following diagnosis.
Design: Scoping review of published literature.
Data sources: A search for published articles was conducted in PsycINFO, Scopus, Ovid and Web of Science databases.
Review methods: The Arksey and O'Malley methodological framework guided the review. Studies were screened independently for inclusion by two persons. A total of 955 studies, after duplicates removed, were found by the database search. From these, 127 full-text articles were retained through the screening of titles and abstracts by two reviewers. The two reviewers assessed 46 full-text articles for eligibility. The final 29 studies identified caregiver experiences, needs, and interventions during the period following a diagnosis of Alzheimer's disease or related dementia in the scoping review.
Results: Twenty-nine studies were organized around three major categories: i) family caregiver experiences on receiving the diagnosis (n = 23), ii) needs during this time of transition (n = 18), and iii) interventions and outcomes to support their transition into the caregiver role (n = 5). While studies may have addressed more than one topic, 16 studies intersected categories of both caregiver experience and needs, and one study intersected categories of needs and interventions. There were several studies that focused more specifically on the caregiver's initial reactions to a diagnosis of Alzheimer's disease or related dementia (n = 9), the emotional responses to the diagnosis (n = 14), changes in personal relationships and responsibilities with a new role (n = 16). Caregiver needs following the diagnosis included knowledge and information (n = 14), emotional and psychological support (n = 11), and assistance with care planning (n = 7). Five papers examined interventions specifically tailored to caregiver needs at this juncture, which support the transition into the caregiver role.
Conclusions: The time of receiving a diagnosis of Alzheimer's disease or related dementia is a critical period in the process of transitioning into caregiver role. This period marks a new phase in the process of caring by family caregivers. Thus, it is important to fully understand the experiences and needs of caregivers and effective interventions in order to better support their transition into this new role.

What is already known about the topic?

- The diagnosis of Alzheimer's disease or related dementia marks the official transition of family members into the caregiver role.
- Being a caregiver implies taking on a new role that involves responsibilities related to caring for people with dementia.
- Transition theory supports the vulnerability of caregivers who are open to health risks during transitions, toward which nursing interventions can facilitate positive outcomes.

What this paper adds

- Caregivers experience psychological distress and changes in relationships with family members and increase in responsibilities in the caregiver role around the time of diagnosis. Particularly, female caregivers seemed to have more family conflict, depressive symptoms and distress compared with male caregivers.

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- Transitioning into the new caregiver role gives rise to needs that include knowledge and information, emotional support including peer support, and assistance with planning care.
- Interventions addressing the unique needs of caregivers during this period are necessary for successful transition into the role.

1. Introduction

There are an estimated 46.8 million people worldwide living with dementia and the number is expected to reach 131.5 million by 2050 (Prince et al., 2016). Dementia poses significant burden on individuals, families, communities, and societies (Alzheimer's Association, 2018). The majority of people with dementia live at home. In the United States, estimates of the proportion of those with dementia living in the community range from 70% to 81%. (U.S. Census Bureau, 2005). It is estimated that 75% of care for people with dementia living in the community is provided by family members and friends (Schulz and Martire, 2004).

The diagnosis of Alzheimer's disease or related dementia, referred to as dementia in this paper, confirms the irreversibility of the illness and marks an official transition of family members into the caregiver role (Aneshensel et al., 1995; Keady and Nolan, 2003). This period is a critical time as family members adjust to the diagnosis, take on new roles and responsibilities, and are faced with challenges of becoming a caregiver. People with dementia need increasing levels of support as the disease progresses in severity. Family caregivers provide extensive care in response to the changing and increasingly demanding circumstances experienced by their loved ones (Ducharme et al., 2011b).

Transition theory can provide guidance in understanding the transition into the caregiving role, and the specific needs of individuals during this time. According to this theory, a transition constitutes a period of instability accompanied by uncertainty that represents a passage from one state to another (Meleis et al., 2000). This theory indicates that individuals may be more vulnerable to health risks during periods of transition, toward which interventions can aim to facilitate positive transitions and thus reduce negative health outcomes (Bohner et al., 2017). A successful role transition relies on the acquisition of proper knowledge and skills, perceived self-efficacy during the transition, and also strong relationships with social support networks (Meleis et al., 2000).

Ducharme et al. (2009) utilized the role transition theory to understand the transition into the caregiving role. In this period, persons with dementia and their families experience feelings of distress and burden and have immediate needs for educational support (Bruce et al., 2008). As they transition into their new roles, family caregivers must meet the challenges of becoming a caregiver (e.g., financial strain), take on new responsibilities (e.g, completion of complex care tasks), and make plans for the future (Keady and Nolan, 2003; Quinn et al., 2008). Caregivers often lack the necessary skills and knowledge for providing care and also experience difficulty in planning ahead for future care needs (Vaingankar et al., 2013). A sufficient understanding of family caregiver experiences and responses around this time of transition can help ensure appropriate support for caregivers.

Recognizing the importance of supporting people with dementia and their family caregivers during the initial stages of the disease, the Scottish government has established a National Dementia Strategy that includes a program to provide families with information and support in the year following a diagnosis of dementia and longer as needed. This integrated model of care provides education about the disease, access to resources, peer support, and assistance with planning for future care. Such a program can potentially build resilience for caregivers of individuals with dementia as they transition into the role, supporting the health and well-being of caregivers, which can impact the quality of care for an individual with dementia (The Scottish Government, 2017).

Although there have been numerous efficacious interventions for family caregivers of persons with dementia (Gitlin and Hodgson, 2015), the field has largely been focused on a reactionary approach to the needs of caregivers. Early intervention with caregivers at this critical juncture may prevent or diminish future adverse caregiver outcomes (Gaugler et al., 2003). As we begin to understand the immediate and distal benefits of supporting successful role transition to caregiving following a formal diagnosis, we can shift the field towards the creation of preventative care guidelines tied to different transition points in the caregiving trajectory, including entry into the role. Since experiences early on in the caregiving trajectory may be important in the formation of later caregiving outcomes (e.g. relinquishing of the caregiver role, caregiver depression, burden), a better understanding of the needs of caregivers following a dementia diagnosis is critical. Interventions offered at particular points in time are more likely to be effective than are interventions provided without consideration for the caregiver's own care trajectory (Nolan et al., 2002; Zarit and Femia, 2008).

An improved understanding of caregiver needs and experiences during the period following dementia diagnosis is needed, as well as the identification of effective interventions to support caregivers as they transition into the caregiver role. The purpose of this scoping review is to describe what is known in the published literature about caregiver's experiences and needs during the period following diagnosis along with interventions to support caregivers at this point in the caregiving career. The specific objectives are: 1) to describe caregiver experiences at the time of the diagnosis of dementia, 2) to identify the needs of caregivers following diagnosis, and 3) to characterize interventions and outcomes for family caregivers targeted to the period following diagnosis.

2. Methods

This scoping review was guided by Arksey and O'Malley's methodological framework (Arksey and O'Malley, 2005) which includes: 1) identifying the research question, 2) searching for relevant studies, 3) selecting studies, 4) charting the data, and 5) collating, summarizing and reporting the results. As an approach to examining a collection of literature in a single review, scoping review methodology does not attempt to address precise intervention research questions, but rather aims to present the breadth and depth of published research on a specific topic (Davis et al., 2009). A scoping review does not typically include/exclude studies based on design or quality assessment (Rumrill et al., 2010; Grant and Booth, 2009). Given the lack of reviews focused on this topic, a scoping review was felt to be the most appropriate methodology for describing the literature around the time of dementia diagnosis and transition into the caregiving role. Although PRISMA guidelines are more specific to systematic reviews and meta-analyses, we also utilized PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) checklist to ensure completeness in the scoping review (PRISMA Guideline, 2009).

2.1. Identifying the research question

Three questions guided the review of the literature:

1) What are the experiences of caregivers at the time the care recipient receives the diagnosis of dementia?
2) What are caregivers' needs following the diagnosis of dementia?
3) What interventions have been targeted at family caregivers at the period following diagnosis and what are the effects of the interventions?

2.2. Searching for relevant studies

A scoping review of the literature was undertaken to address the specific questions related to experiences, needs, and interventions for caregivers around the time of diagnosis. A search for published articles was conducted in PsycINFO, Scopus, Ovid and Web of Science databases. The keywords "diagnosis OR disclosure" AND "psychological aspect OR mental health OR social support OR well-being OR quality of life" AND "carer OR carers OR caregivers OR caregiver OR caregiving" AND "dementia OR mci OR mild cognitive impairment OR Alzheimer's OR Alzheimer disease" were used. Only English language articles were included, with no specified date limits. The literature search was performed between October and December 2017. A hand-search of reference lists on key papers was undertaken and a web-based search of the literature was performed with the same terms as described above.

2.3. Selecting studies

Once duplicates were eliminated, citations were uploaded into Rayyan, a software designed to help researchers collaborate in systematic reviews by facilitating the screening and selection of studies (Ouzzani et al., 2016). Two reviewers independently reviewed titles and abstracts of articles for selection or elimination, and the results of the two reviewers were compared. In cases of uncertainty, the entire text of the article was reviewed.

Inclusion criteria

For inclusion in the review, the research papers met the following criteria: (a) the caregiver was a family member or friend providing care to a person with dementia, including mild cognitive impairment, (b) the article included quantitative or qualitative data (was data-based), and (c) the article was focused on the transition into the caregiving role following a diagnosis of mild cognitive impairment or dementia.

Exclusion criteria

The exclusion criteria were (a) editorials, comments/opinions, abstracts only, and single case studies, (b) studies focusing on children and youth caregivers, (c) studies including professional caregivers as participants, (d) articles not published in the English language, and (e) unpublished studies.

2.4. Charting the data

Full text review was undertaken independently by two reviewers leading to the final selection of articles retained for the review, based on inclusion/exclusion criteria. The following data were extracted: citation and country, study design, time since diagnosis, number and main characteristics of caregivers (e.g., relationship of people with dementia), and main findings around caregiver needs and interventions focused on this time period.

2.5. Collating and summarizing and reporting the results

The results were reported as a narrative summary focusing on three objectives that guided the scoping review. The categorization of article type was done as an iterative process, whereby the authors met to discuss the findings listed in the summary table to ensure that the categories were expansive enough to capture the core findings of each included article. This approach is consistent with a directive content analysis (Potter and Levine-Donnerstein, 1999). Our approach to reviewing and assessing the identified literature was theory-driven. Specifically, our process for reviewing previous literature was focused on examining the phenomenon of role transition through identifying the experiences and needs of caregivers as well as interventions and their outcomes.

3. Results

3.1. An overview of findings of the review

A total of 955 studies (duplicates removed) were identified through the database search (see Fig. 1). From these, 828 articles were excluded during the screening of titles and abstracts and 127 full-text articles were retained for review by two reviewers. Of these, 81 articles were excluded for the following reasons: not data-driven, a focus on formal caregivers, time period was not the time around diagnosis, not relevant to study question, or not published in English. The two reviewers assessed 46 full-text articles for eligibility and 17 studies were again excluded due to description of a service with no data, not being conducted at the time of a diagnosis, not being focused on family caregivers, and not relevant to the study questions. The final 29 articles in this scoping review include systematic reviews, randomised controlled trials, cross sectional or correlational studies, and qualitative studies using various qualitative methodology. In all, we identified 15 qualitative studies (Adams, 2006; Boots et al., 2015; Campbell et al., 2016; Derksen et al., 2005,2006; Innes et al., 2014; Karnieli-Miller et al., 2012; Kuo and Shyu, 2010; Lethin et al., 2016; Manthorpe et al., 2013; Milne et al., 2014; Mountain and Craig, 2012; Pesonen et al., 2013; Quinn et al., 2008; Ward-Smith and Forred, 2005), 11 quantitative studies (Ducharme et al., 2011a; Garand et al., 2005, 2012; Killen et al., 2015; Välimäki et al., 2009, 2012, 2016), including three randomised controlled trials with one booster of the original study (Ducharme et al., 2011b, 2015; Garand et al., 2014; Waldorff et al., 2012), two mixed method studies (Blieszner and Roberto, 2010; Laakkonen et al., 2008), and one literature review (Robinson et al., 2011). Table 1 presents an overview of the included studies. Ten studies used a longitudinal design (Campbell et al., 2016; Derksen et al., 2005, 2006; Ducharme et al., 2011b, 2015; Garand et al., 2014; Innes et al., 2014; Välimäki et al., 2012, 2016, Waldorff et al., 2012) while the remainder were cross-sectional. Seven studies used a grounded theory approach (Adams, 2006; Campbell et al., 2016; Derksen et al., 2005, 2006; Karnieli-Miller et al., 2012; Kuo and Shyu, 2010; Pesonen et al., 2013) and two studies were phenomenological (Adams, 2006; Ward-Smith and Forred, 2005). In 8 of the 29 studies, information was collected on patient/caregiver dyads. Among the 29 studies, 18 studies were from Europe, 9 were conducted in North America, and two studies were from Taiwan and Israel respectively. Sample size in these studies ranged from 2 to 1214 participants. Although there was overlap in terms of the information provided in the studies, 23 studies were primarily focused on the caregiver experience of receiving the diagnosis and transitioning into the caregiver role, and 18 studies described caregiver needs at this juncture. Interventions to support caregivers transitioning into the caregiver role were examined in 5 studies. Sixteen studies intersected categories of both caregiver experience and needs and one study intersected categories of both needs and intervention (see Table 2).

3.2. Caregiver experiences of receiving the diagnosis and transitioning into the caregiver role

Family caregivers of persons with dementia face various challenges following a diagnosis of dementia. Challenges identified within 23 studies were receiving the diagnosis, emotional responses of caregivers to the diagnosis and caregiver role, and an increased awareness of changes in relationships and new responsibilities.

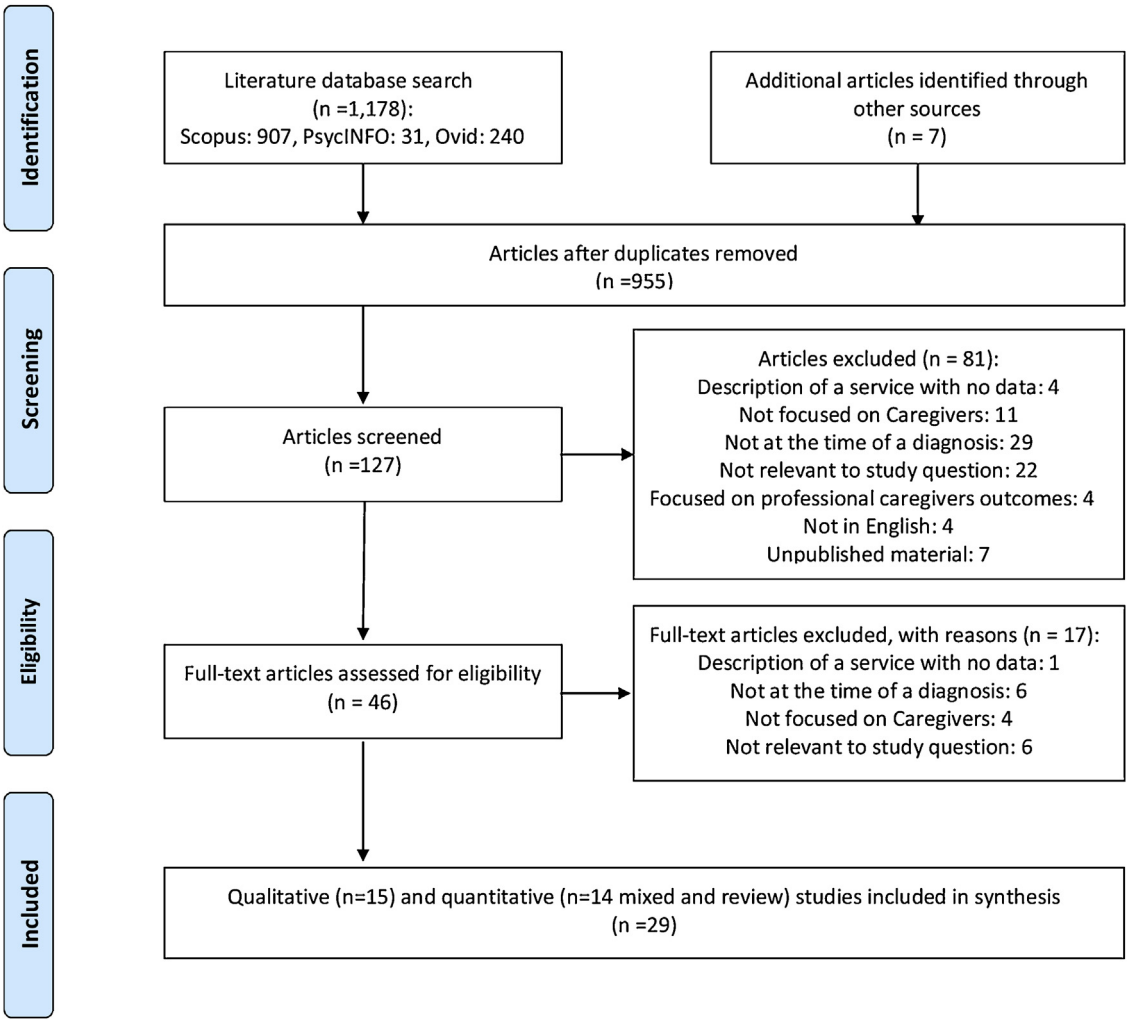

Fig. 1. Flow diagram of selecting studies.

3.2.1. Receiving the diagnosis

Nine studies focused specifically on the caregiver's initial reactions to a diagnosis of dementia (Campbell et al., 2016; Derksen et al., 2005, 2006; Karnieli-Miller et al., 2012; Killen et al., 2015; Laakkonen et al., 2008; Manthorpe et al., 2013; Mountain and Craig, 2012; Ward-Smith and Forred, 2005). All were qualitative studies except for a web-based survey conducted by Killen et al. (2015) that was with 125 caregivers of persons with dementia with Lewy bodies. Collectively, findings indicated that although obtaining a diagnosis was pivotal for the caregiver in terms of being able to move forward, caregivers reported dissatisfaction with the information and support provided at the time of diagnosis. This finding was consistent across studies. Specifically, caregivers indicated that they received very little information about the disease and about resources for support.

3.2.2. Emotional responses

Fourteen studies reported a range of emotional responses of family caregivers related to the diagnosis (Adams, 2006; Blieszner and Roberto, 2010; Boots et al., 2015; Derksen et al., 2005, 2006; Ducharme et al., 2011a; Garand et al., 2005, 2012; Laakkonen et al., 2008; Lethin et al., 2016; Quinn et al., 2008; Robinson et al., 2011; Välimäki et al., 2012, 2016). Adams (2006) conducted a phenomenological study with caregivers of persons with mild dementia or mild cognitive impairment and consistently found negative emotions such as frustration, resentment, and grief among the caregivers. Similar results were found in five studies that described frustration, resentment, and grief at the time following diagnosis over the changes in their relationships and the changes in their future plans (Ducharme et al., 2011a; Garand et al., 2005, 2012; Lakkonnen et al., 2007; Quinn et al., 2008). Findings from very early stage caregivers participating in focus groups underscored the association between denial of the disease and a focus on the losses with increased negative emotions (Boots et al., 2015). In focus groups conducted by Lethin et al. (2016), caregivers reported feeling isolated and alone because formal care was not as supportive as expected. For some, there were feelings of uncertainty as they transitioned into the role (Boots et al., 2015). Caregivers encountered distress while trying to adjust to critical changes in their lives (Quinn et al., 2008; Robinson et al., 2011; Garand et al., 2005). They also reported distress about how to deal with follow-up care for dementia (Laakkonen et al., 2008; Kuo and Shyu, 2010; Pesonen et al., 2013; Välimäki et al., 2012) and about what was causing the difficulties experienced in everyday life (Blieszner and Roberto, 2010; Quinn et al., 2008). Välimäki et al. (2016) conducted a longitudinal study with 236 patient-caregiver dyads. At only 5 months post-diagnosis, caregiver scores on a measure of health-related quality of life were significantly lower than age and gender standardized non-caregiving counterparts.

Table 1
Studies included in the review reporting caregiver experience, needs, and interventions following a diagnosis of MCI or ADRD.

Citation (Country)	Design	Diagnosis and Time	Sample	Focus	Summary of Key Findings
1. Adams (2006) (USA)	Qualitative, phenomenological study, grounded theory analysis	Early/mild dementia or MCI	16 spouses and 4 adult daughters	Transitioning to caregiving role	Experiences of CGs with MCI did not differ from those with mild dementia. CGs took on new tasks and responsibilities, and reported changes in the relationship with person with memory loss (closer relationship but also losses), and experienced negative emotions. Need for support as CGs begin taking on responsibilities early in the trajectory of caregiving.
2. Blieszner and Roberto (2010) (USA)	Mixed methods, face-to-face interviews and open-ended questions	75% of care recipients diagnosed with MCI within 14.5 months	86 CGs	Transitioning to caregiving role	12.5% of CGs reported symptoms consistent with depression. Poorer knowledge of dementia, poorer health, lower religiosity, more stress about memory loss symptoms, less mastery, more perceived burden and need for more frequent coping were associated with increased depressive symptoms.
3. Boots et al. (2015) (Netherlands)	Qualitative, 4 focus group interviews	Early and later stage CGs (included later stage as a comparison)	28 CGs (n = 13 early stage)	Problems, needs and wishes of early stage CGs	4 themes: (i) 'early stage needs paradox': difficult to accept help for fear of stigma even though CGs found it difficult to cope with situation, (ii) barriers to acceptance: denial, lack of knowledge about disease, (iii) facilitators in acceptance: disease-specific knowledge, and (iv) shift from feelings of loss to acceptance: adjusting expectations.
4. Campbell et al. (2016) (UK)	Qualitative, two interviews, grounded theory	Before and after the diagnosis of dementia	5 patient / CG dyads and 2 patients living alone	Experience of diagnosis	There is little stability in the pre and immediate post-diagnostic period. No form of psychological or psychosocial support offered between diagnosis and the transition to community. Little stability in the post-diagnostic phase and uncertainty was a theme through-out.
5. Derksen et al. (2005) (Netherlands)	Qualitative, grounded theory constant comparative analysis, in-depth interview	2 and 10 weeks after the diagnostic disclosure	1 patient / CG dyad	Experience of diagnosis	Three themes identified in the process of diagnostic disclosure: (i) increased awareness of dementia: CG aware of consequences for her personal life, (ii) impact of the diagnosis on their interpersonal relationship: CG realized that more decisions rested on her, trying to find ways to cope with the changes. CG had to change her responses to her husband's behavior, appreciation of his remaining capacities, and (iii) effects on social relationships: sharing diagnosis with children, support from church, future care planning.
6. Derksen et al. (2006) (Netherlands)	Qualitative, grounded theory, semi-structured interviews	2 and 10 weeks after the diagnostic disclosure	18 patient / CG dyads	Experience of diagnosis over time	Themes in the process of diagnostic disclosure for CG: (i) awareness of dementia: diagnosis expected, feelings of loss and grief, consequences for personal life and coping with behavior changes; (ii) changes in their roles and relationship as they took on caregiving role but continuing to do things they enjoy, and (iii) changes in social relationships: support given by children, relatives or friends. Diagnosis of dementia served as impetus for future care planning.
7. Ducharme et al. (2011a) (Canada)	Quantitative, cross-sectional descriptive study	Diagnosed with AD in the past 9 months	122 CGs of an elderly relative	Transitioning to caregiving role	Majority of CGs received little informal support (70-98%, depending on type of support), had poor knowledge of available formal services (70%), and had difficulty planning ahead for future care needs (68%). Compared with male CGs, women seemed to have more problems controlling disturbing thoughts about their new CG role and experienced more family conflicts and psychological distress. Spouse CGs were less able to respond to the relative's disruptive behaviors, made less use of problem-solving strategies, and reported fewer family conflicts in comparison to off-spring CGs.

Table 1 (*Continued*)

Citation (Country)	Design	Diagnosis and Time	Sample	Focus	Summary of Key Findings
8. Ducharme et al. (2011b) (Canada)	Quantitative, RCT baseline, post-test and 3-month follow-up	Diagnosed with AD in the past 9 months (mean of 4 months)	111 CGs (62 in experimental group and 49 in control group)	Intervention study to support transition to CG role (Learning to Become a Family Caregiver)	CGs in experimental group significantly more confident and prepared to deal with caregiving situation, knowledge of services, plan for future care, perceived self-efficacy, and problem-solve compared with CGs in control group. The intervention had no significant effect on use of stress-management strategies, accessing informal support and perceived family conflicts over caregiving.
9. Ducharme et al. (2015) (Canada)	Quantitative, RCT of booster session at 2 weeks following participation in Learning to Become a Family Caregiver study, 6-month follow-up	Diagnosed with AD in the past 9 months	89 CGs (31 experimental group with booster, 29 experimental group without booster, 29 with usual care)	Intervention study to examine impact of booster session	The booster session showed positive effect on preparedness to provide care. Regardless of the booster session, Learning to Become a Family Caregiver continued to have a positive effect on psychological distress and contributed to the emergence of self-efficacy in dealing with caregiving situations. The booster session had no significant effect on knowledge of services, planning for future care needs, and use of reframing as a coping strategy, perceived informal support, and family conflicts.
10. Garand et al. (2005) (USA)	Quantitative, cross-sectional, descriptive correlational study	A recent diagnosis of MCI, within 6 months prior to data collection	27 spousal CGs	Transitioning to caregiving role	CGs experienced elevated levels of task-related responsibilities, subjective CG burden, and depression and anxiety symptoms. Even at the phase of MCI, CGs are beginning to experience distress in association with elevated CG burden. Increased nursing tasks were associated with increased depression.
11. Garand et al (2012) (USA)	Quantitative, cross-sectional study	MCI or early dementia	43 MCI and 30 early dementia CGs enrolled in a clinical trial	Emotional consequences of taking on the role (interviewed prior to trial intervention)	AD CGs endorsed significantly more anticipatory grief than MCI CGs. AD CGs reported greater number of new IADL responsibilities for their family member, greater lifestyle constraints, more problematic behaviors, and a trend for higher number of depressive symptoms. Being a female CG, higher levels of burden, and a higher level of depressive symptoms were significantly associated with higher levels of anticipatory grief.
12. Garand et al. (2014) (USA)	Quantitative, RCT with data collected at 1, 3, 6, and 12 months post-intervention	MCI or early dementia diagnosis within 6 months	43 MCI and 30 early dementia CGs	Intervention study (12-week problem-solving therapy vs. control which was a nutrition class)	CGs in problem-solving therapy group reported significantly lower levels of depressive symptoms across all time points compared with control group. There was a main effect with MCI CGs reporting lower levels of depressive symptoms compared with early stage dementia CGs. CGs in intervention group also reported lower levels of anxiety and negative problem orientation across time points compared with CGs in the control group.
13. Innes et al. (2014) (UK)	Qualitative, semi-structured interviews	Diagnosis within 6 months prior to the interviews	6 patients and 12 CGs	Post-diagnostic support	CGs satisfied with the post-diagnostic support but they had need for more information. They discussed importance of communication between teams, need for information (not always in an appropriate format), how to prepare for what may happen and how to manage it when it does, how to handle symptoms of dementia, and more information about available services.
14. Karnieli-Miller et al. (2012) (Israel)	Qualitative, grounded theory analysis of in-depth interviews	2 weeks after diagnostic disclosure	17 CGs and 10 patients	Experience of diagnosis	CGs reported dissatisfaction due to lack of information and of tailored follow-up processes for implementing recommendations provided by the clinic. CGs were seeking information, guidance, a source of support and advice, and at the same time they had feelings of frustration with the outcome of the consultation which they perceived as ineffective in meeting their needs and also disappointment from the insufficient information provided, content and communication style.

Table 1 (*Continued*)

Citation (Country)	Design	Diagnosis and Time	Sample	Focus	Summary of Key Findings
15. Killen et al. (2015) (UK)	Quantitative, web survey	Time of diagnosis of DLB	122 CGs and 3 patients	Experience of diagnosis	Approximately 50% reported they had not received support at diagnosis. Almost all respondents (96%) desired more information and support in coping with hallucinations. Most respondents (90%) wanted to be given information about the physiological mechanisms of DLB and 80% were keen to learn what others found helpful.
16. Kuo and Shyu (2010) (Taiwan)	Qualitative, grounded theory in-depth interviews	MCI	10 CGs	Transitioning to caregiving role	'Ambivalent normalisation' defined as the process used by CGs to accept and rationalize the situation. This process included three components: subtle changes, optimistic appraisal and ambivalent anticipation. CGs who had developed this process were more likely to adopt multiple effective behavioral approaches to avoid conflict in their daily life and to begin outlining future caregiving tasks.
17. Laakkonen et al. (2008) (Finland)	Mixed methods, cross-sectional postal survey and open-ended question	AD (reflecting on the diagnosis)	1214 spousal CGs (survey) and 38 CGs (open-ended question)	Experience of diagnosis	71% of CGs felt they had received sufficient information about dementia. However, only 50% estimated that their spouses' follow-up care had been well organized. 68% of CGs felt grief and anxiety, loneliness and uncertainty about how to deal with the future of the spouse with AD.
18. Lethin et al. (2016) (Sweden)	Qualitative approach with 4 focus group interviews	Through stages of the disease (focus on data from early stage)	23 spouses and adult children	Transitioning to caregiving role	The dementia diagnosis is a formal entry to a new role as a CG. CGs transition into the role with little preparation and thus have to begin to collaborate with formal care, not knowing their expectations. To facilitate a healthy transition process, CGs have a need for knowledge about dementia and information about available care and services.
19. Manthorpe et al. (2013) (UK)	Qualitative, retrospective and prospective interviews	A dementia diagnosis within the previous 3 months	27 patients and 26 CGs	Experience of diagnosis	Participants experience considerable uncertainty to lengthy assessment process. Information provision and communication were variable, with participants not having questions answered and inadequate information. Support offered was felt to be generic rather than focused on individual needs.
20. Milne et al. (2014) (UK)	Qualitative, evaluation of course for CGs	Recent diagnosis of mild to moderate dementia	113 CGs	Evaluation of multi-component psychoeducational intervention	Psycho-educational interventions can significantly enhance CG well-being especially when well targeted and group-based: greater understanding of dementia (32%) and patience (25%), improved coping skills (36%), social support (36%), learned about services (31%), come to terms with diagnosis (80%).
21. Mountain and Craig (2012) (UK)	Qualitative, a series of individual and dyad interviews	Early stage dementia	5 patient/ CG dyads	Transitioning to caregiving role	The timeliness of diagnosis and the availability of appropriate services following diagnosis were key factors in determining how well individuals coped with receiving the news and managing the consequences in the following weeks and months. CGs felt that a more proactive approach to what to do following diagnosis is needed. They wanted more information about managing unexpected symptoms, maintaining meaningful roles, and managing dementia alongside other conditions.
22. Pesonen et al. (2013) (Finland)	Qualitative, grounded theory, in-depth interviews	Early stage dementia within 6 months of diagnosis	8 patient / CG dyads	Experiences after diagnosis	Diagnosis was experienced as a turning point in the family, posing different psychosocial challenges, and undermining the balance in life. Understanding different phases of the illness is a shared process within the family. CGs manage dementia on the basis of meaningful family relationships, living for today and being an active agent (talking about diagnosis and living their lives).

Table 1 (*Continued*)

Citation (Country)	Design	Diagnosis and Time	Sample	Focus	Summary of Key Findings
23. Quinn et al. (2008) (UK and New Zealand)	Qualitative, exploratory study using semi-structured interviews	Early stages of dementia	34 spouses or partners	Experiences during early stages of caregiving	Four themes emerged: (i) "Don't know what it is": CGs struggled to make sense of dementia; (ii) "Changes in the relationship": impact on their relationship with the care recipients; (iii) "Doing the best we can": CGs were experiencing significant stress in order to adjust to these changes but CGs focused on coping day by day; (iv) "it's not all plain sailing": became tired and upset more easily and found the role more difficult.
24. Robinson et al. (2011) (UK)	Systematic review	Included studies focused on period of transition to dementia	35 papers included in review	Transitioning to caregiving role	CGs must come to terms with taking on more decision-making and increased responsibility whilst trying to maintain an "emotional status quo". People with dementia and their families report that disclosure of diagnosis of dementia should be an ongoing process with the provision of ongoing support and information.
25. Välimäki et al. (2009) (Finland)	Quantitative, cross-sectional study	Recently diagnosed mild AD	170 patient / spousal CG dyads	Outcomes of CG new in the role	Male CGs' sense of coherence was significantly higher than female CGs. Women CGs reported more depressive symptoms and distress than male CGs. No gender differences in reported QoL. Depression and distress were the main predictors of both health-related QoL and sense of coherence.
26. Välimäki et al. (2012) (Finland)	Quantitative, descriptive diary study, inductive content analysis	Approx. 6.7 months after diagnosis	83 CGs' unstructured diaries	Transitioning to caregiving role	Core themes from the diaries: (i) CGs face changes in their personal milieu: transition to the caregiving role that consists of daily care and the responsibilities outside the home; (ii) Family cohesion: embracing what is intact as well as unexpected changes; (iii) Creating a new future: hopeless future and confidence about the future. The process even starts before the diagnosis of AD and has an impact on their future.
27. Välimäki et al. (2016) (Finland)	Quantitative, longitudinal design (36 months – reporting here on baseline data)	5 months, on average, after AD diagnosis	236 patient / CG dyads	Outcomes after diagnosis	CGs had significantly lower health-related QoL than age and gender matched counterparts. Severity of AD was significantly associated with the mobility and depression dimensions of CG's health-related QoL but not with the total health-related QoL index score.
28. Waldorff et al. (2012) (Denmark)	Quantitative, multicenter, RCT	Within 12 months of diagnosis of mild AD	330 patient / CG dyads	Intervention study (intervention of counselling, information and support)	At the 6-month follow-up, CGs in the intervention group had higher scores on QoL and lower depression scores compared with the control group but these differences were statistically significant, using a very conservative p-value of < 0.0005. 12-month outcomes showed no differences by group for QoL or depression.
29. Ward-Smith and Forred (2005) (USA)	Qualitative, phenomenological study descriptive Interviews	Diagnosed within 6 months	18 CGs (adult children)	Experience at time of diagnosis	Obtaining the diagnosis was a pivotal event that led to CGs making plan for the future. All were assisting family member in some way. Recommendations about power of attorney and living wills were helpful but speaking about long-term care at this point was not perceived as helpful. Knowledge about progression of disease limited among participants.

Notes: AD = Alzheimer's disease, ADRD = Alzheimer's disease or related dementia, CG = Caregiver, DLB = Dementia with Lewy Bodies, IADL = Instrumental Activities of Daily Living, MCI = Mild Cognitive Impairment, QoL = Quality of Life, RTC(s) = Randomised Controlled Trial(s).

Table 2
Categories and themes.

Category	Themes	Sources
Experiences of receiving the diagnosis and transitioning into the caregiver role	Receiving the diagnosis	4, 5, 6, 14, 15, 17, 19, 21, 29
	Emotional responses to diagnosis and caregiver role (e.g. negative emotions including anxiety, frustration, grief, feelings of isolation, and uncertainty)	1, 2, 3, 5, 6, 7, 10, 11, 17, 18, 23, 24, 25, 27
	Changes in relationships and responsibilities	1, 2, 4, 5, 6, 7, 10, 11, 14, 16, 19, 21, 22, 23, 24, 26
Needs around the time of diagnosis and transitioning into the caregiver role	Information about the disease and available resources	1, 3, 4, 6, 7, 13, 14, 15, 17, 18, 19, 21, 28, 29
	Emotional and psychological support	3, 4, 7, 10, 13, 14, 15, 18, 19, 23, 24
	Assistance with planning care	3, 5, 6, 7, 13, 14, 18
Interventions		8, 9, 12, 20, 28

Notably, four studies examined differences in emotional responses for men and women caregivers. Compared with men providing care, women caregivers reported more depressive symptoms and distress, associated with lower health-related quality of life (Välimäki et al., 2009, 2016). Ducharme et al. (2011a) surveyed 122 caregivers of an older relative and reported that women seemed to have more problems controlling disturbing thoughts about their new caregiver role, and experience more family conflicts and psychological distress compared with men who are caregivers. Similarly, Garand et al. (2012) also found that women who provide care experienced higher levels of objective caregiving burden and depression levels. Heightened levels of burden and depression found in this study were significantly associated with anticipatory grief.

3.2.3. Changes in relationships and responsibilities

Sixteen studies indicated changes in relationships and responsibilities of family caregivers following a diagnosis of dementia (Adams, 2006; Blieszner and Roberto, 2010; Campbell et al., 2016; Derksen et al., 2005, 2006; Ducharme et al., 2011a; Garand et al., 2005, 2012; Karnieli-Miller et al., 2012; Kuo and Shyu, 2010; Manthorpe et al., 2013; Mountain and Craig, 2012; Pesonen et al., 2013; Quinn et al., 2008; Robinson et al., 2011; Välimäki et al., 2012). The majority of the studies (n = 10) reported that caregivers perceived the diagnosis as a time of increased awareness of the disease, and had a heightened awareness of its impact on their relationship with care recipients as well as the increased responsibility placed of them from the disease (Campbell et al., 2016; Derksen et al., 2005,2006; Garand et al., 2005, 2012; Pesonen et al., 2013; Robinson et al., 2011; Karnieli-Miller et al., 2012; Manthorpe et al., 2013; Välimäki et al., 2012). During this transition, caregivers began to acknowledge changes in their relationship with persons with dementia (Campbell et al., 2016; Derksen et al., 2006; Garand et al., 2012; Pesonen et al., 2013; Quinn et al., 2008). Caregivers experienced changes in balancing their relationship with their care-recipients, restrictions in their lifestyles, learning to cope with and understand their family member's dementia and dealing with the emotional strains of being a caregiver (Adams, 2006; Campbell et al., 2016; Derksen et al., 2005; 2006; Ducharme et al., 2011a; Kuo and Shyu, 2010; Pesonen et al., 2013; Välimäki et al., 2012). Caregivers also reported increased protectiveness and tenderness towards the person with dementia, such as becoming an "*emotional cheerleader or coach*" for the person with dementia (Adams, 2006; Blieszner and Roberto, 2010). Out of the four studies, caregivers took on roles previously fulfilled by their recipients of care, they found they had more responsibilities and they expressed difficulties in adjusting to these new responsibilities (Adams, 2006; Garand et al., 2012; Quinn et al., 2008; Välimäki et al., 2012).

3.3. Needs of caregivers around the time of diagnosis of Alzheimer's disease or related dementia and transitioning into the caregiver role

Caregivers described a variety of needs at the time of diagnosis and as they transitioned into the caregiving role. Eighteen studies highlighted the unique needs of family caregivers during transition upon diagnosis, including knowledge and information, emotional support including peer support, and assistance with planning care.

3.3.1. Knowledge and information

The need for information following the diagnosis was a consistent theme across fourteen studies (Adams, 2006; Boots et al., 2015; Campbell et al., 2016; Derksen et al., 2006; Ducharme et al., 2011a; Innes et al., 2014; Killen et al., 2015; Laakkonen et al., 2008; Lethin et al., 2016; Manthorpe et al., 2013; Mountain and Craig, 2012; Välimäki et al., 2016; Waldorff et al., 2012). Caregivers described a critical need for knowledge about the disease, and information about available supports and services (Adams, 2006; Ducharme et al., 2011a; Innes et al., 2014; Laakkonen et al., 2008; Mountain and Craig, 2012). Communication was perceived as important to the quality of services provided (Innes et al., 2014). The majority of caregivers (75%–91%) requested that information be provided at the time of diagnosis (Ward-Smith and Forred, 2005). Family caregivers identified their interest in information on genetics, research, prognosis, life expectancy, and end-of-life care (Karnieli-Miller et al., 2012; Killen et al., 2015). Caregivers also wanted information about behavioral and psychiatric symptoms of dementia, and how to handle them if they occurred (Campbell et al., 2016; Innes et al., 2014; Karnieli-Miller et al., 2012). More often, however, caregivers reported receiving little information at the time of initial diagnosis, either about the condition or about the resources available to them (Innes et al., 2014; Laakkonen et al., 2008). As stated by a caregiver in focus groups conducted by Lethin et al. (2016), "*we have to educate ourselves*".

In addition to information, as caregivers transitioned into the role following a diagnosis, their need for support from the formal care system increased, including supportive care for the person with dementia and for themselves (Karnieli-Miller et al., 2012; Lethin et al., 2016). However, the majority of caregivers had poor knowledge of available formal services and how to access support (Ducharme et al., 2011a; Karnieli-Miller et al., 2012; Lethin et al., 2016).

3.3.2. Emotional and psychological support

In 11 studies, informal caregivers of individuals with dementia reported the need for psychological and emotional support from healthcare professionals (Boots et al., 2015; Campbell et al., 2016; Ducharme et al., 2011a; Garand et al., 2005; Innes et al., 2014; Karnieli-Miller et al., 2012; Killen et al., 2015; Lethin et al., 2016; Manthorpe et al., 2013; Quinn et al., 2008; Robinson et al., 2011). In several studies, the majority of caregivers reported that they had not received any tangible support at the time of diagnosis

(Campbell et al., 2016; Killen et al., 2015; Manthorpe et al., 2013). In the survey conducted by Ducharme et al. (2011a), almost three quarters of the caregivers reported receiving no emotional support from family or friends. Caregivers stressed the importance of timely guidance tailored to their individual needs that would have helped them cope with their individual situations and the worries that they experienced (Boots et al., 2015; Manthorpe et al., 2013). Caregivers indicated that they would have benefited from talking to someone who could understand their situation and recognize their problems earlier (Boots et al., 2015).

3.3.3. Assistance with planning care

The majority of caregivers wanted to begin planning for their relative's future care needs in seven studies (Boots et al., 2015; Derksen et al., 2005, 2006; Ducharme et al., 2011a; Innes et al., 2014; Karnieli-Miller et al., 2012; Lethin et al., 2016). Boots et al. (2015), however, described the paradoxical nature of the caregiver's situation. While caregivers desired assistance in planning care, they also found it difficult to accept assistance, as they did not want to be seen as needing professional help.

Ducharme et al. (2011a) reported that only about one-third of caregivers had made decisions regarding their relative's future care needs, such as identifying available help or care options. Caregivers had not defined a plan for meeting their relative's future care needs, even if information on services was given at the time of the diagnosis of dementia (Derksen et al., 2005, 2006; Ducharme et al., 2011a). Planning care and support for people with dementia requires addressing the changing needs of service users, as well as personal preferences of caregivers and their specific situations (Innes et al., 2014; Karnieli-Miller et al., 2012). In this respect, family caregiving requires collaboration with formal care to identify and secure support that can be adjusted to individual needs, specific to the stage of the disease of the individual (Lethin et al., 2016).

3.4. Interventions to support caregivers around the time of diagnosis of Alzheimer's disease or related dementia and transitioning into the caregiver role

Few studies (n = 5) identified as a part of this scoping review examined interventions for caregivers as they transitioned into the caregiving role following an dementia diagnosis (Ducharme et al., 2011b, 2015; Garand et al., 2014; Milne et al., 2014; Waldorff et al., 2012). Three studies utilized randomised controlled trials (Ducharme et al., 2011b; Garand et al., 2014; Waldorff et al., 2012) and one study evaluated a booster of the original (Ducharme et al., 2015). One study conducted an evaluation of a multi-component psychoeducational intervention, which was focused on information about the disease, local resources, and providing an awareness of the stresses and strains of caring for a person with dementia (Milne et al., 2014).

3.4.1. Description of the randomised controlled trials

Three randomised controlled trials tested interventions for caregivers during the transition period (Ducharme et al., 2011b; Garand et al., 2014; Waldorff et al., 2012) and one included a booster study (Ducharme et al., 2015). Interventions provided in these studies were similar in that they were multicomponent interventions with a combination of various forms of counseling, information, and support components. The interventions were comprised of individual and family counseling combined with information and support (Waldorff et al., 2012), face-to-face and telephone counseling with a focus on problem-solving therapy (Garand et al., 2014), and in-person counseling and support provided to caregivers in their home (Ducharme et al., 2011b). In two studies, the interventions were delivered by experienced nurse clinicians (Ducharme et al., 2011b; Waldorff et al., 2012), and in the third randomised controlled trial, the self-management intervention was provided by social workers (Garand et al., 2014).

3.4.2. Results of interventions in randomised controlled trials

The three studies reported post-intervention measurement that included the outcomes observed up to the 12-month follow-up (Garand et al., 2014; Ducharme et al., 2011b, 2015; Waldorff et al., 2012). It is difficult to compare the results across these studies as, for the most part, they used different outcomes including caregivers' self-efficacy, preparedness and confidence for caregiving (Ducharme et al., 2011b), depressive symptoms (Garand et al., 2014; Waldorff et al., 2012), quality of life (Waldorff et al., 2012), and anxiety and negative problem orientation (Garand et al., 2014).

Ducharme et al. (2011b) reported that caregivers in the experimental group were significantly more confident in dealing with caregiving situations, perceived themselves to be better prepared to provide care and more efficacious in their caregiver role, were better able to plan for the future care needs of their relative, had better knowledge of available services, and made more frequent use of the coping strategies of problem solving and reframing. The program had no effect on use of stress-management strategies, perceived informal support and family conflicts. In the problem solving therapy, Garand et al. (2014), found significantly reduced symptoms of depression and anxiety and a non-significant reduction in negative problem orientation compared with caregivers receiving the control condition. Similarly, Waldorff et al. (2012) found a decrease in depression for caregivers in the intervention group compared with the control group, as well as improvement in quality of life at the 6-month follow-up. There were no significant differences between the groups at 12 months (Waldorff et al., 2012).

4. Discussion

In this scoping review, we highlighted the evidence from 29 published research papers on critical points regarding caregiver experiences following diagnosis of dementia. Few studies focus on the period following the diagnosis of dementia and its emotional impact on persons with Alzheimer's disease and their caregivers (Carpenter and Dave, 2004). Just one systematic review published in 2011 (Robinson et al., 2011). The current review adds to knowledge in this area, with 18 new studies published since the previous review, including three randomised controlled trials examining interventions to support families transitioning into the caregiving role.

Transition theory (Meleis et al., 2000) provides a lens from which to understand family caregiving, with a focus on reactions of caregivers toward changes in their own roles and factors that may influence their health as they adjust to altered circumstances following diagnosis. The current review demonstrates that during this period of transition, caregivers experience changes upon diagnosis, including changes in their relationship with the recipient of care and new roles and responsibilities. At this point, caregivers need information about the disease and available resources and assistance with planning care, as well as emotional support resources. Interventions may support caregivers during transition following dementia diagnosis with tools and resources such as information, education, psycho-social support, and enhancing problem-solving skills. Targeted and timely interventions are significant to this transition in order to support better outcomes for caregivers and care recipients (see Fig. 2).

For the first objective, this review identified a range of caregiver experiences in relation to coping with their new caregiving role. Caregivers reported experiencing difficulties in adjusting to the new role and emotional responses including grief, anger, and

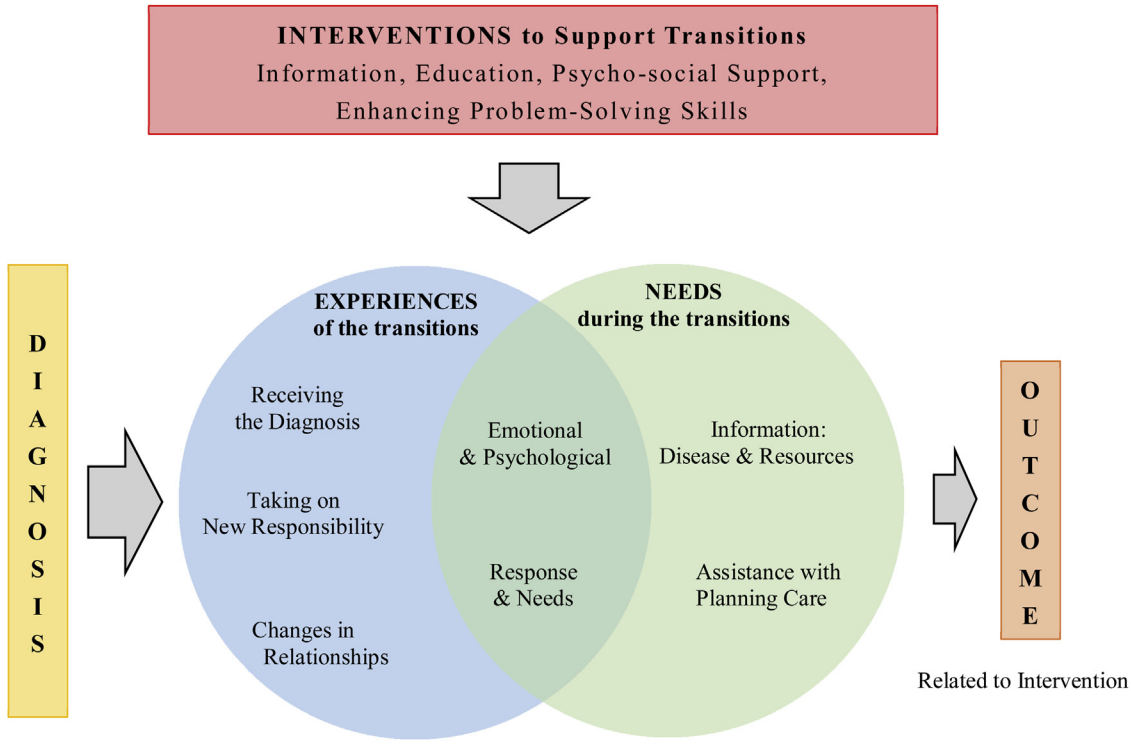

Fig. 2. Transitioning into the role of family caregiver for person with Alzheimer's disease or related dementia.

frustration. This may be related to the altered behaviors of their loved one with dementia. It has been observed that behavioral symptoms impact on the caregiver's role transition and coping at the time of diagnosis. Behavioral changes and problems can be the most distressing aspect for the caregiver in the early stage (Derouesné et al., 2002) and influence caregivers' perception of their relationship with the person with dementia (Carnelley et al., 1996). As this review affirms, even in the early stages, caregivers experience significant strain related to behavioral symptoms and require supportive interventions.

Findings from these studies, regarding the second objective, indicate caregivers' pressing needs for information and education, given at the right time in the right pace. This was consistent across studies and across the time-span of studies. Information at the right time is valuable to caregivers as it helps them to anticipate future events, and to make plans and important decisions. Particularly in the case of new caregivers, the difficulties of their caring situations can be alleviated when they are well-informed in a timely manner (Yeandle et al., 2007). Consequently, support services for caregivers need to be aware of the timely needs of caregivers and be flexible in order to respond with services that are relevant to their needs. The flexibility and the sensitivity of services to the specific needs of caregivers are the key components of the successful transition. The review underscores the need for caregiver information and education at the right time, as well as advice and support by professionals and service providers.

The third objective was to address interventions and outcomes. Yet, only three randomised controlled trials were identified that tested interventions to support successful transition into the caregiver role following a recent diagnosis of dementia. Although the randomised controlled trials presented here focused only on early outcomes, early timing may be crucial because early interventions offer opportunities for caregivers to adapt to the caregiver role and prevent burden in the role (Woods et al., 2003). Garand et al. (2012) reported reductions in depression levels over the one-year follow-up among caregivers in the intervention group (problem-solving therapy) while depression levels in the control group remained high over time. These findings demonstrate that depression occurs early in the caregiving trajectory but can be treated while caregiving burden is relatively low and may support a healthy transition into the caregiving role.

Further, this review suggests that there are differences in the way men and women caregivers are affected by the experience of caregiving. Women reported more emotional distress related to depression, stress, and anxiety compared with men who provide care (Ducharme et al., 2011a; Garand et al., 2012; Välimäki et al., 2009). This has been reported in other studies of family caregiving for a person with some form of dementia (Lee and Tang, 2015; Gallicchio et al., 2002; Pinquart and Sörensen, 2006). What is interesting here is that the gender differences were seen so early in the caregiving role. Women are still more likely than men to take on the caregiving role and may also be juggling work, family responsibilities, and caregiving (Lee and Tang, 2015). Some men may find it difficult to adapt to the caring role and so may be reluctant to access services (Baker and Robertson, 2008; Baker et al., 2010). This difference highlights the importance of individualized assessments and intervention approaches early in the caregiving trajectory.

4.1. Strengths and limitations

We included both quantitative and qualitative studies that reported on family caregiver experiences, needs, and interventions during their transition into the caregiving role following a diagnosis of dementia. A strength of the current review is the breadth of studies included that described the experiences and needs of family caregiver around the time of diagnosis of dementia and interventions to support a healthy transition into the role.

There are limitations in the literature that was reviewed. Few studies included caregivers who belong to racial and ethnic

minority groups. Only two of the 29 studies were based on Asian ethnic communities (Israel in Karnieli-Miller et al., 2012; Taiwan in Kuo and Shyu, 2010). Given a paucity of studies that focused on the culturally different needs of caregivers of persons with dementia (Baker and Robertson, 2008; Baker et al., 2010), it is important to examine how cultural differences impact transitions into the caregiving role. This point could be crucial to tailored support for caregivers as different racial ethnic groups of caregivers may respond to offers of support in different ways or may need different kinds of support. Moreover, differing circumstances of caregivers, including kin relationship, may also affect their ability to care and their need for support. Furthermore, recall bias could be a possibility in some studies as data collection often took place several months after disclosure of the diagnosis. An additional limitation, inherent to scoping review methodology, is that quality assessment was not performed of the included studies.

4.2. Implications for practice and research

To successfully transition into this role, caregivers require information about the disease, its course, and relevant support resources for their loved one with dementia as well as for themselves in this new role. Despite the plethora of current models of support and interventions for caregivers, there is a need for specific interventions tailored to the unique experiences and needs of caregivers who recently learned of the dementia diagnosis.

The time of diagnosis represents complex emotional and psychological responses which may lead to challenges in accepting this new role. As highlighted in this review, while there are many studies that have identified caregiver experiences and needs following diagnosis, there are few studies that have been designed to test interventions at this critical period. Tailored strategies are thus required in order to respond to new caregiver's various needs in timely manner and to support caregiver adjustment to the new role. The field of family caregiving requires research that follows caregivers over longer periods of time post intervention so that we have better information about the long-term effects of intervening at the time of transition into the role and its impact on successful transition and mitigating long-term effects.

Conflicts of interest

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Ethical approval

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References

Adams, K.B., 2006. The transition to caregiving: the experience of family members embarking on the dementia caregiving career. J. Gerontol. Soc. Work 47 (3-4), 3–29. doi:http://dx.doi.org/10.1300/J083v47n03_02.

Alzheimer's Association, 2018. Alzheimer's disease facts and figures. Alzheimers Dement. 14 (3), 367–429.

Aneshensel, C., Pearlin, L., Mullan, J., Zarit, S., Whitlatch, C., 1995. Profiles in Caregiving: the Unexpected Career. Academic Press, San Diego.

Arksey, H., O'Malley, L., 2005. Scoping studies: towards a methodological framework. Int. J. Soc. Res. Methodol. 8 (1), 19–32. doi:http://dx.doi.org/10.1080/1364557032000119616.

Baker, K.L., Robertson, N., 2008. Coping with caring for someone with dementia: reviewing the literature about men. Aging Ment. Health 12 (4), 413–422. doi:http://dx.doi.org/10.1080/13607860802224250.

Baker, K.L., Robertson, N., Connelly, D., 2010. Men caring for wives or partners with dementia: masculinity, strain and gain. Aging Ment. Health 14 (3), 319–327. doi:http://dx.doi.org/10.1080/13607860903228788.

Blieszner, R., Roberto, K.A., 2010. Care partner responses to the onset of mild cognitive impairment. Gerontologist 50 (1), 11–22. doi:http://dx.doi.org/10.1093/geront/gnp068.

Bohner, K., 2017. Theory description, critical reflection, and theory evaluation of the transitions theory of Meleis et al. according to Chinn and Kramer (2011). Adv. Nurs. Sci. 40 (3), E1–E19. doi:http://dx.doi.org/10.1097/ANS.0000000000000152.

Boots, L.M., Wolfs, C.A., Verhey, F.R., Kempen, G.I., de Vugt, M.E., 2015. Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help. Int. Psychogeriatr. 27 (6), 927–936. doi:http://dx.doi.org/10.1017/S1041610214002804.

Bruce, J.M., McQuiggan, M., Williams, V., Westervelt, H., Tremont, G., 2008. Burden among spousal and child caregivers of patients with mild cognitive impairment. Dement. Geriatr. Cogn. Disord. 25 (4), 385–390. doi:http://dx.doi.org/10.1159/000122587.

Campbell, S., Manthorpe, J., Samsi, K., Abley, C., Robinson, L., Watts, S., Bond, J., Keady, J., 2016. Living with uncertainty: mapping the transition from pre-diagnosis to a diagnosis of dementia. J. Aging Stud. 37, 40–47. doi:http://dx.doi.org/10.1016/j.jaging.2016.03.001.

Carnelley, K.B., Pietromonaco, P.R., Jaffe, K., 1996. Attachment, caregiving, and relationship functioning in couples: effects of self and partner. Pers. 3 (3), 257–278. doi:http://dx.doi.org/10.1111/j.1475-6811.1996.tb00116.x.

Carpenter, B., Dave, J., 2004. Disclosing a dementia diagnosis: a review of opinion and practice, and a proposed research agenda. Gerontologist 44 (2), 149–158. doi:http://dx.doi.org/10.1093/geront/44.2.149.

Davis, K., Drey, N., Gould, D., 2009. What are scoping studies? A review of the nursing literature. Int. J. Nurs. Stud. 46 (10), 1386–1400. doi:http://dx.doi.org/10.1016/j.ijnurstu.2009.02.010.

Derksen, E., Vernooij-Dassen, M., Gillissen, F., Olde-Rikkert, M., Scheltens, P., 2005. The impact of diagnostic disclosure in dementia: a qualitative case analysis. Int. Psychogeriatr. 17 (2), 319–326. doi:http://dx.doi.org/10.1017/S1041610205001316.

Derksen, E., Vernooij-Dassen, M., Gillissen, F., Rikkert, M.O., Scheltens, P., 2006. Impact of diagnostic disclosure in dementia on patients and carers: Qualitative case series analysis. Aging Ment. Health 10 (5), 525–531. doi:http://dx.doi.org/10.1080/13607860600638024.

Derouesné, C., Thibault, S., Lozeron, P., Baudouin-Madec, V., Piquard, A., Lacomblez, L., 2002. Perturbations of activities of daily living in Alzheimer's disease: a study of 172 patients with the using a questionnaire completed by caregivers. Rev. Neurol. (Paris) 158 (6-7), 684–700.

Ducharme, F., Beaudet, L., Legault, A., Kergoat, M.J., Lévesque, L., Caron, C., 2009. Development of an intervention program for Alzheimer's family caregivers following diagnostic disclosure. Clin. Nurs. Res. 18 (1), 44–67. doi:http://dx.doi.org/10.1177/1054773808330093.

Ducharme, F., Lévesque Louise, L., Lachance, L., Kergoat, M.J., Coulombe, R., 2011a. Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: a descriptive study. Int. J. Nurs. Stud. 48 (9), 1109–1119. doi:http://dx.doi.org/10.1016/j.ijnurstu.2011.02.011.

Ducharme, F.C., Lévesque, L.L., Lachance, L.M., Kergoat, M.J., Legault, A.J., Beaudet, L.M., Zarit, S.H., 2011b. "Learning to become a family caregiver" efficacy of an intervention program for caregivers following diagnosis of dementia in a relative. Gerontologist 51 (4), 484–494. doi:http://dx.doi.org/10.1093/geront/gnr014.

Ducharme, F., Lachance, L., Levesque, L., Zarit, S.H., Kergoat, M.J., 2015. Maintaining the potential of a psycho-educational program: efficacy of a booster session after an intervention offered family caregivers at disclosure of a relative's dementia diagnosis. Aging Ment. Health 19 (3), 207–216. doi:http://dx.doi.org/10.1080/13607863.2014.922527.

Gallicchio, L., Siddiqi, N., Langenberg, P., Baumgarten, M., 2002. Gender differences in burden and depression among informal caregivers of demented elders in the community. Int. J. Geriatr. Psychiatry 17 (2), 154–163. doi:http://dx.doi.org/10.1002/gps.538.

Garand, L., Dew, M.A., Eazor, L.R., DeKosky, S.T., Reynolds III, C.F., 2005. Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. Int. J. Geriatr. Psychiatry 20 (6), 512–522. doi:http://dx.doi.org/10.1002/gps.1318.

Garand, L., Lingler, J.H., Deardorf, K.E., DeKosky, S.T., Schulz, R., 2012. Anticipatory grief in new family caregivers of persons with mild cognitive impairment and dementia. Alzheimer Dis. Assoc. Disord. 26 (2), 159–165. doi:http://dx.doi.org/10.1097/WAD.0b013e31822f9051.

Garand, L., Rinaldo, D.E., Alberth, M.M., Delany, J., Beasock, S.L., Lopez, O.L., Reynolds III, C.F., Dew, M.A., 2014. Effects of problem solving therapy on mental health outcomes in family caregivers of persons with a new diagnosis of mild cognitive impairment or early dementia: a randomized controlled trial. Am. J. Geriatr. Psychiatry 22 (8), 771–781. doi:http://dx.doi.org/10.1016/j.jagp.2013.07.007.

Gaugler, J.E., Wackerbarth, S.B., Mendiondo, M., Schmitt, F.A., Smith, C.D., 2003. The characteristics of dementia caregiving onset. Am. J. Alzheimers Dis. Other Demen. 18 (2), 97–104. doi:http://dx.doi.org/10.1177/153331750301800208.

Gitlin, J.E., Hodgson, N., 2015. Caregivers as therapeutic agents in dementia care: the context of caregiving and the evidence base for interventions. In: Gaugler, J.E., Kane, R.L. (Eds.), Family Caregiving in the New Normal.. Elsevier Academic Press, London, pp. 305–353.

Grant, M.J., Booth, A., 2009. A typology of reviews: an analysis of 14 review types and associated methodologies. Health Info. Libr. J. 26 (2), 91–108. doi:http://dx.doi.org/10.1111/j.1471-1842.2009.00848.x.

PRISMA Guideline, 2009. PRISMA 2009 Checklist. . http://www.prisma-statement.org/documents/PRISMA%202009%20checklist.pdf.
Innes, A., Szymczynska, P., Stark, C., 2014. Dementia diagnosis and post-diagnostic support in Scottish rural communities: experiences of people with dementia and their families. Dementia 13 (2), 233–247. doi:http://dx.doi.org/10.1177/1471301212460608.
Karnieli-Miller, O., Werner, P., Aharon-Peretz, J., Sinoff, G., Eidelman, S., 2012. Expectations, experiences, and tensions in the memory clinic: the process of diagnosis disclosure of dementia within a triad. Int. Psychogeriatr. 24 (11), 1756–1770. doi:http://dx.doi.org/10.1017/S1041610212000841.
Keady, J., Nolan, M., 2003. The dynamics of dementia: working together, working separately, or working alone? In: Nolan, M., Lundh, U., Grant, G., Keady, J. (Eds.), Partnerships in Family Care. Open University Press, Philadelphia, pp. 15–32.
Killen, A., Flynn, D., De Brún, A., O'Brien, N., O'Brien, J., Thomas, A.J., McKeith, I., Taylor, J.P., 2015. Support and information needs following a diagnosis of dementia with Lewy bodies. Int. Psychogeriatr. 28 (3), 495–501. doi:http://dx.doi.org/10.1017/S1041610215001362.
Kuo, L.M., Shyu, Y.I.L., 2010. Process of ambivalent normalisation: Experience of family caregivers of elders with mild cognitive impairment in Taiwan. J. Clin. Nurs. 19 (23-24), 3477–3484. doi:http://dx.doi.org/10.1111/j.1365-2702.2010.03240.x.
Laakkonen, M.L., Raivio, M.M., Eloniemi-Sulkava, U., Saarenheimo, M., Pietilä, M., Tilvis, R.S., Pitkälä, K.H., 2008. How do elderly spouse care givers of people with Alzheimer disease experience the disclosure of dementia diagnosis and subsequent care? J. Med. Ethics 34 (6), 427–430. doi:http://dx.doi.org/10.1136/jme.2007.021956.
Lee, Y., Tang, F., 2015. More caregiving, less working: caregiving roles and gender difference. J. Appl. Gerontol. 34 (4), 465–483 https://doi.org/10.1177%2F0733464813508649.
Lethin, C., Hallberg, I.R., Karlsson, S., Janlöv, A.C., 2016. Family caregivers experiences of formal care when caring for persons with dementia through the process of the disease. Scand. J. Caring Sci. 30 (3), 526–534. doi:http://dx.doi.org/10.1111/scs.12275.
Manthorpe, J., Samsi, K., Campbell, S., Abley, C., Keady, J., Bond, J., Watts, S., Robinson, L., Warner, J., Iliffe, S., 2013. From forgetfulness to dementia: clinical and commissioning implications of diagnostic experiences. Br. J. Gen. Pract. 63 (606), e69–e75. doi:http://dx.doi.org/10.3399/bjgp13X660805.
Meleis, A.I., Sawyer, L.M., Im, E.O., Hilfinger Messias, D.K., Schumacher, K., 2000. Experiencing transitions: an emerging middle-range theory. Adv. Nurs. Sci. 23 (1), 12–28. doi:http://dx.doi.org/10.1097/00012272-200009000-00006.
Milne, A., Guss, R., Russ, A., 2014. Psycho-educational support for relatives of people with a recent diagnosis of mild to moderate dementia: An evaluation of a 'Course for Carers'. Dementia 13 (6), 768–787. doi:http://dx.doi.org/10.1177/1471301213485233.
Mountain, G.A., Craig, C.L., 2012. What should be in a self-management programme for people with early dementia? Aging Ment. Health 16 (5), 576–583. doi:http://dx.doi.org/10.1080/13607863.2011.651430.
Nolan, M., Ryan, T., Enderby, P., Reid, D., 2002. Towards a more inclusive vision of dementia care practice and research. Dementia 1 (2), 193–211 https://doi.org/10.1177%2F147130120200100206.
Ouzzani, M., Hammady, H., Fedorowicz, Z., Elmagarmid, A., 2016. Rayyan-a web and mobile app for systematic reviews. Syst. Rev. 5, 210. doi:http://dx.doi.org/10.1186/s13643-016-0384-4.
Pesonen, H.M., Remes, A.M., Isola, A., 2013. Diagnosis of dementia as a turning point among Finnish families: a qualitative study. Nurs. Health Sci. 15 (4), 489–496. doi:http://dx.doi.org/10.1111/nhs.12059.
Pinquart, M., Sörensen, S., 2006. Gender differences in caregiver stressors, social resources, and health: an updated meta-analysis. J. Gerontol. B Psychol. Sci. Soc. Sci. 61, 33–45. doi:http://dx.doi.org/10.1093/geronb/61.1.P33.
Potter, W.J., Levine-Donnerstein, D., 1999. Rethinking validity and reliability in content analysis. J. Appl. Commun. Res. 27 (3), 258–284. doi:http://dx.doi.org/10.1080/00909889909365539.
Prince, M., Comas-Herrera, A., Knapp, M., Guerchet, M., Karagiannidou, M., 2016. World Alzheimer Report 2016: Improving Healthcare for People Living With Dementia. Alzheimer's Disease International, London.
Quinn, C., Clare, L., Pearce, A., Van Dijkhuizen, M., 2008. The experience of providing care in the early stages of dementia: an interpretative phenomenological analysis. Aging Ment. Health 12 (6), 769–778. doi:http://dx.doi.org/10.1080/13607860802380623.
Robinson, L., Gemski, A., Abley, C., Bond, J., Keady, J., Campbell, S., Samsi, K., Manthorpe, J., 2011. The transition to dementia-individual and family experiences of receiving a diagnosis: a review. Int. Psychogeriatr. 23 (7), 1026–1043. doi:http://dx.doi.org/10.1017/S1041610210002437.
Rumrill, P.D., Fitzgerald, S.M., Merchant, W.R., 2010. Using scoping literature reviews as a means of understanding and interpreting existing literature. Work 35 (3), 399–404. doi:http://dx.doi.org/10.3233/WOR-2010-0998.
Schulz, R., Martire, L.M., 2004. Family caregiving of persons with dementia: prevalence, health effects, and support strategies. Am. J. Geriatr. Psychiatry 12 (3), 240–249. doi:http://dx.doi.org/10.1097/00019442-200405000-00002.
The Scottish Government, 2017. Scotland's National Dementia Strategy: 2017-2020. . https://www.alzscot.org/assets/0002/6035/Third_Dementia_Strategy.pdf.
U.S. Census Bureau, 2005. 65+ in the United States: 2005. U.S. Government Printing Office, Washington, D.C.
Vaingankar, J.A., Subramaniam, M., Abdin, E., Picco, L., Phua, A., Chua, B.Y., Chong, S. A., 2013. Socio-demographic correlates of positive mental health and differences by depression and anxiety in an Asian community sample. Ann. Acad. Med. Singap. 42 (10), 514–523. http://www.annals.edu.sg/pdf/42Vol-No10Oct2013/MemberOnly/V42N10p514.pdf.
Välimäki, T.H., Vehviläinen-Julkunen, K.M., Pietilä, A.M.K., Pirttilä, T.A., 2009. Caregiver depression is associated with a low sense of coherence and health-related quality of life. Aging Ment. Health 13 (6), 799–807. doi:http://dx.doi.org/10.1080/13607860903046487.
Välimäki, T., Vehviläinen-Julkunen, K., Pietilä, A.M., Koivisto, A., 2012. Life orientation in Finnish family caregivers' of persons with Alzheimer's disease: a diary study. Nurs. Health Sci. 14 (4), 480–487. doi:http://dx.doi.org/10.1111/j.1442-2018.2012.00721.x.
Välimäki, T.H., Martikainen, J.A., Hongisto, K., Väätäinen, S., Sintonen, H., Koivisto, A. M., 2016. Impact of Alzheimer's disease on the family caregiver's long-term quality of life: results from an ALSOVA follow-up study. Qual. Life Res. 25 (3), 687–697. doi:http://dx.doi.org/10.1007/s11136-015-1100-x.
Waldorff, F.B., Buss, D.V., Eckermann, A., Rasmussen, M.L., Keiding, N., Rishoj, S., Siersma, V., Sorensen, J., Sorensen, L.V., Vogel, A., Waldemar, G., 2012. Efficacy of psychosocial intervention in patients with mild Alzheimer's disease: the multicentre, rater blinded, randomised Danish Alzheimer Intervention Study (DAISY). BMJ 345, e4693. doi:http://dx.doi.org/10.1136/bmj.e4693.
Ward-Smith, P., Forred, D., 2005. Participation in a dementia evaluation program: perceptions of family members. J. Neurosci. Nurs. 37 (2), 92–96.
Woods, R.T., Moniz-Cook, E., Iliffe, S., Campion, P., Vernooij-Dassen, M., Zanetti, O., Franco, M., 2003. Dementia: issues in early recognition and intervention in primary care. J. R. Soc. Med. 96 (7), 320–324 https://doi.org/10.1177%2F014107680309600703.
Yeandle, S., Bennett, C., Buckner, L., Fry, G., Price, C., 2007. Managing Caring and Employment. Carers UK, London.
Zarit, S.H., Femia, E.E., 2008. A future for family care and dementia intervention research: challenges and strategies. Aging Ment. Health 12 (1), 5–13. doi:http://dx.doi.org/10.1080/13607860701616317.