Self-Management Support and eHealth When Managing Changes in Behavior and Mood of a Relative With Dementia

An Asynchronous Online Focus Group Study of Family Caregivers' Needs

Judith G. Huis in het Veld, MSc; Renate Verkaik, PhD; Berno van Meijel, PhD; Paul-Jeroen Verkade, MSc; Wendy Werkman, MSc; Cees M.P.M. Hertogh, PhD; and Anneke L. Francke, PhD

ABSTRACT

The current article discusses how and by whom family caregivers want to be supported in self-management when managing changes in behavior and mood of relatives with dementia and whether family caregivers consider eHealth a useful tool for self-management support. Four asynchronous on-line focus groups were held with 32 family caregivers of individuals with dementia. Transcripts of the online focus groups were analyzed using qualitative thematic analysis. Family caregivers need support from professionals or peers in the form of (a) information about dementia and its symptoms, (b) tips and advice on managing changes in behavior and mood, (c) opportunities to discuss experiences and feelings, and (d) appreciation and acknowledgement of caregiving. The opinions of family caregivers about self-management support through eHealth were also reported. Findings suggest a personal approach is essential to self-management support for family caregivers managing changes in behavior and mood of relatives with dementia. In addition, self-management support can be provided to some extent through eHealth, but this medium cannot replace personal contacts entirely.
[Res Gerontol Nurs. 20xx; x(xx):xx-xx.]

 Self-management is a topical theme within health care. Health policies encourage individuals to manage their health themselves, and most individuals prefer to maintain control of their life and health care for as long as possible. A commonly used definition of *self-management* is "the individual's ability to manage the symptoms, treatment,

Ms. Huis in het Veld is PhD Candidate, and Dr. Francke is Professor, Department of Public and Occupational Health, Dr. van Meijel is Professor, Department of Psychiatry, and Dr. Hertogh is Professor, Department of General Practice and Elderly Care Medicine, Amsterdam Public Health Research Institute, VU University Medical Center, Amsterdam; Dr. Verkaik is Researcher and Dr. Francke is also Program Leader, Netherlands Institute for Health Services Research, Utrecht; Mr. Verkade is Researcher, The Geriant Foundation, Region North of Amsterdam; and Ms. Werkman is Researcher, Dutch Alzheimer's Society, Amersfoort, The Netherlands. Dr. van Meijel is also Associate Professor, Inholland University of Applied Sciences, Amsterdam, and Researcher, Parnassia Psychiatric Institute, The Hague, The Netherlands.

Address correspondence to Judith G. Huis in het Veld, MSc, PhD Candidate, Department of Public and Occupational Health, Amsterdam Public Health Research Institute, VU University Medical Center (Room G-423), Postbus 7057, 1007 MB Amsterdam, The Netherlands; e-mail: j.huisinhetveld@vumc.nl.

physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002, p. 178). Self-management includes the ability to choose the extent to which individuals and their families wish to stay in control of their lives and how available care is used (Bodenheimer, Lorig, Holman, & Grumbach, 2002; CBO, 2014).

The term "self-management" is often associated exclusively with activities performed by individuals themselves. However, particularly in individuals with dementia, family caregivers also have self-management tasks, as dementia is a progressive disorder accompanied by increasing dependence of the affected individual on the family caregiver. Corbin and Strauss (1985) distinguish three categories of self-management tasks: "illness work," in the sense of managing medical aspects; "everyday life work," which concerns behavior management; and "biographical work," which concerns managing the emotions that emerge from coping with a chronic disease. As the ability of the ill individual to self-manage decreases, the responsibility for the "work" shifts toward family members (Corbin & Strauss, 1985). In dementia, everyday life work and biographical work tend to be more important than illness work (Martin, Turner, Wallace, & Bradbury, 2013; Mountain, 2006).

Everyday life work requires that certain tasks be performed in a complex context (Corbin & Strauss, 1985). One of the biggest daily challenges for family caregivers constitutes managing changes in behavior and mood of their relative with dementia (Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). Common changes in behavior and mood include agitation, aggression, apathy, and depression (Lawlor & Bhriain, 2001). Changes in behavior and mood are often prompted by interactions between the individual with dementia and his/her family caregivers (Cohen-Mansfield, 2001; Kitwood, 1997), which makes managing these changes even more difficult. Family caregivers can use multiple strategies for managing changes in behavior and mood (de Vugt et al., 2004; Huis in het Veld et al., 2016; Moore, Ozanne, Ames, & Dow, 2013; Turner et al., 2015), such as calming and/or providing encouragement for their relative with dementia (Huis in het Veld et al., 2016). Calming the relative involves remaining tranquil, being patient, and adapting to the mood state of the relative with dementia. Providing encouragement encompasses telling positive stories, using humor, and encouraging activities and distractions (Huis in het Veld et al., 2016).

In addition to managing changes in behavior of their relative, family caregivers also have to self-manage their own stress or other emotions if they are to care for their relatives. Managing behavioral changes and their own stress may cause serious disruption to an individual's biography (Corbin & Strauss, 1985). Self-management strategies used by family caregivers for this purpose include looking for distractions, getting rest, and discussing their feelings and experiences with professionals or other family caregivers (Huis in het Veld et al., 2016).

Faced with these self-management tasks, family caregivers may need support. Previous studies have investigated the overall support needs of informal caregivers of individuals with dementia (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015; McCabe, You, & Tatangelo, 2016; Vaingankar et al., 2013; Zwaanswijk et al., 2013). The current article provides insight into the specific support needs of family caregivers regarding the management of changes in behavior and mood of their relative with dementia as well as the self-management of their own caregiver stress and other emotions. This insight is needed to provide customized self-management support, especially by nursing staff, who are often unaware of the support needs of family caregivers in this regard (Verkaik, van Antwerpen-Hoogenraad, de Veer, Francke, & Huis in het Veld, 2017).

The current article also considers whether eHealth might be a useful tool for self-management support. eHealth is on the rise and offers new opportunities for dementia care (Boots, de Vugt, van Knippenberg, Kempen, & Verhey, 2014; Powell, Chiu, & Eysenbach, 2008). Inspired by Eysenbach's (2001) well-known definition, the current article defines *eHealth* as the provision of dementia-related information and/or support with the aid of computers or related technologies. Several systematic reviews suggest that eHealth in the form of online information and support might be effective (e.g., in managing caregiver stress or other psychological problems) (Boots et al., 2014; Godwin, Mills, Anderson, & Kunik, 2013; McKechnie, Barker, & Stott, 2014; Powell et al., 2008; Wu, Faucounau, de Rotrou, Riguet, & Rigaud, 2009). On the other hand, family caregivers might prefer face-to-face support rather than support through eHealth when managing relatives' behavior or mood changes.

The following research questions are addressed:

- How and by whom do family caregivers want to be supported when managing changes in behavior and mood of their relatives with dementia?
- What do family caregivers think of the application of eHealth as a tool for self-management support for managing behavior changes in their relative with dementia?

TABLE 1

Questions[a] Addressed in Online Focus Groups

Have you received information or support, now or in the past, from health care professionals when coping with changes in the behavior and mood of your relative with dementia? What information or support helped you the most?
Do you feel a need for information or support from health care professionals when dealing with possible changes in the behavior and mood of the individual with dementia?
In addition to face-to-face contact, information and support are increasingly being provided via the internet, e-mail, or cell phone applications (apps). An example is e-mail contact with a case manager, nurse, or other health care professional. How can information and guidance via the internet or e-mail help you and your relative with dementia cope with possible changes in the behavior and mood of your relative with dementia?

[a] Translated from Dutch into English.

METHOD

The methods described herein have been reported in a companion study that used the same methodology (Huis in het Veld et al., 2016).

Design

Online discussions were organized for asynchronous focus groups comprising family caregivers of individuals with dementia. Online focus group discussions involve a secure website where group discussions can take place (Tates et al., 2009). The decision to organize the discussions online was motivated by the fact that this would enable contact with family caregivers who could not easily travel because of the commitment of caring for their relatives with dementia.

Sample and Recruitment

Participants were recruited from an existing nation-wide panel of family caregivers (access http://www.alzheimerpanel.nl). A random selection was made of 240 family caregivers from the 1,200 panel members. Selected family caregivers were sent an e-mail by the Alzheimer's Society, inviting them to take part in the online focus group if they met the specified criteria for inclusion. Inclusion criteria were: the family caregiver (a) is a relative of an individual with dementia who lives at home (not in an institution), (b) has contact (by phone or face-to-face) with the individual with dementia at least once per week, (c) has daily access to the internet during the online focus group period, and (d) is 18 or older.

A total of 37 family caregivers sent an e-mail stating that they met the criteria for inclusion and would like to take part in the focus group discussions. These family caregivers were sent an information letter by post with an informed consent form. In total, 36 family caregivers completed and returned the consent form. Of these individuals, 32 family caregivers participated in the discussions by posting comments on the website. These 32 individuals therefore constitute the study participants.

Asynchronous Online Focus Groups

The main themes addressed in the current article are:
- whether caregivers received information or support when managing changes in behavior and mood of the relative with dementia;
- the support needs of caregivers when managing changes in behavior and mood of the relative with dementia; and
- eHealth as a tool for self-management support.

Table 1 provides examples of questions that were addressed in the online focus groups and form the basis of the current article.

A total of four online focus groups were organized between October 2014 and March 2015. Each focus group had seven to 10 participants. Earlier studies have shown this to be an appropriate number of participants for online discussions (Zwaanswijk & van Dulmen, 2014). Participation was anonymous. The only individuals able to access the private website were those who had received a personal login code from the lead researcher (J.H.). Participants could log in 24 hours per day during a 2-week period. One researcher (J.H.) added a new question every second day, excluding weekends. Participants posted their reactions at times that were convenient for them and they could read contributions of others. Two authors (J.H., R.V.) moderated the discussion by adding questions and sending e-mail messages to participants who had not yet responded.

TABLE 2

Caregivers' Characteristics (*N* = 36)

Characteristic	Mean (*SD*)
Age (years)	61 (42 to 81)
	***n* (%)**
Sex	
Female	32 (89)
Male	4 (11)
Relationship with individual with dementia	
Child or child-in-law	19 (53)
Partner	17 (47)
First symptoms of dementia[a]	
2 to 5 years ago	10 (28)
6 to 10 years ago	8 (22)
11 to 15 years ago	4 (11)
Not reported	14 (39)
Type of dementia	
Dementia (no further description)	16 (44)
Alzheimer's disease	14 (39)
Alzheimer's disease with vascular components	3 (8)
Vascular dementia	1 (3)
Lewy body dementia	1 (3)
Frontotemporal dementia	1 (3)
Highest educational attainment	
Primary school	3 (8)
High school (preparatory to vocational education) and/or vocational training	7 (19)
High school (preparatory to university education)	6 (17)
Applied university or academic university	16 (44)
Missing	4 (11)

[a] According to the family caregiver.

Data Analysis

An iterative process was used for data collection and analysis, which was based on thematic analysis principles (Braun & Clarke, 2006). The analysis started with researchers reading and rereading the transcripts. Relevant excerpts in the transcripts were marked and coded with keywords. Initially, codes were chosen that were close to participants' wording. Related codes were then grouped as a means of identifying themes. In the next step, the relationships be-

tween themes were analyzed (Braun & Clarke, 2006). The MAXQDA-11 software package was used as an aid in the coding process. Analyses were independently performed by two researchers (J.H., R.V.) as a way of improving quality. These two researchers then discussed coding and interpretation of the codes until a consensus was reached. Each of the other authors (B.M., P.J.V., W.W., C.H., A.F.) also read and analyzed one transcript. In addition, they commented on the interim analyses of the online focus group discussions.

Ethical Procedures

The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center. This committee had no objections to the study. All participants received written information about the purpose and method of the online focus groups and signed an informed consent form prior to participation.

RESULTS
Participant Background Characteristics

A total of 36 family caregivers signed up for an online focus group. Of these, 32 family caregivers participated in an online focus group. Participants were partners, children, or children-in-law of an individual with dementia. When asked their relative's form of dementia, more participants mentioned Alzheimer's disease than any other form. Of participants who commented on when they saw the first symptoms, the majority reported 2 to 5 years ago (**Table 2**).

Support Needs

Participants were asked what type of support had helped them now or in the past, and what needs they would have in the future when managing changes in behavior and mood of their relatives with dementia. The elements of self-management support were categorized into: (a) information about dementia and its symptoms, (b) tips and advice on managing changes in behavior and mood, (c) discussing experiences and feelings, and (4) appreciation and acknowledgement of caregiving.

Information About Dementia and Its Symptoms. Information about changes in behavior and mood is important for family caregivers. Knowledge about how the body and mind start to "lose function" as a result of dementia offers an explanation for the occurrence of changes in behavior and mood. This background information helps prevent family caregivers from being taken by surprise by behavioral changes. As one participant commented, "I noticed that after reading about the behavior, I am less surprised

whenever my mother reacts 'strangely' from my point of view." Many family caregivers have read about changes in behavior and/or mood that can occur. Participants reported they attend meetings, such as those held in the Alzheimer Cafe. Case managers were also mentioned as a source of information.

However, information about changes in behavior and mood is not necessarily pleasant and useful for all family caregivers. Some family caregivers, in particular partners, indicated there can sometimes be too much information. This is overload, because not all information about changes in behavior and mood apply to the relative in question with dementia. This overload of information sometimes causes family caregivers to worry unnecessarily about things that end up not being relevant to their situation.

Tips and Advice. Participants reported that they have benefited, now and in the past, from tips and advice from other family caregivers or professionals about how to respond to changes in behavior and mood of their relative with dementia, but they continue to determine what works in each individual situation. Participants considered themselves experts by virtue of their experience. Tips given to family caregivers by professionals, for example, are often tips they had already figured out for themselves, such as avoiding getting into a discussion and staying calm. Despite this, tips from other family caregivers or professionals also serve as support because they provide confirmation of the family caregiver's own approach, successes, and failures. One participant noted:

> Most tips are recommendations that my mother and I had actually already discovered ourselves.… But there are also things that don't work at all…. Tips from other caregivers help, too, sometimes. At any rate, they're a kind of confirmation of your own approach and successes/failures.

Family caregivers receive the most tips from other family caregivers, friends who also have (or have had) a parent with dementia, and professionals (e.g., case managers). Aside from tips and advice from fellow family caregivers, some participants reported that they would also like to attend a course to learn skills that would help them manage their relatives' changes in behavior and mood.

Discussing Experiences and Feelings. Contact with fellow family caregivers is an important form of self-management support. Most participants reported that they like swapping experiences about changes in behavior and mood and how to manage them. Aside from tips and advice, this exchange allows them to let off steam and provides a sounding board. Family caregivers feel supported because they recognize the experiences of other family caregivers, which

confirm that they are not alone in their situation. As one participant stated, "I get a great deal of support from a very good friend, who I can always talk to. The contact with a fellow caregiver is also nice; we can swap experiences and give each other suggestions."

Sons and daughters reported that they share experiences with friends whose parents also have a form of dementia. Sons, daughters, and partners swap experiences with other family caregivers in the Alzheimer Cafe. Partners emphasize that managing changes in behavior and mood is different for them than for children of an individual with dementia. Children return to their own homes at the end of the day, escaping the situation for a while. Partners, on the other hand, live permanently with the individual with dementia in their home. However, one partner reported that it is difficult for children because aside from caring for their parents, they have to take care of their own family.

Appreciation and Acknowledgment. Changes in relatives' behavior and mood form a daily challenge for family caregivers. Participants reported that receiving appreciation and acknowledgment for the everyday care they provide is essential in enabling them to cope with this daily challenge. Changes in behavior and mood are difficult, complex, and different for individuals. Receiving appreciation and acknowledgement from family, friends, and professionals makes family caregivers feel as though they are sharing the care so they do not have to do everything themselves. Family caregivers who do not receive this appreciation and acknowledgement reported that they miss it. A number of participants reported that the circle of individuals who understand their situation keeps getting smaller. They perceived that others believe dementia is annoying. A number of family caregivers feel misunderstood or disbelieved. Family caregivers also feel misunderstood by professionals. An example of this misunderstanding is when a relative with dementia acts differently when others are around, as reported by a daughter in regard to her mother with dementia:

> Because my mother puts on a good show when others are around…they will never know what she is really like. Only the family doctor experienced this, one time. The others don't really believe us, which is what frustrates me the most. Feeling like people don't believe you…. So perhaps that's a job they [the professionals] could do: listening to family caregivers!"

Opinions About eHealth

The online focus groups discussed whether eHealth has a place in support for managing changes in relatives' behavior and mood. Participants were asked if they would

like to receive information and/or support via the internet, e-mail, or smartphone applications (apps). Opinions of family caregivers were categorized into four themes: (a) eHealth via the internet is a good medium for finding information, (b) contact with other family caregivers through eHealth is valuable, (c) a personal approach is essential, and (d) eHealth support is not possible for the relative with dementia.

eHealth via the Internet is a Good Medium for Finding Information. Participants viewed the internet as a good medium for searching and requesting general information about changes in behavior and mood. Family caregivers like accessing information on the internet, because it is available any time of the day. Participants mainly visit the Dutch Alzheimer's Society website if they want information about changes in behavior and mood. Although a large amount of information is available, a number of participants reported that much of the information is only about Alzheimer's disease and not other forms of dementia. Some participants also reported that they would like a website page with frequently asked questions where they could enter symptoms and search for relevant information, or obtain advice about what to do in a certain situation.

Contact With Other Family Caregivers Through eHealth is Valuable. A number of participants reported that they use the internet, e-mail, or smartphone to share their experiences and ask for support and help with changes in their relatives' behavior and mood. Participants who mentioned that they have contact with other family caregivers via the internet reported that this is valuable to them. Others who do not yet have contact with other family caregivers reported that sharing experiences and getting good tips could be valuable to them. This contact could be possible through a forum or with an app where family caregivers and professionals can talk to one another. Some participants reported that they use a website for sharing experiences with other family caregivers within their own circle, such as family or friends. A number of family caregivers also reported that they use the smartphone app Alzheimer's Assistant:

> I use the Alzheimer's Assistant almost every day, mostly to write my report of the day and share it with family who live further away and my three children. This way, they are aware of the day-to-day life of their father and brother-in-law...I also write about my own emotions so that there will be no "surprises" if there are big changes. They all enjoy it very much, and I feel like I'm not alone.

A Personal Approach is Essential. As mentioned above, participants reported that information via the internet, e-mail, or smartphone can be useful. They mentioned

general information about changes in behavior that is applicable to different phases of dementia. Participants reported that finding or getting information, advice, and tips about their personal situation is more difficult via eHealth. Support through eHealth is often seen as impersonal and distant. Family caregivers are afraid that they will miss the nuances and misinterpret things when communicating through eHealth. Not only are changes in behavior and mood different for every individual with dementia, family caregivers also handle them differently. Consequently, advice and tips aimed at a specific situation need a personal approach. Face-to-face contact with friends, family, or professionals is important, according to participants. Participants also emphasized that support through eHealth cannot replace face-to-face contact. Information and support through eHealth can be seen as an additional service, but should not replace direct contact, as one participant stated:

> For me the advantage of support via the internet, e-mail, or apps is that I can take the time for it when it's convenient for me. I see this support as support and not as a substitute. It is a supplement to my need for information and communication about this subject. It would be a drawback if this were to replace direct contact or conversations.

eHealth is Not Possible for the Relative With Dementia. Most participants reported that information and/or support through eHealth is not possible for individuals with dementia, as learning new things is difficult for these individuals. Using a cell phone or computer makes their relative with dementia nervous. Digital support is a step too far for individuals with dementia and is therefore not (or no longer) an option.

DISCUSSION AND IMPLICATIONS

Family caregivers perceived information about dementia, tips and advice, talking about experiences, and appreciation and acknowledgement of caregiving as important elements of self-management support when managing changes in behavior and mood of their relatives with dementia. Family caregivers reported that information about dementia and the illness course was vital in understanding the changes in their relatives' behavior and mood. Different types of information sources were mentioned, such as peers, nurses, and case managers. However, some family caregivers indicated that sometimes they were overloaded with information. Therefore, they had to select information that was relevant to their specific context. In addition, the information, tips, and advice that family caregivers received often simply confirmed what they already knew. Even so, they found support for their successes and failures in managing their relatives' changes in behavior and mood.

Participating family caregivers often searched for information on the internet, and some used online forums to meet peers. They found eHealth via the internet to be a good medium for looking for information, sharing experiences, and asking for help. Family caregivers mentioned the ability to look up information at any time as one advantage of the internet.

Furthermore, family caregivers needed to talk about experiences. They mentioned the difficulty of accepting that their loved one was changed. Learning to manage emotional impacts and changing circumstances is part of the biographical work required to manage the illness (Lorig & Holman, 2003). Sharing experiences and letting off steam with other family caregivers or professionals gives family caregivers a feeling that they are not alone. Individuals who do not have this kind of support revealed that this is a great lack in their lives. Some family caregivers reported that they lost contact with friends and family due to misunderstandings.

Acknowledgement by peers and health care professionals is also an important aspect of self-management support. Being acknowledged as a caring family member and an expert in the care of his/her loved one is often of great importance to the family caregiver. eHealth might be helpful in providing this kind of support. However, participants in the current study indicated that in many cases eHealth is not geared to their personal situation. Family caregivers note that changes in mood and behavior are different for each individual with dementia and family caregivers also differ in their approach.

PRACTICAL RECOMMENDATIONS

The current study suggests that eHealth can be a valuable addition to but cannot entirely replace personal contact with professionals. Moreover, participating family caregivers considered eHealth inappropriate for use by their relatives with dementia. Nevertheless, a recent systematic review (D'Onofrio et al., 2017) established that in the early stages of dementia, technologies could support individuals with dementia.

In addition, the current study shows that it is crucial that family caregivers receive appreciation and acknowledgement for what they do, and that they can swap experiences, for instance with nurses or other professionals. In another study, it was found that nurses are not always aware that family caregivers need support (Verkaik et al., 2017). Because even subtle behavioral changes can lead to distress, anxiety, and loneliness (Pozzebon, Douglas, & Ames, 2016), it is essential that family caregivers be ac-

knowledged and supported by health care professionals. Therefore, an awareness that support and acknowledgment of family caregivers is important should be promoted (e.g., in training programs and campaigns).

It is also important that nurses, case managers, and other professionals tailor their support to the needs of individual family caregivers. Professionals can take these needs into account by explicitly inquiring about them. In doing so, it is essential that they acknowledge family caregivers and show appreciation of their work in the tough task of providing care.

In the further development of self-management support, how to customize support in a way that will empower family caregivers in managing mood and behavioral changes must be considered. An example of such support could be online information and tips combined with online personalized support from a health care professional. However, support via eHealth will not be able to replace face-to-face contact with professionals (e.g., case managers, nurses, family physician).

STRENGTHS AND LIMITATIONS

Online focus groups seemed to be a good way of discussing issues with often busy and burdened family caregivers, as there was no travel time involved in participating in the study. Another advantage of this method was that family caregivers did not have to arrange for someone to take over the care tasks, as they were able to take part in the online focus group in their own home at a time that was convenient for them (Zwaanswijk & van Dulmen, 2014).

In some previous online focus group studies, it appeared to be difficult to stimulate a lively discussion (de Lange et al., 2018; Tates et al., 2009; Zwaanswijk & van Dulmen, 2014); however, this was not the case in the current study. Family caregivers reacted to the questions of the moderators but also commented on the posts of other participants. This interaction could be related to the perceived relevance of the topics addressed: changes in behavior and mood in individuals with dementia are common and these changes often impact the daily life of caregivers (Zwaanswijk et al., 2013).

The online focus group study had a number of limitations. First, family caregivers with a high level of education were overrepresented, and self-management support needs might be different for individuals with less education (Black et al., 2013). A second limitation is that the participating family caregivers were all members of a family caregiver panel run by the Dutch Alzheimer's Society. This group may be more informed on developments in self-

management support interventions and eHealth and have more computer skills than the average family caregiver. Therefore, the current study results cannot be assumed to apply to the entire population of family caregivers of individuals with dementia. However, future generations of family caregivers can be expected to have better internet access (and skills) and will therefore be able to make more use of the possibilities that eHealth offers.

CONCLUSION

Support for family caregivers in their self-management of changes in behavior and mood of their relatives with dementia can take different forms: information, tips and advice, opportunities for discussing experiences and feelings, and appreciation and acknowledgement. Self-management support for family caregivers can be provided to some extent through eHealth, but this cannot replace personal contact entirely. Support must always be geared to the personal situation.

REFERENCES

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: A review. *Patient Education and Counseling, 48,* 177-187.

Black, B.S., Johnston, D., Rabins, P.V., Morrison, A., Lyketsos, C., & Samus, Q.M. (2013). Unmet needs of community-residing persons with dementia and their informal caregivers: Findings from the maximizing independence at home study. *Journal of the American Geriatrics Society, 61,* 2087-2095.

Bodenheimer, T., Lorig, K., Holman, H., & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA, 288,* 2469-2475.

Boots, L.M., de Vugt, M.E., van Knippenberg, R.J., Kempen, G.I., & Verhey, F.R. (2014). A systematic review of internet-based supportive interventions for caregivers of patients with dementia. *International Journal of Geriatric Psychiatry, 29,* 331-344. doi:10.1002/gps.4016

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. *International Psychogeriatrics, 27,* 927-936. doi:10.1017/s1041610214002804

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3,* 77-101.

CBO. (2014). *Care module self-management 1.0. Supporting self-management in people with one or more chronic diseases* [article in Dutch]. Retrieved from http://www.kennispleinchronischezorg.nl/docs/KCZ/Zorgmodule_Zelfmanagement_1.0.pdf

Cohen-Mansfield, J. (2001). Nonpharmacologic interventions for inappropriate behaviors in dementia: A review, summary, and critique. *American Journal of Geriatric Psychiatry, 9,* 361-381.

Corbin, J., & Strauss, A. (1985). *Managing chronic illness at home: Three lines of work.* Retrieved from http://www.uio.no/studier/emner/matnat/ifi/INF5200/v13/undervisningsmateriale/corbin-strauss.pdf

de Lange, J., Deusing, E., van Asch, I.F., Peeters, J., Zwaanswijk, M.,

Pot, A.M., & Francke, A.L. (2018). Factors facilitating dementia case management: Results of online focus groups. *Dementia (London), 17,* 110-125. doi:10.1177/1471301216634959

de Vugt, M.E., Stevens, F., Aalten, P., Lousberg, R., Jaspers, N., Winkens, I.,...Verhey, F.R. (2004). Do caregiver management strategies influence patient behaviour in dementia? *International Journal of Geriatric Psychiatry, 19,* 85-92. doi:10.1002/gps.1044

D'Onofrio, G., Sancarlo, D., Ricciardi, F., Panza, F., Seripa, D., Cavallo, F.,...Greco, A. (2017). Information and communication technologies for the activities of daily living in older patients with dementia: A systematic review. *Journal of Alzheimer's Disease, 57,* 927-935. doi:10.3233/jad-161145

Eysenbach, G. (2001). What is e-health? *Journal of Medical Internet Research, 3*(2), E20.

Godwin, K.M., Mills, W.L., Anderson, J.A., & Kunik, M.E. (2013). Technology-driven interventions for caregivers of persons with dementia: A systematic review. *American Journal of Alzheimer's Disease and Other Dementias, 28,* 216-222. doi:10.1177/1533317513481091

Huis in het Veld, J., Verkaik, R., van Meijel, B., Verkade, P.J., Werkman, W., Hertogh, C., & Francke, A. (2016). Self-management by family caregivers to manage changes in the behavior and mood of their relative with dementia: An online focus group study. *BMC Geriatrics, 16,* 95. doi:10.1186/s12877-016-0268-4

Kitwood, T. (1997). *Dementia reconsidered: The person comes first.* Buckingham, UK: Open University Press.

Lawlor, B., & Bhriain, S.N. (2001). Psychosis and behavioural symptoms of dementia: Defining the role of neuroleptic interventions. *International Journal of Geriatric Psychiatry, 16*(Suppl. 1), S2-S6.

Lorig, K.R., & Holman, H. (2003). Self-management education: History, definition, outcomes, and mechanisms. *Annals of Behavioral Medicine, 26,* 1-7.

Martin, F., Turner, A., Wallace, L.M., & Bradbury, N. (2013). Conceptualisation of self-management intervention for people with early stage dementia. *European Journal of Ageing, 10,* 75-87. doi:10.1007/s10433-012-0253-5

McCabe, M., You, E., & Tatangelo, G. (2016). Hearing their voice: A systematic review of dementia family caregivers' needs. *The Gerontologist, 56,* e70-e88. doi:10.1093/geront/gnw078

McKechnie, V., Barker, C., & Stott, J. (2014). Effectiveness of computer-mediated interventions for informal carers of people with dementia: A systematic review. *International Psychogeriatrics, 26,* 1619-1637. doi:10.1017/s1041610214001045

Moore, K., Ozanne, E., Ames, D., & Dow, B. (2013). How do family carers respond to behavioral and psychological symptoms of dementia? *International Psychogeriatrics, 25,* 743-753. doi:10.1017/s1041610213000070

Mountain, G.A. (2006). Self-management for people with early dementia: An exploration of concepts and supporting evidence. *Dementia, 5,* 429-447.

Powell, J., Chiu, T., & Eysenbach, G. (2008). A systematic review of networked technologies supporting carers of people with dementia. *Journal of Telemedicine and Telecare, 14,* 154-156. doi:10.1258/jtt.2008.003018

Pozzebon, M., Douglas, J., & Ames, D. (2016). Spouses' experience of living with a partner diagnosed with a dementia: A synthesis of the qualitative research. *International Psychogeriatrics, 28,* 537-556. doi:10.1017/s1041610215002239

Tates, K., Zwaanswijk, M., Otten, R., van Dulmen, S., Hoogerbrugge, P.M., Kamps, W.A., & Bensing, J.M. (2009). Online focus groups as a tool to collect data in hard-to-include populations: Examples

from paediatric oncology. *BMC Medical Research Methodology, 9,* 15. doi:10.1186/1471-2288-9-15

Turner, R.M., Hinton, L., Gallagher-Thompson, D., Tzuang, M., Tran, C., & Valle, R. (2015). Using an Emic lens to understand how Latino families cope with dementia behavioral problems. *American Journal of Alzheimer's Disease and Other Dementias, 30,* 454-462. doi:10.1177/1533317514566115

Vaingankar, J.A., Subramaniam, M., Picco, L., Eng, G. K., Shafie, S., Sambasivam, R.,…Chong, S.A. (2013). Perceived unmet needs of informal caregivers of people with dementia in Singapore. *International Psychogeriatrics, 25,* 1605-1619. doi:10.1017/s1041610213001051

Verkaik, R., van Antwerpen-Hoogenraad, P., de Veer, A., Francke, A., & Huis in het Veld, J. (2017). Self-management support in dementia care: A mixed methods study among nursing staff. *Dementia (London), 16,* 1032-1044. doi:10.1177/1471301216632416

Wu, Y.H., Faucounau, V., de Rotrou, J., Riguet, M., & Rigaud, A.S. (2009). Information and communication technology interventions supporting carers of people with Alzheimer's disease: A literature review [article in French]. *Psychologie & Neuropsychiatrie du Vieillissement, 7,* 185-192. doi:10.1684/pnv.2009.0175

Zwaanswijk, M., Peeters, J.M., van Beek, A.P., Meerveld, J.H., & Francke, A.L. (2013). Informal caregivers of people with dementia: Problems, needs and support in the initial stage and in subsequent stages of dementia: A questionnaire survey. *Open Nursing Journal, 7,* 6-13. doi:10.2174/1874434601307010006

Zwaanswijk, M., & van Dulmen, S. (2014). Advantages of asynchronous online focus groups and face-to-face focus groups as perceived by child, adolescent and adult participants: A survey study. *BMC Research Notes, 7,* 756. doi:10.1186/1756-0500-7-756