

# ALWAYS LOOK ON THE BRIGHT SIDE

Positive aspects of living with dementia: an exploratory qualitative  
multiple-case study

Name / executive researcher	Ms. Eline Dusee (ED), registered nurse (RN)
Student number	3784452
Status	Final version
Date	July 1 <sup>th</sup> 2016
University	University of Utrecht, master student Clinical Health Sciences, program Nursing Science, UMC Utrecht
Supervision	Dr. Carolien Smits, dr. Harmieke van Os-Medendorp
Second encoder	Janine Roenhorst (JR)
Institution of internship	Windesheim University of Applied Sciences, Zwolle, the Netherlands.
Research group:	Innovating in older adults
Contemplated magazine	International Psychogeriatrics (impact factor 1.934)
Requirements contemplated magazine	Harvard referencing system, no fixed word limit for articles, abstract 250 words
Words	3768
Criterion for transparent reporting	COREQ
Words Dutch abstract	294
Words English abstract	300

## NEDERLANDSE SAMENVATTING

**Achtergrond:** Dementie is een gevreesde ziekte onder de ouder wordende mens. Dit wordt mede veroorzaakt door media en onderzoek die doorgaans een negatief beeld schetsen van de ziekte. Er is noodzaak om ook de mogelijke positieve kanten van dementie te belichten met als doel het reduceren van het bestaande stigma en een bijdrage te leveren aan een dementievriendelijke samenleving.

**Doel:** Exploreren van de positieve aspecten in het leven met dementie vanuit de perspectieven van personen met dementie, hun informele mantelzorger en professional.

**Methode:** Een verkennende meervoudige case studie bestaande uit vier casussen. Elke casus bestond uit een persoon gediagnosticeerd met dementie, zijn informele mantelzorger en professional. Data collectie bestond uit semigestructureerde interviews en cultural probes techniek. Cultural probe omvatte het maken van foto's van positieve momenten door de informele mantelzorger. Een within-case analyse van resulterende transcripten werd uitgevoerd, gevolgd door een cross-case analyse. De studie werd uitgevoerd tussen februari en mei 2016.

**Resultaten:** Drie thema's die verband houden met positieve aspecten werden geïdentificeerd: (1) Het zijn de kleine dingen die er toe doen, (2) omringd worden door geliefden en (3) het leven is wat je er zelf van maakt.

**Conclusie en implicaties van belangrijkste bevindingen:** Hoewel informele mantelzorgers de minste positieve aspecten blijken te ervaren, laat deze studie zien dat het leven met dementie niet enkel gekenmerkt wordt door een scala aan belemmeringen. De bevindingen uit deze studie kunnen bijdragen aan de verwezenlijking van een meer positieve houding ten aanzien van dementie. Het wordt aanbevolen om de inzichten uit deze studie te gebruiken in educatieve interventies en columns in krant of online, zodat het negatieve imago kan worden gereduceerd en verdere ontwikkeling van een dementie-vriendelijke samenleving wordt ondersteund.

Trefwoorden: dementia [MeSH], positive aspects, person [MeSH] with dementia, caregiver [MeSH], professional, multiple casestudy

## SUMMARY

**Background:** Dementia is a disease that is feared amongst older people. A lot of this fear is due to research and media creating a stigma by often only discussing the negative aspects of the disease. In order to reduce this stigma and to contribute to a dementia-friendly society, there is a need to extend dementia research to examine positive aspects of the disease.

**Aim:** To explore any positive aspects of living with dementia, from the perspectives of persons diagnosed with dementia, their informal caregivers and professionals.

**Methods:** This research was conducted using an exploratory multiple-case design, involving four cases. Each case consisted of a person diagnosed with dementia, his or her informal caregiver and professional. Data collection consisted of semi-structured interviews and cultural probes methods. During cultural probe, the informal caregiver was asked to make photos of positive moments. A within-case analysis of resulting transcripts was performed followed by a cross-case analysis. The study was conducted between February and May 2016.

**Results:** Three themes regarding the positive aspects of dementia were identified: (1) It's the little things that matter, (2) being surrounded by loved ones, and (3) life is what you make of it.

**Conclusion and implications of key findings:** Although informal caregivers seem to experience the least positive aspects, this study shows that living with dementia is not only characterized by a range of difficulties. Findings from this study may contribute to people having a more positive attitude towards dementia. It is recommended to use the insights from this study in educational interventions and articles for newspapers or on the web, in order to reduce the negative image of dementia that people have and to further support the development of a dementia-friendly society.

Keywords: dementia [MeSH], positive aspects, person [MeSH] with dementia, caregiver [MeSH], professional, multiple case study

## INTRODUCTION

Dementia is one of the most feared diseases amongst older people (1-3), of which Alzheimer's disease is both the most well-known and most prevalent variant of dementia. General characterizations of dementia are amnesia, loss of intellectual capacity, personality changes and an inability to accomplish daily activities (4). Unfortunately, dementia still cannot be cured (5,6). It is estimated that between 5.5 and 6.1 million Europeans suffer from dementia (7). As a result of an increasingly aging population, it is predicted that the prevalence of dementia will grow to a worldwide figure of 74.7 billion by 2030 (8).

Over recent decades, a lot of research has been done on the impact of dementia on someone's life. This research has often focussed on negative aspects, like losing social networks as a result of the disease (5,9-15). In addition, research indicates that media tends to increase the stigmatization of the term dementia (16,17) as it is one of the most feared illnesses in western countries (11). Stigma has been defined as a comprehensive individual experience in which social environment and revelations of disease is related to affect self-esteem and personal identity (18). The consequences of the stigma in dementia may result in pessimistic attitudes among professionals (19). Moreover, it can affect a person with dementia and his or her informal caregiver (18), resulting in reduced perceived quality of life (6). Joy Watson wrote a personal narrative about her experience of living with Alzheimer's disease for the past two years (20). She found that people often have misperceptions about people with dementia, believing that they are old people in wheelchairs who are not able to converse (20). The quality of the latter source may be less reliable as it is single personal story. Research has also revealed that persons diagnosed with dementia fear that others relate the term 'dementia' with being 'mindless' or 'demented' (9).

The focus on the negative changes in someone's life when dementia is diagnosed, and the negative image that characterizes dementia, ignores the positive aspects that a person with dementia, and his or her informal caregiver or professional may experience (21). Currently, there are only relatively small amounts of literature that examine the positive aspects of diseases, however, this research is slowly expanding, particularly in regards to caregiving studies (22). In this area, positive aspects experienced by caregivers have been operationally defined as satisfaction, uplifts, rewards, gratifications, growth and meaning, enjoyment, and benefits (23). In the context of this study, an informal caregiver is a family member who is involved and supervises the daily care of a person with dementia. A professional is a healthcare worker who provides care to a person with dementia, in order to,

for example, accomplish activities of daily living. Lloyd (2014) and Cheng (2015) both performed a review of the positive aspects of caregiving in dementia. It is striking that both authors found similar positive aspects, such as feelings of satisfaction, relationship gains like emotional intimacy, expressed pride to be able to care for a partner, and positivity and humour being cultivated (22,24). Similar positive aspects of caregiving were found in a systematic review of caregivers of cancer patients (25). In this study, Li and Loke (2013) revealed that although caregiving has been described as burdensome, marital caregivers also cited experiencing various positive aspects of caregiving, such as feelings of being rewarded (25). Although the authors found almost exactly the same positive aspects, a side note has to be made. Because the authors of the latter review did not appraise the quality of the articles included in their study, this may have limited the quality of their review. A recent systematic review published by Wolverson et al (2016) examined positive experiences people have when living with dementia (26). They found activities, such as walking and housework, were seen as worthwhile efforts (26). However, their research was limited to only one perspective; people with dementia (26), and their research did not discuss caregivers or professionals experiences.

Although the negative aspects of dementia should not be ignored (27), there is a need to recognize the positives sides of the disease, in order to reduce stigma around dementia (27-29). The Dutch Secretary of Health, Martin van Rijn, has promoted a society in which people dare to talk openly about dementia, a so-called “dementia friendly” society (30). By achieving a balanced image of the realities of dementia, the quality of life for individuals with dementia, as well as the quality of life for their partner, may be enhanced (6). In her personal narrative, Joy Watson stated that humour and having fun is a very important coping strategy when living with dementia (20). Moreover, gaining an understanding of the facets that allow individuals living with dementia to have a more positive experience could contribute to the development of interventions that support persons with dementia, informal caregivers and professional caregivers with the disease (6). By integrating these positive aspects with their daily professional caregiving, nurses may be able to enhance the quality of life of their care-receivers (6).

## PROBLEM STATEMENT AND AIM OF RESEARCH

Dementia is currently hindered by the singular negative image. Very little research has been done about how, and to what extent, persons with dementia and their informal caregivers and professionals experience the positive sides of the disease. Therefore, the aim of this research is to explore the presence of any positive aspects of living with dementia, using the

perspectives of individuals with dementia, informal caregivers, and professionals. The findings of this research may help to reduce negative views of dementia and could support investments in the creation of a dementia-friendly society. By showing the bright sides of living with dementia, people may adopt a more positive attitude towards the disease. The results could also be used in educational interventions for people with dementia and their caregivers and professionals.

## METHOD

### Study design

This study followed an exploratory multiple-case multisite design (31). A multiple-case design was an appropriate design to gain in-depth insight into the positive aspects of dementia that individuals with dementia and their informal caregivers and professionals experience, within a real-life, contemporary context (31). The study was conducted between February and May 2016 in the southern part of the Netherlands.

### Population and domain

The study sample consisted of four cases in which each case involved a person with dementia, his or her informal caregiver and professional. Cases were selected following purposeful maximum sampling (32), in order to gain different perspectives on the positive aspects of dementia, and to best be able to generalize the findings (32). Cases were recruited in the southern part of the Netherlands through a general practice (GP) and an organization for social work. Two cases were selected prior to study onset and remaining cases were selected after completing these first two cases. The variables used when selecting participants were different ages, genders, marital statuses, housing and the time that had passed since dementia was first diagnosed. This allowed the study to maximise its variation in regards to the positive aspects of dementia that were discussed.

In order to be eligible to participate, a *person with dementia* had to meet the following criteria: (1) Dutch speaking, (2) diagnosed with dementia and able to conduct a conversation, (3) receiving assistance, provided by a professional caregiver, in one or more activities of daily living (ADLs) or instrumental activities of daily living (IADLs), (4) the capacity to provide informed and voluntary consent. Criteria for an *informal caregiver* were: (1) Dutch speaking and (2) being a family member of the person with dementia. A *professional* had to be (1) registered nurse or nurse assistant, (2) Dutch speaking and (3) providing care for the person with dementia within the case for at least 6 months.

## **Data collection**

Semi-structured interviews were performed with the addition of a cultural probes technique. Cultural probing is a data collection method in which a participant is asked to perform tasks with the intention to arouse them to look at and think about their environment (33). In the context of this study, the cultural probe consisted of asking informal caregivers to take photos of positive moments. These photos were discussed in interviews with the informal caregivers. In order to increase the validity of the study, the topics of the interview guide were derived from the concepts of positive aspects of caregiving in dementia that were defined by Kramer (1997) and Lloyd (2014): satisfaction, uplifts, rewards, gratifications, growth and meaning, enjoyment and benefits (22,23). The interview guide is presented in appendix A.

In each interview demographic information was gathered in order to gain insights into gender, marital status, age, type of informal caregiver (e.g. spouse or daughter), years of involvement as professional, the time since dementia was diagnosed and how the person with dementia experienced the diagnosis. All of the interviews were audio recorded on a smartphone, and field notes were made. Each interview lasted 20 to 60 minutes and took place at participants' homes or workplaces. In total, 12 interviews were performed, of which one case involved two informal caregivers, as the person with dementia was no longer able to take part in an in-depth conversation because of deterioration. The study started with a pilot interview, which helped to refine data collection.

## **Data analysis**

The data analysis was based on principles described by Creswell (2013) and Yin (2014) (31,32). Audio tapes of the participants' interviews were transcribed verbatim and data was organized and managed using NVivo 11 software. The first step in the analysis was to describe participants in terms of their demographic information. Next step was performing a within-case analysis, which consisted of the creation of themes within each case. This meant that the data of each interview was coded, categorized and reconstructed in a way that captured the important concepts of positive aspects of dementia. The within-case analysis was done by analysing photos taken by informal caregivers. In order to establish an initial set of codes, encoding of the first three interviews was performed separately by two data coders (ED and JR). Subsequently, a cross-case analysis was conducted across the cases. The cross-case analysis started with the creation of word tables that displays the themes from each case. These themes were then examined in order to distinguish themes that were common and different between all of the cases (31).

## **Ethical issues**

Ethical approval (no. 16.0120) was obtained from the Medical Research Ethics Committee (MREC) at Isala in Zwolle. Informed consent was given by all participants. For interviews with persons with dementia, both the authorisation of the informal caregiver and assent of the person with dementia were sought. In order to assure the anonymity of the participants, pseudonyms were used in the presentation of results.

## **RESULTS**

The participants included three female persons with dementia, three male spouses, two adult daughters and four female professionals. Participants with dementia ranged from 70 to 87 years old and informal caregivers' ages varied from 52 to 83 years old. Professionals' ages ranged from 41 to 46 years old. Further characteristics of participants are shown in Table 1. In total, 15 photos were taken by the informal caregivers a task which they thought was enjoyable. However, they sometimes found it difficult to handle the camera in a right way. Participants spoke openly about their experiences and the positive aspects of life with dementia, which resulted in a comprehensive description of the diverse essential elements. All cases pronounced positive aspects, but in general informal caregivers quickly felt back on the negative experiences in life. Due to a limited sample size, data saturation was not reached. Findings were discussed based on the following themes: (1) *It's the little things that matter*, (2) *being surrounded by loved ones*, and (3) *life is what you make of it*. Table 2 presents the illustrative quotes on the emerged themes.

(Place here: Table 1 Demographic information of participants)

### *It's the little things that matter*

As dementia progresses, gratification and enjoyment are found more and more in smaller, less intensive activities in life such as going out for coffee. Where a holiday was once a way to enjoy life, respondents now perceived a walk through the park as a worthwhile getaway. The photos of positive moments taken by the informal caregivers showed similar activities, such as sitting in the sun or proudly presenting a drawing made by a grandchild. Additionally, two participants who lived at home specifically mentioned how they tried to enjoy their life more consciously nowadays, attempting to continue the activities that they could still carry out.



Informal caregivers noticed that they appreciated seeing their spouse enjoying an activity, such as seeing a visiting family member, without being involved in it themselves. This was also seen in the photographs, where informal caregivers mostly were not present in the picture. Persons with dementia expressed enjoyment in activities with others. However, informal caregivers who had full-time care for the person with dementia mentioned that they found gratification during activities without the presence of their spouse, like going out to play golf or ping-pong.

Discussing old memories, for example the birth of children or grandchildren, turned out to be a positive aspect. It was also a way to involve a person with dementia in conversations, because talking about actualities often does not make sense anymore. By talking about issues they still remembered, individuals with dementia felt a sense of pride, as they could still participate. It also gave them a reason to laugh.

#### *Being surrounded by loved ones*

Participants mentioned that they appreciated having family members visit and visiting relatives at their places. Especially the visit of children and grandchildren was appointed by all cases as something valuable. Some informal caregivers and individuals with dementia mentioned that relatives showed more interest in them nowadays, simply by asking how they were doing. They also felt that some children were visiting them more often than before. Being surrounded by relatives and friends was something that was considered of great value.

Spousal informal caregivers particularly noticed that a positive element in their life was being together with the person with dementia. Three cases mentioned that they had a sense of pride that they could still live together at home and that they could take care of each other. Few couples also expressed that they have come closer together as spouses. One person with dementia, who lives in a residential facility, mentioned that meeting new people at the nursing home was something really positive. This was confirmed by their informal caregiver, who took photos of her mother together with her new friend.

Having a supportive environment also encouraged feelings of positivity, because in former times spouses were always there for their children and other relatives, and now they receive support from them in return. This manifests itself in small things, like a daughter buying groceries or taking the person with dementia out, so that the informal caregiver can do something for himself. Participants mentioned feeling more appreciative of their loved ones than before, because of the situation.

*Life is what you make of it*

Especially persons with dementia mentioned that having Alzheimer's disease is something that you cannot control, and therefore you need to make the best of it. All of the people with dementia who were interviewed experienced a low burden of disease, which gave the informal caregiver a sense of pride that their spouse still had a positive view on life. Professionals within two cases complemented this by expressing that there is substantial awareness of the disease amongst people with dementia, but not that much understanding of the disease. Speaking openly about dementia was a skill that informal caregivers learned during a caregiving course. This had positive aspects to it, as it allowed the taboo of speaking about dementia to be more easily broken. They also perceived that it felt like a liberation to be able to talk about dementia openly.

The use of humour was mentioned by almost every participant as an important tool to break the ice and put the situation in perspective. Making jokes was also mentioned by the participants as a way to laugh and to enjoy the moment. Use of humour by professional caregivers during activities of daily caregiving was also very appreciated by both the person with dementia and their informal caregiver. Some participants spoke about the use of self-deprecation in order to make the situation less fraught.

[\(Place here: Table 2 Illustrative quotes of emerged themes on positive aspects of living with dementia\)](#)

## **DISCUSSION**

The aim of this study was to explore positive aspects of living with dementia throughout three perspectives. Individuals with dementia, their informal caregivers and professionals experienced several positive elements in life and these elements can be divided into three main themes. Positive facets in life were found mainly in the little things in life, such as going out for coffee. Being surrounded by loved ones contributed to feelings of gratification. Participants explained how they tried to make the best of the situation, by looking at the bright sides of life, and by speaking openly about dementia and using humour to make the situation less fraught.

According to the description of 'It's the little things that matter', corroborating findings were found by the study of Moot (2010) (35). Moot (2010) studied how older people without

dementia gave meaning to their lives, and found that older persons tried to maintain activities by adapting them to their limitations. This resulted in less intensive activities and enjoyment with more awareness (34). This is also consistent with the Baars (2005) theory, that hypothesizes that the vulnerability of older people makes them cherish what they *do* have (35). This study revealed that being surrounded by loved ones is essential when living with dementia, which is in accordance with the findings of Jonas-Simpson & Mitchell (2005) who studied quality of life for persons living with dementia (36,37). Cheng et al. (2015) examined 669 diaries describing caregivers' experiences and the daily experiences of their relatives with Alzheimer's disease (24). They found that caregivers developed closer relationships with the person with dementia, which partly reflects the findings in this study where some participants mentioned being closer as spouses. Also, Loyd et al. (2014) found in their critical review that relationship gains were a positive aspect of caregiving for individuals with dementia (22). The systematic review of Wolverson et al. (2015) examined positive experiences in the lives of persons with dementia and found concepts such as personal growth (26). In this study, both informal caregivers and persons with dementia did not experience any personal growth, however, this may be explained by the cognitive deterioration of the individuals with dementia in this study. According to the description of 'Life is what you make of it', Loyd et al. (2014) and Wolverson et al. (2015) both found humour to be an important aspect when making a positive out of a negative situation (22,26). This corroborated the findings in this study, where the use of humour was mentioned in all cases as being very important. In summary, literature shows that experienced positive aspects of living with dementia are similar to other research areas over comparable points.

### *Limitations and strengths*

This study is the first to explore the positive aspects of living with dementia from three perspectives. In former studies professionals were not included, however, it was expected that they would provide valuable insights about the positive aspects of dementia. As the recruitment of participants was a laborious process, this study only included female individuals with dementia and almost all of the informal caregivers were their husbands. It turned out to be a challenge to obtain rich data from the interviewed participants with dementia, even though some had only recently received their diagnosis. All individuals with dementia were open to discussing their dementia, but it was difficult for them to perform an in-depth conversation. Nevertheless, this study provides rich insights into the bright sides of living with dementia from three different perspectives. A strength of this study is the variety of professionals, as they each had different professions within the healthcare sector. The credibility of this study is enhanced by analysing the first three interviews separately using

two data coders (ED, JR). Despite the restricted scope of the study, it contributes to the development of a more positive attitude towards dementia.

This study confirms that dementia is not only experienced as a range of difficulties and stressors, but that it also has positive aspects. This study, together with Wolverson et al. (2016) provides a complete description of the positive aspects of living with dementia (26). By using the results of this study in educational interventions both informal caregivers and professionals can develop a more positive attitude towards dementia. To maintain hope and meaning in life, the focus should lie on the abilities of the person with dementia instead of their disabilities. Currently, both research and media tend to focus on the end stage of dementia, in which disabilities as a result of the disease are more common (20). To achieve a more positive attitude, it is necessary to include the media in this process, for instance through articles in a newspaper or on the web. By putting a spotlight on the subject, the creation of a dementia-friendly society can be supported and the stigma of dementia may be reduced. Future research should explore whether investments that have been made in the creation of a dementia-friendly society is bearing fruits. It would also be interesting to examine the positive aspects of dementia in more advanced stages of dementia to explore whether the same positive aspects exist.

## **CONCLUSION**

To reduce negative connotations about dementia, it is important to illuminate and understand the disease from a more positive perspective. The intention of this study was not to trivialize the difficulties and challenges of dementia, but to achieve a balanced perspective regarding living with dementia. It can be concluded that positive aspects do exist, although informal caregivers generally experience the least positive elements. Positivity is mainly experienced by continuing a positive attitude in life and enjoying the little and less intensive facets. By focussing on these activities, positivity can still be achieved. Another important aspect is the presence and support of relatives. Individuals with dementia and their professionals and informal caregivers have similar positive experiences to older adults without dementia over comparable points. Achieving a more positive view in society of dementia may promote the further development of a dementia-friendly society. This may ultimately lead to a greater perceived quality of life from the person with dementia and their informal caregiver.

## DECLARATION OF CONFLICTING INTERESTS

The author declares that there is no conflict of interest.

## ACKNOWLEDGEMENTS

My thanks go to Carolien Smits, Harmieke van Os, Janine Roenhorst and all participants for their contributions to this research report.

Table 1. Demographic information of participants

Case	Participant*	Age	Sex	Marital status	Year of diagnosis	Type of informal caregiver	Years of involvement as professional caregiver
Case #1	PWD	87	Female	Widow	2013	Daughter	3 months
	IC	57	Female				
	PR	46	Female				
Case #2	IC	52	Female	Married	2015	Daughter	1 year
	IC	80	Male			Husband	
	PR	45	Female				
Case #3	PWD	82	Female	Married	2013	Husband	3 years
	IC	83	Male				
	PR	42	Female				
Case #4	PWD	70	Female	Married	2015	Husband	8 months
	IC	71	Male				
	PR	41	Female				

\* Abbreviations: PWD = person with dementia, IC = informal caregiver, PR = professional

Table 2. Illustrative quotes of emerged themes on positive aspects of living with dementia

<i>It's the little things that matter</i>	
Person with dementia	<i>"There are still plenty of fun things to do. I can still ride my bike. As long as I can manage."</i>
Informal caregiver	<i>"I have all the photobooks down there and then I choose one book, her first photobook, so really from the past. And then she speaks incessantly!"</i> <i>"That's a point of engagement to me to charge my battery. Putting my</i>

	<i>mind somewhere else for a while. Even when it is just a simple game of billiards.”</i> <i>“In former times everything was taken for granted, going out was something quite ordinary. Nowadays we enjoy everything with more awareness.”</i>
Professional	<i>“She really enjoys having visitors, also the drawings that she gets from the grandchildren. She hangs them on her closet and shows them to everyone, “Look, that’s what my great-grandchild made for me!”</i>
<i>Being surrounded by loved ones</i>	
Person with dementia	<i>“I have a friend here, and she always comes to see me and talk to me. I really like to see her.”</i>
Informal caregiver	<i>“When she is among people, well well well, then she can reel off her tape, it works perfectly! Then we go out to have dinner with friends, and then there are no problems at all. That all goes like a rocket.”</i>
Professional	<i>“You are automatically going to appreciate your relatives more as you need more help or care”</i> <i>“She really loves her friends, family and grandchildren. Then I see a real sense of glee, as a family member comes to visit her.”</i>
<i>Life is what you make of it</i>	
Person with dementia	<i>“With Easter, I don’t have to confess at church, because I forget everything anyway.”</i>
Informal caregiver	<i>“It feels like a relief. And you will only find out when you meet other people who have put it away. They are now having a lot of trouble. We’ve been honest and open about dementia from the beginning.”</i>
Professional	<i>“To talk openly about dementia and using humour at the same time, that breaks the taboo more easily”.</i>

## REFERENCES

- (1) Pin, S., Bodard, J., Richard, J-P. Different perspectives on Alzheimer’s disease: perceptions, opinions and attitudes among the general public, immediate assistants and professional assistants. *Evolutions* 2011, may:25.
- (2) Aminzadeh F, Byszewski A, Molnar FJ, Eisner M. Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives. *Aging Ment Health* 2007 May;11(3):281-290.
- (3) Bond, J., & Corner, L. Researching dementia: Are there unique methodological challenges for health services research? *Ageing & Society* 2001;21(01):95-116.
- (4) World Health Organization. Dementia. 2015; Available at: <http://www.who.int/mediacentre/factsheets/fs362/en/>. Accessed October/04, 2015.

- (5) Basun, H., Ekman, S-L., Englund, E., Gustafson, L., Lannfelt, L., Nygård, L., et al. About dementia. Clinical picture, investigation, care, and nursing. Stockholm: Förlaget Hagman 1999.
- (6) Steeman E, de Casterle BD, Godderis J, Grypdonck M. Living with early-stage dementia: a review of qualitative studies. *J Adv Nurs* 2006 Jun;54(6):722-738.
- (7) Alzheimer Europe. Dementia in Europe Yearbook 2013. 2013:1-256.
- (8) Alzheimer's Disease International. World Alzheimer Report 2015. The Global Impact of Dementia. Available at: <http://www.worldalzreport2015.org/>. Accessed Oktober/20, 2015.
- (9) Langdon SA, Eagle A, Warner J. Making sense of dementia in the social world: a qualitative study. *Soc Sci Med* 2007 Feb;64(4):989-1000.
- (10) Naue U, Kroll T. 'The demented other': identity and difference in dementia. *Nurs Philos* 2009 Jan;10(1):26-33.
- (11) Van Gorp B, Vercruyse T. Frames and counter-frames giving meaning to dementia: a framing analysis of media content. *Soc Sci Med* 2012 Apr;74(8):1274-1281.
- (12) Sweeting H., & Gilhooly, M. Dementia and the phenomenon of social death. *Sociology of Health & Illness* 1997;19(1):91-117.
- (13) Svanstrom R, Dahlberg K. Living with dementia yields a heteronomous and lost existence. *West J Nurs Res* 2004 Oct;26(6):671-687.
- (14) Almberg B, Grafstrom M, Winblad B. Caring for a demented elderly person--burden and burnout among caregiving relatives. *J Adv Nurs* 1997 Jan;25(1):109-116.
- (15) Winslow BW, Carter P. Patterns of burden in wives who care for husbands with dementia. *Nurs Clin North Am* 1999 Jun;34(2):275-287.
- (16) Clarke JN. The case of the missing person: Alzheimer's disease in mass print magazines 1991-2001. *Health Commun* 2006;19(3):269-276.
- (17) Kirkman AM. Dementia in the news: the media coverage of Alzheimer's disease. *Australasian Journal on Ageing* 2006;25(2):74-79.
- (18) Reynolds L, Innes A, Poyner C, Hambidge S. 'The stigma attached isn't true of real life': Challenging public perception of dementia through a participatory approach involving people with dementia (Innovative Practice). *Dementia (London)* 2016 Mar 1.
- (19) Moore V, Cahill S. Diagnosis and disclosure of dementia--a comparative qualitative study of Irish and Swedish General Practitioners. *Aging Ment Health* 2013;17(1):77-84.
- (20) Watson J. Is it possible to live well with dementia? *Dementia (London)* 2016 Jan;15(1):4-5.
- (21) Peacock S, Forbes D, Markle-Reid M, Hawranik P, Morgan D, Jansen L, et al. The Positive Aspects of the Caregiving Journey With Dementia: Using a Strengths-Based Perspective to Reveal Opportunities. *Journal of Applied Gerontology* 2009;29(5):640-659.

- (22) Lloyd J, Patterson T, Muers J. The positive aspects of caregiving in dementia: A critical review of the qualitative literature. *Dementia (London)* 2014 Dec 29.
- (23) Kramer BJ. Gain in the caregiving experience: where are we? What next? *Gerontologist* 1997 Apr;37(2):218-232.
- (24) Cheng ST, Mak EP, Lau RW, Ng NS, Lam LC. Voices of Alzheimer Caregivers on Positive Aspects of Caregiving. *Gerontologist* 2015 Jan 21.
- (25) Li Q, Loke AY. The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psychooncology* 2013 Nov;22(11):2399-2407.
- (26) Wolverson EL, Clarke C, Moniz-Cook ED. Living positively with dementia: a systematic review and synthesis of the qualitative literature. *Aging Ment Health* 2016 Jul;20(7):676-699.
- (27) Louderback P. Elder Care: A Positive Approach to Caregiving. *Journal of the American Academy of Nurse Practitioners* 2000;12(3):97-100.
- (28) Berg-Weger, M., McGartland Rubio, D., Tebb, S. Strengths-Based Practice With Family Caregivers of the Chronically Ill: Qualitative Insights. *Families in Society: The Journal of Contemporary Social Services* 2001;82(3):263-272.
- (29) Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: rounding out the caregiver experience. *Int J Geriatr Psychiatry* 2002 Feb;17(2):184-188.
- (30) Werkgroep Vanuit Dementie Bekeken. Op weg naar een dementievriendelijke samenleving. 2015; Available at: <https://www.rijksoverheid.nl/binaries/rijksoverheid/documenten/rapporten/2015/12/16/op-weg-naar-een-dementievriendelijke-samenleving/op-weg-naar-een-dementievriendelijke-samenleving.pdf>. Accessed March/17, 2016.
- (31) Yin RK. *Case Study Research: Design and Methods*. 5th ed. United States of America: Sage Publications; 2014.
- (32) Creswell JW. *Qualitative Inquiry & Research Design: Choosing Among Five Approaches*. 3rd ed. United States of America: Sage Publications; 2013.
- (33) Gaffney G. *Cultural Probes. Information & Design*. Last Updated, unknown; Available at: <http://infodesign.com.au/usabilityresources/culturalprobes/>. Accessed December/12, 2015.
- (34) Moot N. "Je bent blij dat je je ogen weer open doet, want dan ben je d'r nog." Exploratief vooronderzoek naar ouderen en zingeving. *University of humanistics Utrecht* 2010:37.
- (35) Baars J. 'De existentiële zin van ouder worden.' . Kwekkeboom, M H & WijnenSponselee, M Th 2005;Zin geven: noties rondom vraagstukken van zingving als je ouder wordt of moet leven met een beperking(Breda, Avans Hogeschool).
- (36) Jonas-Simpson, C., & Mitchell, G.L. Giving voice to expressions of quality of life for persons living with dementia through story, music, and art. *Alzheimer's Care Quarterly* 2005;6:52-61.



(37) Steeman, E., Tournoy, M., Grypdonck, J., Godderis, J., & Dierckx De Casterle, B. Managing identity in early-stage dementia: Managing a sense of being valued. *Aging & society* 2013;33:216-242.

## APPENDIX A

### Interview guide

Concepts defined by Kramer (1997) and Lloyd (2014)	Interview questions
Satisfaction & acceptance	<p>1. In hoeverre hebt u door de aanwezigheid van dementie een positievere houding ontwikkeld ten aanzien van het leven? <i>(Professional: In hoeverre is er door de aanwezigheid van dementie een positievere houding ontwikkeld ten aanzien van het leven?)</i></p> <p>2. Wat waardeert u meer in het leven nu dementie zijn intrede heeft gedaan? <i>(Professional: Wat waardeert dit echtpaar/deze familie meer nu dementie zijn intrede heeft gedaan?)</i></p> <p>3. Waar bent u, ondanks dat u of uw partner dementie heeft, erg trots op? <i>(Professional: Waar is dit echtpaar of deze familie erg trots op, ondanks dat er sprake is van dementie?)</i></p> <p>4. Wat doet u of uw partner om de beperkingen van dementie te accepteren? (Bijvoorbeeld leven van dag tot dag) <i>(Professional: Wat doet dit echtpaar of deze familie om de beperkingen van dementie te accepteren? (Bijvoorbeeld leven van dag tot dag).</i></p> <p>5. Wat vindt u bruikbaar in het omgaan met spanningen en uitdagingen die gemoeid zijn met dementie? (Bijvoorbeeld bijeenkomsten in Alzheimer Café) <i>(Professional: Wat is voor dit echtpaar/familie bruikbaar in het omgaan met spanningen en uitdagingen die gemoeid zijn met dementie? Bijvoorbeeld bijeenkomsten in Alzheimer Café)</i></p>
Uplifts	<p>1. In hoeverre gaan mensen in uw omgeving anders met u om nu u dementie hebt? (onderliggende topics: zijn ze geduldiger? Meer respectvol? Waarderen ze u meer?) <i>(Professional: In hoeverre gaan mensen in de omgeving anders met dit echtpaar/familie om nu er sprake is van</i></p>

	<i>dementie? (onderliggende topics: zijn ze geduldiger? Meer respectvol? Waarderen ze hen meer?)</i>
Rewards, relationship gains & gratifications	<p>1. In hoeverre zijn er door dementie hechtere relaties ontstaan tussen u en uw echtgenoot/kinderen? <i>(Professional: In hoeverre zijn er door dementie hechtere relaties ontstaan binnen deze familie, of tussen het echtpaar?)</i></p> <p>2. In hoeverre bent u uw naasten meer gaan waarderen, en zo ja hoe ziet u dat dan of waar merkt u dat aan? <i>(Professional: In hoeverre is dit echtpaar/deze familie naasten meer gaan waarderen, en zo ja hoe ziet u dat dan of waar merkt u dat aan?)</i></p> <p>3. In hoeverre nemen uw kinderen/kleinkinderen of andere familie meer tijd en/of moeite voor u en uw partner nu dementie zijn intrede heeft gedaan? (onderliggende topics: ziet de familie elkaar vaker, komen ze vaker langs?) <i>(Professional: In hoeverre nemen de kinderen/kleinkinderen of andere familie meer tijd en/of moeite voor deze familie nu dementie zijn intrede heeft gedaan? Onderliggende topics: ziet de familie elkaar vaker, komen ze vaker langs?)</i></p>
Growth & meaning	<p>1. In hoeverre is er sprake van spirituele groei, doet u tegenwoordig bijvoorbeeld meer met het geloof? <i>(Professional: In hoeverre is er sprake van spirituele groei, doet dit echtpaar of deze familie bijvoorbeeld tegenwoordig meer met het geloof?)</i></p> <p>2. In welke andere zaken bent u gegroeid? (Bent u bijvoorbeeld geduldiger of makkelijker/gemakzuchtiger geworden, bent u zichzelf of uw partner meer gaan waarderen?) <i>(Professional: In welke andere zaken is dit echtpaar of deze familie gegroeid? (Zijn zij bijvoorbeeld geduldiger geworden of makkelijker/gemakzuchtiger, is er meer waardering voor de partner?)</i></p>
Enjoyment	<p>1. Welke activiteiten onderneemt u tegenwoordig in het leven om plezier te ervaren, om te genieten van het leven? (Bijvoorbeeld bij vrienden op bezoek gaan)</p>

	<p><i>(Professional: Welke activiteiten onderneemt dit echtpaar of deze familie tegenwoordig in het leven om plezier te ervaren, om te genieten van het leven? Bijvoorbeeld bij vrienden op bezoek gaan).</i></p> <p>2. Aansluitend op vorige vraag: In hoeverre is dat veranderd nu er sprake is van dementie? Geniet u bijvoorbeeld van andere dingen?</p> <p><i>(Professional: In hoeverre is dat veranderd nu er sprake is van dementie? Geniet dit echtpaar of deze familie bijvoorbeeld van andere dingen?)</i></p> <p>3. In hoeverre onderneemt u tegenwoordig bepaalde activiteiten met de gedachte 'nu kan het nog'? Zijn er bepaalde wensen, zoals bijvoorbeeld een bepaalde reis?</p> <p><i>(Professional: In hoeverre onderneemt dit echtpaar of deze familie tegenwoordig bepaalde activiteiten met de gedachte 'nu kan het nog'? Zijn er bijvoorbeeld wensen, zoals bijvoorbeeld een bepaalde reis?)</i></p> <p>4. Wat betekent humor voor u in relatie tot dementie? (onderliggende topics: meer humor? Zelfspot? Worden er grapjes over de ziekte gemaakt met als uitgangspunt het gebruiken van humor om van negatieve situatie een positieve te maken?)</p> <p><i>(Professional: Wat betekent humor voor dit echtpaar of deze familie in relatie tot dementie? (onderliggende topics: meer humor? Zelfspot? Worden er grapjes over de ziekte gemaakt met als uitgangspunt het gebruiken van humor om van negatieve situatie een positieve te maken?)</i></p> <p>5. In hoeverre vindt u vreugde/blijdschap in het ophalen van herinneringen van vroeger? (bijvoorbeeld foto's, trouwdag, kinderen werden geboren)</p> <p><i>(Professional: In hoeverre vindt dit echtpaar of deze familie vreugde/blijdschap in het ophalen van herinneringen van vroeger? (bijvoorbeeld foto's, trouwdag, kinderen werden geboren)</i></p>
Benefits	<p>1. In hoeverre hebt u door dementie bepaalde competenties ontwikkeld, bijvoorbeeld nieuwe vaardigheden zoals ?</p>

	<i>(Professional: In hoeverre zijn er door dementie bepaalde competenties ontwikkeld bij dit echtpaar/deze familie, zoals bijvoorbeeld nieuwe vaardigheden?)</i>
Discussing photos (informal caregiver)	<ol style="list-style-type: none"> <li>1. Wat ziet u op de foto?</li> <li>2. Wat betekent deze foto voor u?</li> <li>3. Wat was de aanleiding voor dit positieve moment?</li> <li>4. Doen dit momenten, zoals op de foto, zich vaak voor?</li> </ol>