

Dementia: relationship changes and positive aspects

A qualitative study into positive aspects of relationship changes between a person with dementia and their caregiving child.

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Abstract

Dementia: relationship changes and positive aspects

Background: The number of people with dementia is increasing. Seventy per cent of people with dementia in the Netherlands receive informal care (e.g. from their child). Research indicates that the relationship between a person with dementia and their child changes. Thereby, research indicates that a positive parent-child relationship is a protective factor for well-being. However, evidence is lacking on this subject in dementia and this suggests that more research is needed. The present study can lead to the improvement of care for people with dementia and their informal caregivers.

Aim: The study aims to explore the positive aspects of changing relationships between informal caregivers and their parents with dementia, as experienced by the caregivers.

Methods: The study has a qualitative design with a descriptive phenomenological approach. Data were gathered through 13 semi-structured interviews; Colaizzi's method was used for analysis.

Results: Two themes with four subthemes were identified. The first theme consists of the benefits of seeing positive aspects during a grim process and the subthemes of relationship benefits and personal benefits. The second theme includes the need to sustain positive moments and the actions taken to do so, along with the subthemes of seeking contact and taking enjoyment in their parents' pleasure.

Conclusions: The study identifies the positive aspects of the relationship changes during dementia as relationship and personal benefits, during a grim time and makes clear that sustaining interaction is important for the study participants.

Implications and recommendations: Professionals must pay more attention to the quality of the relationship between an informal caregiving child and their parent with dementia. Future research should focus on factors that influence the quality of these relationships.

Keywords: *qualitative research, dementia, relationships, positive aspects*

Nederlandse samenvatting

Dementie: relatieveranderingen en positieve aspecten

Achtergrond: Het aantal mensen met dementie neemt snel toe. Dementie leidt tot beperkingen in de sociale en professionele prestaties. Zeventig procent van mensen met dementie in Nederland ontvangt mantelzorg van bijvoorbeeld kinderen. Uit onderzoek is gebleken dat de kwaliteit van de relatie tussen een ouder en kind beschermend is op de kwaliteit van leven. Daarnaast blijkt dat deze relatie verandert op het moment dat de ouder dementie krijgt. Er is weinig bekend over positieve aspecten in deze veranderende relatie. Meer kennis hierover kan leiden tot een betere ondersteuning van mantelzorgers en hun ouder met dementie.

Doel: Het doel van deze studie was om te verkennen wat positieve aspecten zijn in de veranderende relatie tussen mantelzorgers en hun ouder met dementie, ervaren door de mantelzorger.

Methode: Er is bij deze kwalitatieve studie gebruik gemaakt van een beschrijvende fenomenologische benadering. Dertien semigestructureerde interviews zijn afgenomen bij mantelzorgers. Colaizzi's methode is gebruikt om de interviews te analyseren.

Resultaten: Er werden twee thema's met vier sub-thema's gevonden. Als eerste voordeel van positieve aspecten in een onverbiddelijk proces met sub-thema's relatievoordelen en persoonlijke ontwikkeling en als tweede de noodzaak en acties tot het behouden van interactie met sub-thema's het contact zoeken en zien genieten doet genieten.

Conclusie: Deze studie heeft de ervaring met de positieve aspecten in de veranderende relatie bij dementie geïdentificeerd als relatievoordelen en persoonlijke voordelen gedurende een onverbiddelijk proces en maakte de noodzaak duidelijk van het behouden van de interactie tussen mantelzorgers en hun ouder met dementie.

Implicaties en aanbevelingen: Professionals moeten meer aandacht hebben voor de kwaliteit van de relatie tussen een ouder met dementie en het mantelzorgende kind. Toekomstig onderzoek moet zich richten op de factoren die van invloed zijn op de kwaliteit van de relatie.

Sleutelwoorden: kwalitatief onderzoek, dementie, relaties, positieve aspecten

Introduction

The World Health Organization has urgently called to make dementia a care priority because of its threat to global health¹. As the population ages, the number of people with dementia is increasing rapidly².

The fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) defines dementia as a major neurocognitive disorder³. The DSM-V lists six domains which can be affected by dementia: complex attention, executive function, learning and memory, language, perceptual motor function, and social cognition³. Changes to these functions can cause difficulties with everyday activities and significantly limit social and professional performance⁴.

The number of people with dementia worldwide was 46.8 million in 2015, and it will increase to 131.5 million by 2050². In the Netherlands, the number of people with dementia in 2014 was 260,000⁵. Approximately 50,000 of these people were living in nursing homes⁶.

Informal care is provided to 70% of Dutch people with dementia⁷. Informal caregivers are unpaid carers who have a relationship or an emotional involvement with the person they care for (e.g. spouses, children, parents, or neighbours)⁸. On average, 300,000 informal caregivers provide 20 hours of care per week to people with dementia for an average duration of five years⁷. Informal caregivers to people with dementia in the Netherlands provide support in different categories: personal care (e.g. washing and dressing), domestic help, providing guidance (e.g. arranging assistance and handling administrative matters), nursing care (e.g. preparing and giving medication), and offering emotional support and supervision^{7,8}.

Giving care to a person with dementia can be very burdensome^{7,9,10}. In order to reduce this burden on informal caregivers, research has focused on the characteristics of either the person with dementia or the informal caregiver, and the impact of those characteristics on the caregiver's stress^{9,10}. Professionals (e.g. nurses or case managers) are expected to assess the burden placed on informal caregivers and to provide interventions to limit their stress levels⁹. This is seen as a vital aspect of the quality of care given to people with dementia and their informal caregivers⁹.

In the Netherlands, 60% of informal caregivers share their caregiving responsibilities with a professional carer (e.g. a nurse or case manager). This collaboration is not always satisfactory for informal caregivers. In 2014, research indicated that 37% of Dutch informal caregivers felt that insufficient attention was given to their well-being⁸.

In the last 15 years, more research has focused on the positive aspects of caregiving in order to gain insight into the overall experience, and through understanding the results, be

able to better support informal caregivers¹¹⁻¹³. A review conducted in 2014 focusing on carers' perceptions of the positive caregiving process found that different groups of caregivers experienced intrinsic rewards¹⁴, such as emotional rewards, personal growth, religious and spiritual growth, and feeling that the relationship strengthened as positive outcomes of caregiving¹⁴.

The relationship quality between a parent (without dementia) and child has been identified as a protective factor for the well-being of both the parent and the child^{15,16}. Little research has focused on relationships involving people with dementia¹⁷⁻¹⁸, but these studies have found that informal caregivers struggle to maintain a relationship with their relative with dementia and they describe changes in the relationship¹⁷⁻¹⁸. Informal caregivers feel that they have to adjust to different responsibilities and new roles¹⁷.

Informal caregivers also experience a decline in the quality of their interactions with the person with dementia and face dilemmas in how to maintain the relationship¹⁷. Bjørge et al. found that informal caregivers want to emphasize the positive aspects of the relationship and that the quality of the current relationship influenced their role as an informal caregiver¹⁸.

However, despite the suggestion that the quality of the relationship is a protective factor for well-being, evidence is lacking on this subject in dementia; this suggests that more research is needed. The outcomes of the present study could lead to a better understanding of the needs of caregivers and their parents with dementia. This could lead to changes in nursing education and improved professional care for people with dementia and their informal caregivers.

Aim

The study aims to explore the positive aspects of the changing relationship between informal caregivers and their parents with dementia, as experienced by the caregivers.

Methods

Design

In this qualitative study, a descriptive phenomenological approach was used to gain insight into the lived experiences of children who are informal caregivers¹⁹⁻²¹. Using a qualitative research design gives participants the opportunity to speak in their own words and this provides more in-depth information and can lead to deeper insights on relationship changes, as compared to quantitative approaches²². Phenomenological research focuses on the lived experiences described by participants who reflect on them and assign meaning²⁰. The lived experiences were therefore recorded through semi-structured interviews in order to gather

rich, in-depth data²².

Population and domain

This study focuses on the experiences of children who are informal caregivers of parents with dementia.

Consistent with the qualitative research design, purposeful, maximum-variation sampling was used to select participants²⁰. The variation was applied to the living situation of the parent (at home or institutionalised), gender, care combinations, and dementia stage. This variation was chosen with the expectation of gaining rich data. Participants were included if they (1) provided informal care to a parent diagnosed with Alzheimer's disease or vascular dementia; (2) provided informal care that fell into at least one of the following categories: personal care, domestic help, guidance, nursing care, emotional support, or supervision; (3) were able to speak about positive aspects within the relationship; (4) had experience with sharing caregiving duties with a professional (e.g. nurse or case manager); (5) were 18 years or older; and (6) spoke Dutch. The two dementia types were chosen because they are the most common and together represent 70-90% of all dementia cases worldwide²³. The results are therefore more likely to be applicable to a large population. One exclusion criterion was applied to the subgroups: a potential participant was excluded if (s)he s/he provided informal care to a parent with young onset dementia (YOD). People with YOD are diagnosed before the age of 65 and therefore experience different challenges that have a greater impact on their and their children's lives compared to older people (65+)²⁴.

To fully understand the meaning participants give to their experiences, saturation of data is needed. Code saturation is described as 'getting no new information', and meaning saturation is described as 'understanding it all'²⁵. In this study, meaning saturation was pursued through 16 to 24 interviews²⁵.

Data collection

The data collection took place between March 1st 2017 and May 12th 2017. Data were collected using semi-structured interviews at a time and place preferred by the participant.

A topic list (Appendix III) was composed with the help of existing literature on relationships in dementia¹⁵⁻¹⁸. Each interview started with the question '*Can you tell me how you experienced the start of the dementia process?*' At the end of the interview, participants were asked about their characteristics as well as those of their parents. This included their parents' dementia stage, assessed using the Global Deterioration Scale (GDS)²⁸. Although its clinimetric properties are reported contradictorily²⁸⁻³¹, this instrument is widely used in the

Netherlands.

All interviews were performed by the first author (W.R) who is a registered nurse. Supervision during the data collection was provided by the second author (C.S.), an experienced researcher. This guidance consisted of reading the transcript of the first interview and discussing the interview techniques of the first three interviews, in order to improve the data collection. Discussion on the findings was done after five and after ten interviews.

Data analysis

All interviews were tape-recorded and transcribed verbatim²⁰. Following Colaizzi's method of analysis²², the researcher (W.R) used bracketing by setting aside her own thoughts, ideas, and feelings about the topic under study²² before starting the analysis. This is a way to open up to the participants' experiences²². After this, each transcript was read several times and significant statements were extracted using the computer software program NVivo, version 11 (QSR International, Doncaster, Australia); these statements were labelled with codes. A second researcher (L.K.) performed these steps independently.

The third step consisted of a discussion between the two researchers about the codes and the meaning of the extracted statements. Discussion took place until consensus was reached. Codes were clustered into themes and subthemes by the two researchers who referred back to the transcripts to validate them²². The first author (W.R.) wrote a meaning description of the results.

Procedures

Participants were initially approached by case managers (in the case of the community-dwelling population) or by nurses in nursing homes (for the institutionalised population). After a verbal explanation by the case manager or the nurse, permission to give their contact details to the first author was asked. First contact was, following participants' choice, made via email or telephone. The information was provided verbally and in writing, and participants were able to ask questions. All participants received the information letter by email.

Participants were asked to reflect on their willingness to participate and were encouraged to discuss participation with family or friends. After at least a four-day period an appointment was set for the interview. Before the start of the interviews the first author checked if there were any questions or doubts that needed to be discussed.

Ethical issues

This study does not fall within the scope of the Medical Research Involving Human Subjects Act (WMO). Confirmation on this point and permission to start the study was obtained from the Medical Ethical Committee of Isala Hospitals in Zwolle, the Netherlands. The study is registered under the number 170224. The study followed the ethical principles of the Declaration of Helsinki (2013 edition)³².

Written informed consent was obtained from all participants before the start of the interviews. Participants could stop the interview at any time without providing an explanation.

Results

The first author contacted a total of 20 potential participants, of whom four did not meet the inclusion criteria (one had a parent with a different diagnosis, two were daughters-in-law, one had a father with YOD). Two potential participants were not able to schedule an appointment due to their personal circumstances, despite being willing to participate. One potential participant decided not to participate after receiving more information on the study. A total of 13 participants, comprised of ten women and three men, agreed to join the study. Participants lived in the central and northern parts of the Netherlands.

The interviews were conducted at a location preferred by each participant. Five were held in a meeting room at a nursing home, and all other interviews were conducted at the participants' homes. Each interview lasted between 27 and 73 minutes. All 13 interviews were included in the analysis.

Sample characteristics

The mean age of the participants was 54.1 years. The number of years of informal caregiving ranged from 3 to 24 years.

The hours of informal caregiving per week varied from 3 to 105 hours. This was due to the living situation of the parent; the time spent on care was greater with community-dwelling parents than with parents who were institutionalised. The two participants spending the most hours on care per week had moved their parents into their homes. A brief overview of the characteristics of the participants is given in Appendix I, table 1.

Three different parent-child combinations, mother-daughter, father-daughter and mother-son, were included in the study (Appendix I, table 2). One participant talked about both of her parents with dementia although her father had already passed away. We decided to include both of her caregiving experiences in the qualitative analyses because the experiences were inseparable. Due to her father passing away earlier, not all characteristics were applicable

and they are therefore not presented in the table. An overview of the characteristics of the 13 parents described by their caregivers is presented in Appendix I, table 3.

Interview results

Overall, participants experienced a change in roles in relation to their parents as the dementia progressed. They primarily described it as a gradual process in which they had to adapt to the situation and to the needs of their parents, even though physical problems could speed up the process in some cases. One participant said:

'I cannot identify a turning point where I stopped feeling like her daughter and became the mother, or the caretaker, or the supervisor. The process has been so gradual.' (p.8)

As a result of the analyses, the meaning of the lived experience of the positive aspects in the changing relationship between informal caregivers and their parents with dementia was formulated into two main themes with four subthemes: [1] Benefits during a grim process and the subthemes (a) relationship benefits and (b) personal benefits; and [2] the need to and actions taken to sustain positive moments and the subthemes (a) seeking contact and (b) enjoying the happiness. A meaning description is presented in Appendix II, figure 1.

1. Benefits by positive aspects in a grim process.

Participants described how they experienced the path leading to a dementia diagnosis and the impact it had on their lives. They described feelings of powerlessness, sadness, and mourning. They were clear in stating that the process in itself was not a positive one. They were also able to reflect on and talk about the positive aspects of the relationship they had with their parents when they were asked to do so.

a. Relationship benefits.

Most participants experienced an improvement in their relationship with their parent with dementia. They described an increased awareness of the affection from their parent and an increased acceptance of each other in the relationship. Participants said that, due to caregiving, the frequency of contact between themselves and their parents increased. In addition, increased physical contact was named as an important contributor to the strengthening of the relationship. This could refer to more frequent physical contact or even the fact that a parent accepted physical contact. Participants described that the character of their parents changed in positive ways. As a result of the dementia process, some participants experienced major positive changes in their relationship compared to the

situation prior to the onset of dementia. These positive changes led to an improvement in the relationship the participants had with their parents. Participants experienced fewer conflicts with their parents. They described memory loss as having benefits when it came to quarrels, conflicts, or relational problems: because their parents forgot the quarrels, the participants could start over and act in a different way without having a conflict. In case of relational problems a major change was identified. One participant described how the memory loss caused by dementia allowed her to renew her relationship with her mother.

'The positive side of this is that because of her memory loss, my mother luckily forgets the accusations and the misery that are caused by family conflict.' (p.6)

Another participant described the major change she experienced in her relationship with her father and in the way she perceived him.

'If my father had died before he got dementia, I would have described our relationship in a totally different way: I would have said that I had an autocratic father and that we had little contact. And now I would say I got to know him in different ways, more fully. So I can say that I learned to appreciate him.' (p.3)

b. Personal benefit.

Participants stated that due to the dementia process of their parents, they experienced positive personal development. They described their own successes in handling their parents' personal care where professionals sometimes failed. They gained more self-confidence in the way they acted in relation to their parents: they took charge and set boundaries on the behaviour of their parents.

'That I am able to help her to find a solution for some issues or provide practical help, I can make a real difference and that gives me self-confidence.' (p.5)

2. The need to sustain positive moments and actions taken to do so.

Participants not only experienced positive changes in their relationship but were able to describe their needs towards the relationship and talk about strategies they used to sustain contact and positive moments with their parents.

a. Seeking contact.

Participants described an eagerness to sustain the relationships they had with their parents. It was important for them to have interaction between their parents and themselves,

although they described a loss in the quality of these interactions. Participants described feeling happy if their parents recognised them as their children. They enjoyed the moments in which their parents would take on a parenting role as they did before. They imagined that if the interaction disappeared and they could not share important things anymore, it would make the situation harder. Other participants who had already experienced the increased disappearance of interaction stated that the moments of interaction were the best moments they had with their parent.

'I just appreciate the short moments of interaction. Whenever she has such a moment, it is very important for me.' (p.5)

b. Finding enjoyment in their parents' pleasure.

Participants reported that their parents' joy was important and that if their parents enjoyed a situation, a moment, or an activity, it brought joy to them as well. Their own interests or comfort were of little concern to them. Seeing their parents happy also made them less critical of the actions of professional caregivers. Humour was mentioned as an important contributor to shared moments of joy. They described planning moments or activities that both the parents and children enjoyed as a way of connecting with their parents. One participant described it as follows:

'Yes, those are the moments I cherish. She can be very apathetic: she sits at the table and stares, but when I start the music she likes and give her a glass of wine, she enjoys it for a short time. And after that she is apathetic again, then I start talking to her about the past, and then she lights up and talks to me.' (p.11)

Participants with institutionalised parents stated that after their parents moved to an institution they felt they had more time and opportunity to sustain their relationship with their parents by doing pleasant activities. They felt their role before their parents were institutionalised was more focused on practical issues instead of maintaining a positive relationship.

'When she lived at home, you got to visit her, but at the same time you always had something that needed to be done, and that could lead to conflicts. Now she lives in the nursing home, and it is very nice that I can focus on the fun things.' (p.1)

Discussion

This study aims to explore the positive aspects of the changing relationships between informal caregivers and their parents with dementia, as experienced by the caregivers. Participants experienced positive changes and moments in their relationship with their parents during a grim process. The relationships improved and were strengthened thanks to more physical contact, increased visits, and positive changes in character. Due to memory loss, conflicts disappeared or were forgotten. Participants described their eagerness to maintain interaction with their parents and create positive moments through mutually enjoyable activities. They also experienced positive moments through enjoying their parents' pleasure. Participants with parents in care homes appreciated having more opportunities and time to sustain their relationship than before the institutionalisation.

Some of our outcomes are in line with existing research on the positive outcomes of caregiving: Bjørge et al.¹⁸ have described role changes between informal caregivers and people with dementia as well as the wish to emphasise the positive aspects of these relationships. The personal development of the caregiver and the experience of the strengthening of the relationship were also identified in earlier research focused on carers' perceptions of the positive caregiving process¹⁴.

Participants experienced an eagerness to sustain the interaction with their parents. Although evidence is lacking on the consequences of (dis)continuity in parent-child relationships, studies have been conducted on relationship continuity between spouses and people with dementia³³. Evidence suggests that the (dis)continuity of the relationship is a factor impacting emotional well-being³³.

The outcome of our study suggests that postponement of admission to a nursing home can lead to a decrease of positive moments caused by practical matters. This may have an effect on the quality of the relationship and therefore the quality of life^{15,16}. To limit and identify the burden placed on informal caregivers of people with dementia living at home, the concept of perseverance time was studied in earlier research to identify influencing factors³⁴. Perseverance time is the duration that informal caregivers expect to be able to continue their care³⁴. Happiness of the informal caregiver was one of the positively correlated factors with perseverance time³⁴. The decrease of positive moments or happiness participants experienced in our study can therefore be a factor influencing perseverance time. Nurses and case managers could direct their attention to the potential decrease of positive moments caused by the necessity of concentrating on practical matters and integrate this information into the decision-making process regarding potential institutionalisation.

The outcomes of this study should be seen in light of its strengths and limitations. The

study was peer-reviewed by experienced researchers to increase its overall quality and to prevent subjectivity²⁰. The independent extraction of significant statements increases the trustworthiness²⁰. The use of the consolidated criteria for reporting qualitative research (COREQ) checklist³⁵ increases reliability and reproducibility²⁰. There are, however, some limitations. The inclusion did not result in the minimum of 16 interviews needed for meaning saturation²⁵, however there was sufficient variation in the sample, matching with the explorative nature of this study. This is shown in the hours of caregiving, years of caregiving, and GDS scores of the parents. Less successful was the intended gender variation: we included only three men and there was no father-son combination. We did not return the results of the analyses to the participants', which has an effect on this study's validity²².

Although this study suggests a difference between the possibilities of maintaining a positive relationship between community-dwelling informal caregivers and informal caregivers of institutionalised people with dementia, the study was not designed to detect other factors of influence. Further research should focus on factors influencing the positive relationship between parents with dementia and their informal caregivers. Interventions should be developed to enable nurses to identify and reduce the risk of deterioration in the quality of the parent-child relationship and thereby the quality of life.

Conclusion

This study identifies that caregivers experienced a strengthening or improvement of the relationship during a grim process. They described personal benefits and an eagerness to maintain interaction and found enjoyment in their parents' pleasure. Nurses may direct attention to the possible decrease of the positive relationship through practical matters and may consider this in the decision-making process concerning institutionalisation. Future research should focus on other factors influencing the quality of these relationships.

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Appendix I -Tables

Table 1. Participant Characteristics

N = 13	N (%)	Mean	Range
Gender			-
Female	10 (76.9)	-	
Male	3 (23.1)	-	
Age	-	54.1	41-63
Marital stage		-	-
Married or in a relationship	9		
Single	4		
Work situation			8-60 hours per week
Working full-time	2	-	
Working part-time	10	-	
Retired	1	-	
Years of informal caregiving	-	9	3-23
Time spend in hours per week	-	21.5	3-105

Table 2. Overview of the included informal care combinations, N=14

Mother – Son	3
Mother – Daughter	9
Father – Daughter	2

Table 3. Characteristics of the people with dementia

N=13ⁱ	N (%)	Mean	Range
Gender		-	-
Female	12 (92.3)		
Male	1 (7.7)		
Age		84.5 years	71-96 years
70-79 years	4		
80-89 years	5		
>90 years	4		
Marital stage		-	-
Married	2		
Widowed	11		
Living situation		-	-
Community-dwelling	5		
Institutionalized	8		
Diagnosis		-	-
Alzheimer's disease	8		
Vascular dementia	5		
Stage of dementia (GDS)			3-7
GDS ⁱⁱ 1-3	2	-	
GDS 4,5	5	-	
GDS 6,7	6	-	
Years since diagnosis		4.8 years	0 – 16 years
<1	3		
1	2		
2	3		
3	1		
>3	4		

i Characteristics of a father who passed away are not included. He died at age 84, had vascular dementia and was not institutionalised until the last week of his life when he had acute physical complaints.

ii Stage of dementia according to the Global Deterioration Scale²⁸

Appendix II – Description of the results

Themes	Subthemes	Formulated meaning
Benefits of positive aspects during a grim process	Relationship benefits	Experienced an increased acceptance, an increased awareness, increased physical contact, the frequency of contact increased, positive effect of memory loss on quarrels or relational conflicts, renewed the relationship or created a more positive image of the parent.
	Personal benefits	Experienced more self-confidence, learned to set boundaries, experienced positive moments through handling situations.
The need to and actions taken to maintain positive moments	Seeking contact	Eagerness to have interaction, happiness about recognition as their child and acting as a parent.
	Finding enjoyment in their parents' pleasure	Enjoying the happiness of the parent, using humour and activities to create happiness.

Appendix III - Interview guide

Topics	Question
The dementia process	Can you tell me how you experienced (the start) of the dementia process?
Changes in the relationship	Can you tell me how the relationship with your parent changed What changed in concrete terms? (Give examples.) Can you tell me what you feel is the biggest change in the relationship between you and your parent? (Has it improved or deteriorated? Interaction?)
Maintaining the relationship	Can you tell me what is important in your relationship with your parent? How do you try to maintain those things?
Positive aspects	Do you experience positive moments with your parent that are important for both of you? Can you give me an example? Can you clarify what these moments mean for the relationship between you and your parent?
Working with professional carers	Can you tell me about your experiences working with professional carers regarding the care for your parent?
The role of professionals in supporting positive aspects	Can you tell me how the nurse or case manager could support you in maintaining or improving your relationship with your parent? Can you give me an example of what would be nice for you and/or your parent? (What should they do and what should they stop doing?)