




Title: A qualitative study of family members experiences of their loved one developing dementia and their subsequent placement in a nursing home

Running title: Family members experiences with a dementia diagnosis

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Keywords: Dementia; Family members; Primary healthcare team; Nursing home; Experiences

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ABSTRACT

Aim: To investigate family members' experiences with receiving help and support while of their loved one develops dementia and their subsequent placement in nursing homes.

Background: As the dementia disease progresses, some family members will struggle with the option of nursing home placement. This situation can precipitate feelings of anger, disappointment, and guilt, all of which can be overwhelming.

Methods: A qualitative descriptive study with in-depth interviews ($n = 19$) was carried out in several nursing homes of Slovenia's North Eastern region.

Results: Inductive thematic analysis identified two main themes: (i) Developing the diagnosis and (ii) Accommodation process. Family members noticed the progressive behavioural changes in their loved ones. While they were searching for help at the primary healthcare level, they experienced a lack of help and support.

Conclusions: When family members detect behavioural changes in their loved ones, the primary healthcare team should establish an early diagnosis of dementia and provide adequate decision-making support.

Implications for Nursing Management: The findings are useful to prepare guidance for a family member to inform them of the types of support available and from which associations and

organisations. To achieve adequate management support, primary healthcare teams need to be aware of family member experiences.

Keywords: Dementia; Family members; Primary healthcare team; Nursing home; Experiences

Introduction

The development of health and economic systems has contributed to an increased life expectancy of the population worldwide. Consequently, the possibility of developing chronic non-communicable diseases (e.g. cardiovascular disease, cancer, chronic obstructive pulmonary 4 disease, neurologic disease and diabetes) and specific degenerative diseases among older people increases as well (Benziger, Roth, & Moran, 2016). One of these diseases is dementia, which is not part of a healthy ageing (Walmsley & McCormack, 2016). It is estimated that 7.7 million people worldwide develop dementia (Chen & Lin, 2019).

Providing appropriate healthcare and support services allows older people living with dementia to live in community settings as long as possible (Foley, Boyle, Jennings, & Smithson, 2017). Such healthcare and home support for people living with dementia at home can be provided by community nurses, help at home and home care assistants, personal assistants, residential daycare in nursing homes, and partial payment for family members (FM) wages lost due to caring responsibilities (Genet et al., 2011; Meglič Črnak et al., 2014). Forbes et al. (2012) describe six stages of dementia care progress from the FMs perspective: recognizing the symptoms, receiving a diagnosis, losing independence, initiating and using home care and respite services, long-term care placement, and end-of-life care-related decisions. It is known that the progression of dementia from the FMs perspective involves small changes in everyday life, adaptations to everyday life, and their loss of everyday life (Clemmensen, Busted, Søbørg, & Bruun, 2019). If the FMs get enough support from the primary healthcare team, nursing home placement could be delayed (Giezendanner et al., 2019). As the disease continues and progresses, it is even more important for FMs to be supported by dementia care services (Lord et al., 2020). FMs often wonder for how long they will be able to take care of an older person living with dementia at home and when it is time to seek help to alleviate the significant burden often felt by the whole family (Cole, Samsi, & Manthorpe, 2018). Cole et al. (2018) also found that there is no “right time” to move the loved one to a nursing home, but the decision is often made when it is realised that care at home is no longer sustainable.

FMs who care for an older person living with dementia allow them the most extended inclusion in their home environment and postpone moving to a nursing home (Koplow et al., 2015). Caring for loved ones with dementia is strongly associated with depression, anxiety, sleep disorders, and emotional burden in FMs (Chang, Chiou, & Chen, 2010; Graneheim, Johansson, & Lindgren,

2014; Rosa et al., 2010). When they can no longer provide care, many FMs consider a nursing home placement (Cole et al., 2018; Foley et al., 2017; Graneheim et al., 2014). A nursing home placement of an older person living with dementia is one of the most challenging decisions for FMs, even though registered nursing staff can provide 24-hour nursing care (Graneheim et al., 2014; Seiger Cronfalk, Ternestedt, & Norberg, 2017). FMs can feel anger as they cannot take care of their loved one living with dementia (Graneheim et al., 2014; Lord, Livingston, Robertson, & Cooper, 2016). FMs can also feel guilt, loneliness, sadness, and disappointment at letting down the loved one by deciding to move to a nursing home (Cole et al., 2018; Graneheim et al., 2014; Høgsnes, Melin-Johansson, Norbergh, & Danielson, 2014; Seiger Cronfalk et al., 2017). Such decision can be extremely difficult, especially if FMs have inadequate support (Lord et al., 2016) or even don't get it. There are various modes of support (Goeman, Renehan, & Koch, 2016), but the experiences of FMs with such help and support are not researched enough. However, there is a gap in the experience of FMs in providing help and support since diagnosis, progression dementia, and providing support in their subsequent placement a loved one in a nursing home. Lord et al. (2016) recommended further research on improving providing help and support to FMs and caregivers of people with dementia. For that reason, this study presents the FMs experiences with receiving help and support while their loved one was developing dementia and their subsequent placement in a nursing home.

Method

Study Design

We carried out a qualitative descriptive approach (Sandelowski, 2000), using in-depth interviews. The qualitative descriptive design allows the researcher to get closer to the data and offers a comprehensive summary (Sandelowski, 2000) of FMs experiences with developing dementia and the subsequent placement of their loved ones in the nursing home. The consolidated criteria for reporting qualitative research (COREQ) was used (Tong, Sainsbury, & Craig, 2007).

Setting and participants

We used purposive sampling (Polit & Beck, 2012; Polit & Beck, 2017). The study was undertaken in several nursing homes in Slovenia's North Eastern region. We targeted FMs who

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have experiences with their loved ones developing dementia and their subsequent placement in a nursing home. A total of 274 family members were identified from nursing homes' electronic data systems and invited to participate in the study. The FM who gave the consent was chosen randomly. In qualitative research, there are no strictly recommended criteria regarding how many participants should be included (Polit & Beck, 2012; Polit & Beck, 2017). However, we followed the Creswell and Creswell (2018) suggestion of the required sample size in qualitative studies between five to 25 participants. Twenty-four FMs consented to participate in the study voluntarily and without any remuneration. For the recruitment of participants, we followed eligibility criteria (Table 1).

Table 1. Eligibility criteria for including participant

Data collection and analysis

Data were collected through in-depth interviews between March and May 2018 by the first author. Open-ended questions were used as present in Appendix 1. All the interviews were held in a private visitor's room in the nursing home where privacy and absence of interruption were assured. At the beginning of each interview, demographic data were collected. The researcher conducted one interview with each FM, which lasted between 40 and 70 minutes. Data collection ended after 19 interviews started to reach data saturation (Polit & Beck, 2012; Polit & Beck, 2017). Five FMs who gave consent was not included in the study. We send them a thankyou note. All the interviews were audio-recorded, verbatim transcribed, and analysed without returning to participants for comment and/or corrections.

An inductive approach with thematic analysis was based on Braun and Clarke (2014) guidelines. All transcripts were anonymized to protect participants' identities and also checked for accuracy. All the interviews were imported into the ATLAS.ti 8 program. The analytical process involves (1) repeated listening of the recordings until a sense of the interview was achieved, (2) line by line coding independently by three researchers, and then all four researchers together (3) synthesised codes into themes, (4) review themes, and (5) named themes (Braun & Clarke, 2014). All the discrepancies were discussed between authors until a consensus was reached. Each stage of data analysis was reinforced using the field notes.

Ethical considerations

Before the research commenced, approval was gained from the relevant ethics commission (038/2018/1273-2/501). The participants were informed in writing of the purpose and objectives of the study. Furthermore, it was made explicit that participation was voluntary, anonymity and confidentiality were guaranteed, and withdrawal from participation at any stage of the research was possible. The study strictly adheres to the ethical principles of the Declaration of Helsinki (World Health Organization, 2001), and the provisions of the Oviedo Convention (Council of Europe, 1997).

Findings

Nineteen interviews were completed with 12 (63.2%) females and 7 (36.8%) males. They were all in a close relationship with older people living with dementia in a nursing home. Three (15.8%) of them were spouses of the older people, and eleven (57.8%) were children of an older person living with dementia; five (26.4%) were grandchildren (Table 2). The average length of stay of the older people living with dementia in the nursing home at the time of this study was one and a half years. Almost all interviewed FMs visited their loved one every day (10.5%).

Table 2 . Socio-demographic characteristics of participants ($n = 19$)

The inductive thematic analysis led to the identification of two main themes: (i) Developing the diagnosis and (ii) Accommodation process (Table 3).

Table 3. Overview of data synthesis consisting of main themes, subthemes and associated codes.

Developing the diagnosis

Within the main theme "Developing the diagnosis", two secondary level subthemes were identified: Expressed changes and Searching for help.

Expressed changes

All interviewees ($n = 19$) observed changes in the older person, i.e. the changes were not typical for normal behaviour. The most shocking for them was that their loved one was no longer recognising them and could no longer talk to them and that they repeated words or the same questions constantly. We named them cognitive changes:

FM3: "...when she did not recognise us...she did not even know who we are... This was the worst experience in my life..."

Besides cognitive changes, behavioural changes began to occur in the older person living with dementia. Family members ($n = 14$) pointed out that they had the most problems at night. Night wandering episodes were also presented, and the older person living with dementia began to confuse night and day. The FM had to get up at night and look for their parents, husband or wife.

FM12: "I had to stay awake with him at night because he could not sleep and wandered around...he asked to make him coffee because he thought it was a day."

Others ($n = 5$) had problems with clothes because the person was not aware that they went out naked in the street looking for their clothes. One FM felt ashamed because neighbours mocked them while they did not know what was happening.

FM18: "He took his clothes off and ran naked along the street so that all his neighbours could see him."

All FMs described how the symptoms intensified and led them to consider the option to move their loved one to the nursing home. Signs that the disease began to appear can progress slowly, unequally or steadily. Family members had to face that their loved ones could not perform daily living activities without help and support. They were no longer reliable in their mobility, and incontinence began to appear. If they had been exposed to various infections, their disease deteriorated. Such behavioural changes lead FMs to the crisis moment. At that point, they realised they could not take care of them anymore. They decided to find some help.

FM 4: "She became very aggressive in the end. We felt frightened."

Searching for help

The interviewees ($n = 19$) at first did not realise all the symptoms, or they did not see them as genuine. As soon as they realised that they would need help, they tried to search for solutions. Most often, they turned to a primary healthcare team, and they also sought out help from various institutions.

FM9: "We turned to healthcare system, and they just gave us some flyers. We were very disappointed as we expect much more solid support."

Dissatisfaction regarding help from the primary healthcare team could be identified from all the FMs' data, which suggests that there is insufficient assistance available in Slovenia from voluntary organisations and dementia care services.

FM16: "Well...we even do not know that we could get help from home assistance...We first heard about voluntary organisation [referring to Spominčica – Alzheimer Slovenia] after few months grandfather living in the nursing home."

Only one FM got support from the voluntary organisation in the form of telephone-advice how to communicate with people living with dementia.

FM17: "...I was so despaired... I do not know how to talk with him, because he was so aggressive... I just called the number on that flyer..."

All FMs showed interest in finding information because they searched for it to a significant extent via television, radio and the internet.

FM15: "I heard and read what they publish daily in newspapers."

The interviews showed us that all FMs were visibly disappointed by a country that did not offer them adequate assistance.

Accommodation process

Within the second main theme "Accommodation process", three secondary level subthemes were identified: Adjusting; Experience and Caring.

Adjusting

When the FM was faced with transferring an older person living with dementia to a nursing home, they found this very difficult. A person accepts decisions in different ways and reacts to given situations differently, but in all respects, emotions are often what guide people. Guilt, sadness, anger, shame and fear were mostly expressed by many FMs ($n = 17$).

FM4: "It is complicated for me because my mother never wanted to go into a nursing home, she never agreed with me, and it is so much harder to take such decisions, because of my feeling of shame and guilt, that I cannot take care of her anymore..."

FM19: "... I was so sad... I felt that I disappointed him... My family were not able to take care of him anymore while we give our best... My feeling of sadness is harrowing, as he does not recognise me anymore..."

The disease progressed to the point that the FMs ($n = 19$) must decide on nursing home accommodation. Some ($n = 7$) interviewees already had to take this decision while their loved one was in the hospital, as the condition was such that it was not possible to care for them at home. The results show how difficult it is for them to face such a decision.

FM11: "It is a challenging moment... You try to throw it off as if it does not matter, but it touches you very deeply... then it went so far that my mother and I were exhausted..."

Experience

We noticed that all FMs had spent difficult moments during the transfer of their relative to a nursing home. Furthermore, the FM realised that the decision was taken, but they were allayed when they realised that their loved one received all the necessary care.

FM4: "... it is not good, but it does not seem to be something terrible, what comes just comes, and you must somehow accept it."

With all the decisions and strong emotions, some interviewees felt that they had done everything they could to help them. Once FMs experience the nursing home placement as the last station for the loved one, it takes some time to accept those feelings.

FM15: "I am very calm because I know that I have done everything in my power."

Caring

The nursing staff greatly influence the life of the older person living with dementia in nursing homes. All FMs want their loved ones to get all the care that they could not provide them at

home. Nursing staff establish a special bond with the family. When FMs come to visit, they can see the staff are professional and working hard to perform professional care and do everything for their loved one. Hence, FMs are satisfied with the kind and friendly caring staff attitude.

FM5: "... I think that the staff here do everything for my mom, and it seems to me that it would be unfair to demand any more of them."

They are grateful that staff care so well for their loved ones.

FM1: "... the warmth that this person gets is essential."

The FMs observe the situation in the nursing home. With this, FMs ($n = 12$) expect that caring can be even better and that the situation can still improve. The FMs ($n = 7$) noted that the staff were overburdened. They believe that there is not enough staff.

FM2: "There could be more staff, and I find it sad that in the afternoon, only two persons are working, I think that is far too few personnel..."

Some FMs advised that more staff should be appointed. Family members wish that their loved one could spend more time in the natural surroundings with the staff in attendance and have access to more activities. If so, they could then devote themselves to each loved one in their unique way, and thus the family could also spend more time with the older person.

FM1: "It would be good if the physiotherapist would deal with them, and even only move their hands a little. In the afternoons, a person could be engaged in some activity, like a memory or mind game. For example, one person could be solely responsible for this."

Despite the emotional challenges associated with placing their loved ones in the nursing home, some FMs felt that ultimately it enabled them to go on with their lives. Some FMs continue to struggle with emotions like guilt and sadness, notably during visits to the nursing home. Most FMs expressed that their loved one appeared to be happy when they visited the nursing home.

Discussion

This study aimed to investigate FMs experiences of their loved one developing dementia and their subsequent placement in nursing homes.

In all interviews, the FMs noticed behaviour changes in their loved one that was not usual before they developed dementia. Most shocking for them was discovering that the loved one living with dementia sometimes no longer recognised them and repeated the same words and questions. They decided to seek help from their primary healthcare team because the situation was unmanageable. The FMs expressed that they did not get enough support from their primary healthcare team. For example, the family doctor gave them "only two flyers", and the FMs did not receive enough verbal information from the primary healthcare team about what to expect and how to prepare. Based on that, the FMs tried to get pieces of information on the internet and other media about what dementia is and how to care for a person living with dementia. According to the interviewees, much more should be done in advertising and awareness-raising. Help was not sought from voluntary organisations, because they did not know they existed.

With the advancing symptoms of dementia, the increasing burden on FMs led to a point where they could not cope anymore. When FMs experience a lack of support and symptoms increase, a decision for nursing home placement is often made. Research findings frequently reported that professionals showed poor recognition of behavioural and psychological symptoms of dementia and FMs' burdens as the most common reasons for care placements of older persons living with dementia (Chang & Schneider, 2010; Lord et al., 2016; Toot, Swinson, Devine, Challis, & Orrell, 2017). Findings from this study also show that FMs need help when their loved ones develop dementia, and they search for help from the primary healthcare team as the first point of contact. FMs experiences show that they have not received adequate support or assistance from primary healthcare teams, deepening their sense of burden (Cole et al., 2018; Lord et al., 2016). Reducing FMs burden and postponing transfer to a nursing home can be ensured by appropriate assistance from the primary healthcare team and adequate support of other dementia care services. According to Cole et al. (2018), the shortage of adequate support to FMs is a significant indicator for deciding to move their loved ones into a nursing home. The biggest problem highlighted by the FMs is the lack of support and continuity from the diagnosis, the disease progression, and especially when deciding for home placement.

After the decision is made, FMs mostly expressed guilt, fear, anger, and shame while preparing their loved ones for nursing home placement. Similarly, other researchers also reported fear (Hellström & Torres, 2016; Kristiansen, Normann, Norberg, Fjelltun, & Skaalvik, 2017), loneliness, guilt, sadness (Graneheim et al., 2014), pain and emotional distress (Argyle, Downs, & Tasker, 2010). We found that guilt and helplessness were mostly felt by those FMs who did not want to place their older person living with dementia, but the situation forced them into it. The most common reasons for placement were the need for professional care, a lack of help and support at the primary healthcare level and other organisations (Lord et al., 2016). Behavioural and psychological symptoms of dementia are common (Resnick et al., 2018), and when they increase, this leads FMs to the crisis moment to decide on nursing home placement. The most common reasons were progressive symptoms of dementia and an inability to care at home.

Similarly, Graneheim et al. (2014) reported FMs feelings of guilt while being forced to decide about nursing home placement. Adequate support from nursing home staff helps reduce FMs feelings such as guilt, sadness, fear, anger, and helplessness (Graneheim et al., 2014; Lord et al., 2016). Nursing home staff have an essential role in providing emotional support in reducing burden and depression among FMs (Müller, Lautenschläger, Meyer, & Stephan, 2017). The FMs reported that their concerns were allayed when they were satisfied with the nursing care provided to their loved ones. Graneheim et al. (2014) also reported that FMs were satisfied when their loved one received good quality of care. Their satisfaction and gratitude for caring, warm-heartedness, kindness, professionalism, and trustworthiness of the nursing staff were also highlighted in this study. Our study results are consistent with those of Seiger Cronfalk et al. (2017), who found positive experiences of relief and reassurance that their loved one had sufficient care and lived in a safe environment. Verbeek (2017) stated that cooperation with family, nursing staff and the loved one is essential and a crucial element of person-centred healthcare (Chen, Lin, Chen, & Loh, 2017; McCormack & McCance, 2006). Nursing staff must be educated and trained in providing adequate support and help to FMs. Nursing management must create the conditions for FMs to be provided with continuous help and support from the diagnosis, during the disease's progression, and during nursing home placement making-decision. This help and support must be available from both the primary healthcare team, social services, nursing homes and organizations and societies. It is important that all institutions are connected and work well in coordination with each other. Only in this way will FMs receive

appropriate and timely professional help and support that will give them a sense of security. 24-hour telephone call help should be considered, where FMs in need can get help and support immediately.

Strengths and limitations

As this is a qualitative study drawn from interviews with 19 FMs of people living with dementia the results are not generalisable but may be relevant to other FMs coping with the decision of nursing home placement and also for the primary healthcare team members. This study presents a snapshot of the situation in Slovenia and could be transferable to other countries with similar health systems. The sample was quite heterogeneous concerning gender, age, and family relationship. Therefore, the sample may also have an impact on the transferability of findings. To minimise the impact of subjectivity in the analytical process, all the authors participated in the data analysis to strengthen interpretation and ensure credibility. However, this study throws light on an essential aspect of dementia care from the perspective of FMs and the lack of support from the primary healthcare team.

The implication for nursing management

Our findings have significant implications for nursing management and clinical practice. When FMs detect behavioural changes of their loved ones, the management has to establish the primary healthcare team's conditions to ensure the early recognition of dementia and provide enough emotional support and information. Primary healthcare teams have to be informed and aware of FMs experiences with facing the diagnoses and decision of nursing home placement of their loved one. It is also crucial that primary healthcare teams cooperate well with organizations and societies to advocate for help and support for FMs, helping reduce the distress and burden of FMs of people living with dementia.

Furthermore, it is necessary to investigate the most effective and supportive ways for FMs to provide care for a person living with dementia at home for as long as possible. Our findings show that the primary healthcare system is not effective in establishing an early diagnosis. There is also a need to determine why adequate support and management for FMs are not provided at the primary healthcare level and determine when the optimal time for moving an older person living with dementia into a nursing home.

Conclusions

The findings of this study can help FMs and primary healthcare teams in understanding and cope with nursing home placement decisions for an older person living with dementia. Primary healthcare teams must be competent in early diagnosis and provide sufficient support to FMs in reducing feelings of guilt while they have to decide on a nursing home placement.

In this study, insufficient diagnosis and lack of support at the primary healthcare level were found. Further research should be conducted to establish the primary healthcare system's gap in establishing an early diagnosis to provide adequate support for FMs.

There is also a need for further research to explain the differences from the spouse, son, or daughter perspective of their nature of the lived experience of their loved one developing dementia and their subsequent placement in a nursing home.

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Table 1. Eligibility criteria for including participant

Research sample / population	Inclusion criteria	Exclusion criteria
	Adult persons (18+ years) that they were a spouse or next of kin or the child of the residents	Children up to 18 years and they are not next of kin
Family member	The residents of the family member had a diagnosis of dementia	The residents of the family member had no diagnosis of dementia
	The residents of the family member had lived in the nursing home for at least one month	The residents of the family member of newly placed residents (less than one month)
	The family member visits the residents at least once a week	The family member visits their loved one less than once a week.

Table 2. Socio-demographic characteristics of participants ($n = 19$)

Variable	Frequency	Percentage
Age		
< 40	5	26.3
41 - 50	4	21.0
51 - 60	7	36.9
61 - 70	3	15.8
Sex		
Female	12	63.2
Male	7	36.8
Education		
Secondary school	11	57.9
High School	2	11.0
Bachelor degree	4	21.0
Master/Doctoral degree	2	11.0
Occupation		
Employed	12	63.2
Unemployed	4	21.0
Retired	3	15.8
Relationship		
Son	4	21.0
Daughter	7	36.9

Variable	Frequency	Percentage
Spouse	3	15.8
Grandson/daughter	5	26.3
Frequency of Visits		
Every day	2	10.5
Several times a week	5	26.3
At least once a week	12	63.2
Loved one living with dementia at home (years)		
< 1	1	5.2
1 - 3	11	57.9
4 - 6	7	36.9
Length of loved one living in the nursing home (months)		
< 1	2	10.5
2-6	5	26.3
7-12	7	36.9
> 12	5	26.3

Table 3. Overview of data synthesis from main themes, subthemes and associated codes

Main themes	Secondary level subthemes	Descriptive primary level subthemes	Free codes
Developing the diagnosis	Expressed changes	Cognitive changes	Repetition; Word-finding difficulties; Forgetting; Difficult communication; Difficulty with identifying faces or objects
		Behavioural changes	Disorientation at night; Anxiety; Running without clothes; Dehumanising
		Crisis moment	Incontinence; Fall; Steep progression; Infection
	Searching for help	Advice	Not enough advice form primary healthcare team; Not enough advice psychiatrist
		Assistance	Home support; Not enough support; Family support
		Information	Too late; Family doctor does not give enough information; Looking for information by yourself; Not enough written material; Voluntary organisations
		Media	Daily newspaper; Internet; Radio; conversation
Accommodation process	Adjusting	Emotions	Lousy conscience; Tears; Crying; Feeling bad; Feeling guilty; Sadness; Fear; Anger
		Feelings	Feels sorry; Strong; Fatigue; Did not deserve; Deeply touched; Shame
	Experience	Become reconciled	No longer able; Destiny; Come what may
	Caring	Staff	Kind-hearted person; Friendly staff; Satisfaction; Trust; Overburden; Professional care