

Research Article

The Well-Being of People with Dementia in Sweden and Hungary from the Perspective of Relatives: A Qualitative Interview Study

Jenny Nilsson ¹, Judit Staller ^{1,2}, Berit Gesar ^{1,3} and Ingrid From ¹

¹School of Health and Welfare, Dalarna University, 79188 Falun, Sweden

²Department of Nursing, Faculty of Health Sciences, Semmelweis University, 1088 Budapest, Hungary

³Department of Orthopaedic, Falun Hospital, Falun, Sweden

Correspondence should be addressed to Ingrid From; ifr@du.se

Received 11 November 2022; Revised 13 May 2023; Accepted 23 June 2023; Published 22 July 2023

Academic Editor: Tommaso Martino

Copyright © 2023 Jenny Nilsson et al. This is an open access article distributed under the Creative Commons Attribution License, which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

Background. Dementia not only has a negative effect on a person's well-being, but it also affects the well-being of their relatives. In this study, we examined how relatives perceive the well-being of people with dementia who live in nursing homes and how nursing staff contribute to the well-being of the residents they care for. **Method.** A qualitative study with a phenomenographic approach was applied. Ten individual semistructured interviews were conducted, five in Sweden and five in Hungary. In this study, the COREQ checklist for qualitative studies was followed. **Results.** The perceptions relatives had of what constituted well-being resulted in five categories of factors that could impact negatively or positively on a person's well-being: "Nursing care is adapted to the needs of the person with dementia," "Nursing is carried out by a sustainable care team," "The social needs of the person with dementia are met," "The person with dementia participates in meaningful activities," and "The person with dementia shows signs of feeling well." **Conclusion.** From relatives' perspective, well-being can be created for people with dementia if nursing is person-centred and managers allow staff more time to socialize with the person with dementia. Relatives are essential cooperative partners in person-centred dementia care. **Relevance to clinical practice.** Person-centred care is essential. Relatives, nurses, and managers are important partners in making it possible. Competence in dementia and knowledge of values and ethics are needed to provide autonomy and well-being. **Patient or Public contribution.** Ten relatives were selected through purposive sampling. In Hungary, the relatives were invited to take part in the study and given information about it by an operational manager. In Sweden, this process was carried out by a dementia nurse. Transcribed content of semistructured interviews was analyzed using a phenomenographic method.

1. Background

More and more people are living longer, and the proportion of the population over 65 years is increasing both in Sweden and Hungary [1, 2].

Dementia has a negative effect on a person's quality of life and well-being [3]. Vince et al. [4] underlined that the psychological and social aspects of a person's life were crucial for the experience of well-being for people with dementia. Well-being could be maintained if those with dementia were able to maintain their previous lifestyle as much as possible and maintain a sense of identity.

When a person suffers from dementia, relatives are also affected by the disease [5]. Dahlrup [6] described how the relatives of people with dementia often experience a stressful life situation, due to constantly having to support the person with dementia. By close collaboration between family members and caregivers which is the basis of person-centred care, family members can not only share and receive personal but also professional knowledge. This in turn leads to an improvement in the daily life of the person with dementia in a nursing home [7, 8].

People with dementia often suffer from various behavioural and psychological symptoms of dementia (BPSD) [9];

in fact, 80–90% of people with dementia have some form of BPSD [10]. Symptoms of BPSD can be delusions and hallucinations and also behavioural issues such as shouting, anger, screaming, confusion, suspicion, and disturbed circadian rhythm [11]. There is no general treatment for BPSD; thus, the symptoms must be identified, interpreted, and seen in their context before measures are proposed [12]. According to Maki et al. [9], person-centred care is the best method of care for both care recipients and family members. It is planned interprofessionally with the family based on the person’s life story [13]. Person-centred care leads to lower levels of BPSD and increased well-being, particularly in older people’s care and among people with dementia [14].

Studies have shown that dementia and well-being can be reconciled. By having a person-centred approach, where the needs of the people with dementia are in focus, better care can be provided. It is essential to ask for and use the perspective of family members since relatives can support caregivers in their care work. Therefore, the aim of this study is to describe how relatives perceive the well-being of people with dementia who live in nursing homes in Sweden and Hungary.

2. Methods

2.1. Study Design. Empirical qualitative inductive research method was chosen, using semistructured interviews conducted in Sweden and Hungary and analysed by using a phenomenographic approach. This study followed the COREQ checklist for qualitative studies.

2.2. Sample. A total of ten relatives were interviewed (for characteristics see Table 1). The participants were selected through purposive sampling performed by a dementia nurse in Sweden and by an operations manager at a nursing home in Hungary. The criterion for inclusion in this study was that the participants were related to a person diagnosed with moderate or severe dementia and that the person with dementia had been living at the nursing home for at least six months.

2.3. Setting. In Sweden, four interviews were conducted in a separate location at the nursing home where the person with dementia lived and one was performed using digital communication due to the COVID-19 pandemic lockdown. In Hungary, four interviews were performed using digital communication due to the COVID-19 pandemic lockdown and one in a separate location at the nursing home.

2.4. Data Collection. An information letter and consent form was sent to the nurse responsible for the dementia care in the municipality in Sweden and a manager at the nursing home in Hungary. The interviews were semistructured and lasted between 20 and 40 minutes each, and an interview guide was used. The interview guide contained four open questions which focused on well-being.

TABLE 1: Characteristics of participants.

Number of participants	Country	Gender	Relationship
1	Hungary	Woman	Daughter
2	Hungary	Woman	Daughter
3	Hungary	Man	Grandchild
4	Hungary	Woman	Daughter
5	Hungary	Woman	Wife
6	Sweden	Woman	Partner
7	Sweden	Man	Son
8	Sweden	Woman	Partner
9	Sweden	Woman	Daughter
10	Sweden	Woman	Daughter-in-law

2.5. Data Analysis. The recorded interviews were transcribed after all interviews had been completed. The material was then condensed by each interviewer separately. The authors analysed the material together. A phenomenographic analysis was carried out according to the following steps [15]. The transcribed material was read thoroughly so that the authors *got to know the material*. The material was *condensed*, and the most relevant statements in the material were selected and then *compared*. Elements which appeared similar were *grouped* into categories. *Articulation* was then made to describe the essence of each category. Appropriate names were chosen so that the categories were *labelled*. The labelled categories were *contrasted* with each other in relation to similarities and differences.

2.6. Ethical Aspects. Ethical permission was approved by the Research Ethics Board (FEN) at a university in Sweden (Reference ID: 7.1.1-2020/1250) and by the Hungarian Medical Research Council in Hungary (Reference ID: IV/704-1/2021/EKU).

3. Results

The analysis resulted in five qualitative descriptive categories that describe how relatives perceive well-being of the person with dementia (Table 2).

3.1. Nursing Is Adapted Based on the Needs of the Person with Dementia. All the participants perceived that if the nursing care is adapted based on the needs of the person with dementia, the person with dementia experienced well-being. If the person with dementia showed signs of feeling good, this indicated that the caregivers had noticed the needs of the person with dementia and their situation. But the participants wanted the caregivers to pay more attention to symptoms of ill health and inform the relatives about this to a greater extent than what was currently done. In Hungary, it was considered that increased confidence in the caregivers could arise when they listened to the relatives and could give a more detailed account of how the person with dementia was doing.

“So, if you see that your mother is okay /.../. Then it’s soothing, yes. Because it means that they are aware of how she is.” (Hungarian participant 2).

TABLE 2: Categories that emerged based on the interviews.

Relatives perceive that the person with dementia can experience well-being when				
Nursing care is adapted based on the needs of the person with dementia	Nursing is carried out by a sustainable care team	The social needs of the person with dementia are met	The person with dementia participates in meaningful activities	The person with dementia shows signs of feeling well

The Hungarian informants expressed shortcomings in meeting the basic needs of the person with dementia. The assumption was that the caregivers were not able to detect whether the person with dementia needed new clothes or help with feeding. The fact that the basic needs of a person with dementia were not met by caregivers was perceived having a negative impact on the well-being of a person with dementia.

“/.../ he had been wearing the same T-shirt for five days, a dark green, short-sleeved T-shirt. Not his at all /.../. No long sleeves, even though I have left warm clothes.” (Hungarian participant 5).

If caregivers had an empathetic and professional approach, this had a positive effect on the well-being of the person with dementia.

Things that were perceived as professional by the informants were when the caregivers were happy, could joke, and could deal adequately with difficult behaviour from the person with dementia.

“He likes when caregivers speak with “straight pipes” and he likes to joke, he needs that kind of personality around him to feel good.” (Swedish participant 10).

According to the participants, it was important for the well-being of the person with dementia that caregivers had come to know the care recipients and their life story. When the caregivers knew their life story, they could avoid situations where the person with dementia became angry or upset.

“/.../ if someone has had difficult experiences, the staff knows this, and they can be more careful when they take care of them.” (Hungarian participant 3).

Particularly important for the well-being of the person with dementia was the fact that the caregivers motivated and encouraged the person with dementia to participate in joint meals or other activities at the nursing home. The participants believed that this should be done even if the person with dementia did not want to participate in the activity. In Sweden, the participants believed that it was possible to motivate the person with dementia by being happy and radiating positive energy around them and that this approach had a positive effect on the well-being of the person with dementia. The Swedish participants emphasized, however, that the staff must also respect the fact that sometimes the person with dementia did not want to participate and displayed this. In Hungary, on the other hand, it emerged that participants felt that the person with dementia

should not always decide for themselves whether or not they would participate in activities.

“/.../ once my mother said she did not want to go, it was decided that she would stop going there. It should not be left to them (the decision), the staff should exert a little more pressure /.../. She was never allowed to go on excursions even though I paid for it.” (Hungarian participant 1).

From both countries, the participant said that the autonomy of the person with dementia was not always respected. In Hungary, this could be reflected in the staff pulling up the bed gates so that the person with dementia could not get out of the bed and in Sweden that the person with dementia was not allowed to choose their clothes themselves. The informants said that the person with dementia found it frustrating when they did not get or could not do what they wanted anymore after moving into the nursing home and that they were dependent on help from others.

“/.../ what can increase well-being is if they can be as independent as possible /.../. as in my mother’s case who does not realize that she cannot go to the toilet herself. It is the lack of independence that is difficult for her to accept.” (Swedish participant 9).

In the Hungarian interview, the perception was that the caregiver’s view of their work affected the well-being of the person with dementia. If the caregivers had empathy and did their work in a good way, the participants had confidence in the staff, which in turn had a positive effect on the well-being of the person with dementia. When there was a specific person in the care staff who was responsible for the person with dementia, it had a positive effect on the well-being of the person with dementia.

3.2. Nursing Is Carried Out by a Sustainable Care Team.

There was consensus among the participants regarding the influence of the team of caregivers on the well-being of the person with dementia. The participants “praised” the caregivers and felt that they were doing a good job, but that shortage of staff resulted in shortcomings in nursing care. It could result in the person with dementia not receiving stimulus or outdoor activities as they needed and a stressful workload for the carers. The participants felt that, in a dementia nursing home, “life” should be a little slower; thus, it takes more time for people with dementia to do things.

“/.../ there is not enough staff to take them out in the garden and stay with them there for support and supervision.” (Hungarian participant 4).

A high rate of staff turnover with lot of temporary staff had a negative impact on the well-being of the person with dementia. The Swedish participants emphasized that it was not appropriate to have a lot of temporary staff in a dementia care nursing home. It was important that person with dementia had caregivers they recognised and that the caregivers knew the person with dementia. It was also very important that the caregivers worked according to the same routines. They must have the same people around them.

“There have been a lot of new staff last year and then the old people get very worried.” (Swedish participant 8).

Some dissatisfaction was expressed by the participants in Hungary who felt that the caregivers could do more for the person with dementia as relatives pay a fee for the care provided. The participants in Hungary also emphasized the importance of management presence, competence, personal qualities, and leadership skills, as these had a great influence on the staff's working methods and working conditions in the nursing home.

“The attention and competence of the management is what is most important.” (Hungarian participant 1).

3.3. The Social Needs of the Person with Dementia Are Met. If the social needs of the person with dementia were met, this could create well-being. This could be achieved, for example, by having the caregiver close by, providing comfort and holding hands. The interviews revealed that companionship was important for well-being and that the most important aspect of companionship was being able to talk to others and be part of a group.

“When you can sit down and talk to him, to sit like this and talk, that he loves. To be able to talk a little about old times and the people he remembers.” (Swedish participant 10).

Visits by relatives could lead to well-being, and this was also something that the participants from both countries agreed on. According to the participants, those with dementia appreciated visits and seemed happy when they saw relatives. The participants also described how the person with dementia was able to show that they missed their relatives. Due to the restrictions in the community caused by the COVID-19 pandemic, relatives had not been able to see the person with dementia as much as before. Relatives perceived that this could lead to the person with dementia forgetting about them or feeling lonely.

“/.../ when he has not been allowed to meet anyone for a long time, it has been difficult. It's almost like he's forgetting them. It is not kept alive” (Swedish participant 8).

In the Hungarian interviews, they expressed a desire for the institution to create more options for socializing for people with dementia. This emerged as a result of the COVID-19 restrictions in the community.

3.4. The Person with Dementia Participates in Meaningful Activities. The participants agreed that meaningful activities for people with dementia could create well-being. The meaningful activities consisted of activities based on the interests of the person with dementia. The activity could consist of going outside, playing games, looking at photos, and reading books. The participants believed that if the person with dementia was stimulated, their cognitive abilities would not decrease as quickly as they did without stimulation.

Outdoor activities could create well-being for the person with dementia according to the participants. For example, being able to sit on a nice patio or in the garden was perceived to create a sense of well-being for the person with dementia. The participants felt that the person with dementia was happy when going outside and that being outside could have a calming effect.

“She was a gardener /.../. She loves nature very much. And it so happened that her new room was the second room from the garden /.../. It gave a positive effect which was very good. Already the second day she cleared the weeds.” (Hungarian informant 3).

It was also important to spend time outdoors so that the person with dementia would not experience isolation.

“Because you have to get out, you have to get some fresh air. And get other sights and sounds than what you get in here. Because otherwise you become so totally isolated.” (Swedish participant 9).

There was also a consensus in both countries that entertainment could create well-being for the people with dementia. Entertainment could consist of various group activities such as music, singing, drawing but also reading loud or participating in dog or music therapy as the Hungarian participants mentioned. However, the participants indicated that all group activities were currently paused due to the restrictions imposed by the COVID-19 pandemic.

Entertainment could also consist of spontaneous activities such as going out into the garden, watching TV together, or putting on some calm music when the person with dementia was going to rest. Calm music in the common dining room could result in the person with dementia starting to talk to other people. Music could also lead to a sudden return of mobility in person with dementia who had previously been barely able to move. Physical activity and movement were also something that informants felt could lead to well-being in the person with dementia, as was evident in the interviews in Sweden. However, the participants felt that physical activity did not happen to the extent that they would have liked and that physical functions decreased if the person with dementia was not allowed to move.

“He could even talk when he was allowed to move. It takes everything away when you are not allowed to move.” (Swedish participant 6).

3.5. *The Person with Dementia Shows Signs of Feeling Well.*

The informants described various signs that indicated that the person with dementia was experiencing well-being. These signs included when the person with dementia was perceived as happy when they laughed or described in words that they were having a good time.

“He has gained weight, so he is happy, he is well and happy. And the staff also say that he is a good and happy old man” (Swedish participant 10).

The participants also described various signs that indicated that the person with dementia was experiencing anxiety. Anxiety could arise in the person with dementia if someone disagreed with them or if there was a very noisy environment around them. A sign of anxiety was when the person with dementia showed signs of depression. This could be manifested by them calling their relatives and crying and complaining. Other signs of distress described were when the person with dementia was “fussy” or had “sleeping days” and when the person with dementia showed signs of suspicion or jealousy.

“She says that she thinks there is another lady here at the accommodation that dad longs for. / . . . / then she’s sorry for that.” (Swedish participant 9).

Various impairments related to dementia had a negative impact on the well-being of people with dementia, according to the participants in Sweden. This could be that the person with dementia was unable to express themselves adequately or felt that those around them did not understand what they were saying.

“She is probably suffering deep down, perhaps still from not being able to express what she wants.” (Swedish participant 7).

Participants also described how the well-being of the person with dementia was negatively affected by their impaired senses and that this could lead to isolation.

“/ . . . / She has very poor eyesight as well. // She does not see what is on the plate, but she tries. So poor eyesight and such poor hearing, you get a little.” (Swedish participant 9).

4. Discussion

Well-being, according to the interviewed relatives in this study, could arise if caregivers customized the nursing work according to the needs of the person with dementia. This result is consistent with the person-centred care, in which healthcare staff should have a person-centred approach in which the person’s needs are central [16]. In this study, one of the needs that the person with dementia had could be that the nursing staff had knowledge about the resident’s life story in order to be able to customize the care and treatment for those residents based on this knowledge. A patient’s life

story is one of the key components in person-centred care [17]. Woods and Subramaniam [18] concluded in their study that if the nursing staff know about the life story of the person with dementia, it is easier for caregivers to understand the person with dementia, and Cooney and O’Shea [19] believed that this made it easier to counter BPSD. The results of this study can also be linked to the research of Cooney et al. [20] that showed that if the care staff base their work on the life story of the person with dementia, the interaction can feel enjoyable and create meaning for both the person with dementia and the care staff. Nursing work based on a person’s life story should be a guide in the care work and thus leads to improved well-being and health for both the person with dementia and the care staff and indirectly also for relatives.

It appeared that the person with dementia did not always get their basic human needs satisfied and that impacted negatively on the well-being of the person with dementia. The results are regrettable and were largely because the care staff could not identify the needs of the person with dementia. Most people who work in older people’s care are nursing assistant with a shorter theoretical education in nursing or are staff without any nursing education [1, 12]. In several studies [21–23], it has been shown that professional development among care staff can lead to the care recipient’s quality of life and patient safety improving. Socialstyrelsen [12] also explains that in order to provide good care and attention to people with dementia, care staff need specialised skills in the area. In order for the care staff to be able to deliver person-centred care and pay attention to the individual needs of the person with dementia, it is recommended that an increase in the competence of the care staff is needed. Professional development of care staff should create conditions for the person with dementia to get their needs satisfied and therefore have the opportunity to experience well-being.

The results showed that well-being can be achieved when the social needs of the person with dementia were satisfied. Lawrence et al. [24] concluded in their study that the most appropriate way to spend time with people with dementia was one by one, especially with persons with advanced dementia. Edvardsson et al. [25] researched the closeness of people with dementia and found that if the care staff was close and had a positive and person-centred way with a “cordial,” “warm,” and “fun” approach, this had a positive effect on the well-being of those with dementia. Bollig et al. [26] described that the well-being could be strengthened if the care staff created conditions for social interactions. The relatives wanted the person with dementia to get more visits from family and friends as it could otherwise lead to the person with dementia to forget them and that the person with dementia felt lonely. Ådnanes et al. [27] confirm in their study that it is important for mental well-being that care recipients maintain relationships with their families and friends. It is thus considered important for the informants that the care staff have the opportunity to spend time with the person with dementia. In addition, the care staff should have an easy-going and empathetic approach and those with dementia

are given the opportunity to maintain their social contacts in order to maintain well-being.

In this study, it was considered that well-being could be created if the person with dementia participated in activities that were meaningful. This was something that the relatives wanted the person with dementia to get more of. Istvandy [28] describes in their literature review that entertainment had a positive impact on the mental well-being of people with dementia. The entertainment could create reminiscence and conversations, which was confirmed in the interviews from Hungary where the relatives said they thought that calm music in the dining room contributed to conversations arising between the care recipients. The informants in this study expressed a desire for the person with dementia spending more time together with their carers. Physical activity and being able to move around were perceived as important for the well-being of the person with dementia. Physical activity can lead to improved health and reduced use of medication in people with dementia [29].

The results of the interviews showed that all relatives believed that having a sustainable care team had a positive impact on well-being of the person with dementia. The relatives believed that there were too few care staff and that in the event of a shortage of staff, many different and untrained temporary staff were used. This could result in care staff not being able to provide good care. In dementia care, it is important to strive for continuity where the person with dementia does not encounter too many different people during everyday life [12]. The results showed that leadership was important and that the presence of management had a decisive role in the quality of care as the informants believed that it creates order in the care work structure. Research by Rokstad et al. [30] showed that a management style that is focused on people and relationships is associated with higher job satisfaction. Such management leads to an increased desire to remain at their current workplace and providing better care for people with dementia. The same research also showed that if the manager of the nursing homes took an active part in the care, the care staff saw them as role models [30]. A relationship-oriented and present leadership seems to be preferable in dementia care as it increases the volition of the care staff to remain in the workplace, which in turn leads to less need for temporary staff.

This study showed that relatives felt that the person with dementia experienced well-being when they showed outward signs of feeling well. The result can be compared with the approach that Nordenfelt describes that “when you feel good, you are healthy” [31], p. 31.), when the person with dementia showed signs of feeling well, the relatives experienced the person with dementia as healthier. Health can be explained as a person’s mental and physical condition that is often characterized by the person’s well-being and usually the person’s ability to achieve their goals in life [31]. One way for the person with dementia to experience well-being is when the care staff work to retain their sense of identity and to create the opportunity for the person with dementia to maintain his or her previous lifestyle as much as possible [4]. The results of this study also showed that malaise could occur, and it is considered by the authors of this study that it

is important to work preventively so that malaise does not arise. By using the life story of the person with dementia, it may be easier to understand the person with dementia [18]. Symptoms, such as anxiety, must be interpreted and seen in context before appropriate measures are decided [12]. In order to create appropriate treatment strategies, it is important to involve relatives [24]. Thus, it is considered important that the care staff can work in a person-centred way, which enables the person with dementia to achieve their set life goals. If the care staff is working proactively, with the support of the life story and relatives’ perspective, measures and strategies can be developed for managing people with dementia that are showing signs of malaise. Through such work, the person with dementia should be able to experience well-being instead of malaise.

4.1. Strengths and Limitations. The *trustworthiness* of this study has been ensured in several ways. It has been sought to reflect the participants’ perceptions of well-being as closely as possible to the participants’ descriptions. *Credibility* was increased by the fact that the data collection process was written down and carefully followed. *Credibility* was confirmed by reviewing and evaluating the design and analysis of the study repeatedly during the course of the study by all authors jointly. The informants varied in their characteristics regarding their different relationships to the person with dementia, their different ages, and their different gender. The variation that occurred was not something that was pre-determined and was not part of the inclusion criteria but may have contributed to the *credibility* of the study. The condensed data were analysed and interpreted by all authors continuously which may have strengthened the *credibility* of the study. The interviews provided adequate and appropriate transcribed text and quotations which may have contributed to the *confirmability* [32]. Since the recorded material was transcribed and condensed after all the interviews were conducted and not immediately following each interview, the authors may have reduced the risk of bias influencing the subsequent interviews. The characteristics of the informants have been presented, and the process by which the informants were selected has been outlined. The context in which the interviews were conducted has also been described. Thanks to this information, the results of this study could be *transferable* to other contexts [33]. The *dependability* of the data material, mainly in the category of “*The social needs of a person with dementia are met,*” may have been more obvious because of the COVID-19 pandemic due to the lack of social contact. This can be seen as a weakness of this study.

5. Conclusion

This study provides a basis for the adaptation and ultimate improvement of older people’s care. In so doing, it can also contribute to more cost-effective dementia care. Well-being can be achieved for people with dementia if their care is person-centred and based on their life history. Relatives are an important partner in the development of a more person-centred dementia nursing care.

5.1. Relevance to Clinical Practice. Professional caregivers need to demonstrate an increased awareness of the care recipient's life history and to make this life history central to their nursing practice. They should also look to develop their professional competence so that they can identify the needs of people with dementia and meet them appropriately. Managers should create a care system that allows their professional caregivers to spend quality time with the person with dementia and create good relationships in dementia care so that there is continuity within the work team. Quality time should involve the greater participation of the individual's relatives. Caregivers need to be aware that nursing means supporting the maintenance of social contacts. Developing a set of core values and competences for care providers within dementia care in both Sweden and Hungary is necessary.

Data Availability

No data other than those contained in the study's interview material were used to support the findings in this study.

Consent

All participants gave their consent regarding the publication of the study.

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

JN and JS carried out the design and implementation of work in collaboration with IF. JN and JS collected the data. JN and JS performed the data analysis, and the findings were discussed between all the authors (JN, JS, BG, and IF) continuously, and all the authors contributed to the final results and discussion sections. JN and JS designed, wrote, and discussed the manuscript, and everyone in the research group commented on the script. All the authors have read and approved the final manuscript.

Acknowledgments

We are grateful for the support from all who contributed to the completion of this study. We thank all *informants* for enriching the interviews. We thank *dementia nurse* and *operations managers* for their efficient work of finding suitable informants. We would also like to thank the *university lecturers* for their solid commitment and *student colleagues* for pleasant and enlightening discussions. We thank *relatives* and *friends* for emotional support and last but not the least our *life partners* for their perseverance and loving support.

References

- [1] Government Offices of Sweden, "Framtidens äldreomsorg [The elderly care of the future]," 2018, <https://www.regeringen.se/artiklar/2018/06/framtidens-aldreomsorg/>.
- [2] A. Gyarmati, "Idősödés, idősellátás Magyarországon: helyzetkép és problémák [Aging and care for the elderly in Hungary: situation and problems]," 2019, <http://library.fes.de/pdf-files/bueros/budapest/15410.pdf>.
- [3] R. Dahms, E. Cornelia, and F. Drin, "Evaluation of a music intervention on well-being and behavior of people with dementia using dementia care mapping," *Elderly Health Journal*, vol. 6, no. 2, pp. 122–130, 2020.
- [4] A. Vince, C. Clarke, and E. L. Wolverson, "The meaning and experience of well-being in dementia for psychiatrists involved in diagnostic disclosure: a qualitative study," *International Psychogeriatrics*, vol. 29, no. 1, pp. 93–104, 2017.
- [5] M. Takter and M. Andersson, "Jag trodde det låg på mig... en studie av anhörigas situation vid omfattande omsorg och vård i hemmet [I thought it was on me... a study of relatives' situation at extensive care and care at home]," 2019, <https://motenmedborgarportal.malmo.se/welcome-sv/namnderstyrelser/halsa-varld-och-omsorgsnamnden/mote-2019-12-17/agenda/jag-trodde-det-lag-pa-mig-en-studie-av-anhorigas-situation-vid-omfattande-omsorg-och-varld-i-hemmetpdf?downloadMode=open>.
- [6] B. Dahlrup, *Family Caregiving, a Long and Winding Road. Aspects on burden and Life Satisfaction Among Caregivers from the General Population Study 'Good Aging in Skåne' and Effects of Psychosocial Intervention*, Lund University, Lund, Sweden, 2015.
- [7] K. Ekström, S. Spelmans, G. Ahlström et al., "Next of kin's perceptions of the meaning of participation in the care of older persons in nursing homes: a phenomenographic study," *Scandinavian Journal of Caring Sciences*, vol. 33, no. 2, pp. 400–408, 2019.
- [8] L. J. Hoek, J. C. van Haastregt, E. de Vries, R. Backhaus, J. P. Hamers, and H. Verbeek, "Partnerships in nursing homes: how do family caregivers of residents with dementia perceive collaboration with staff?" *Dementia*, vol. 20, no. 5, pp. 1631–1648, 2021.
- [9] Y. Maki, T. Sakurai, J. Okochi, H. Yamaguchi, and K. Toba, "Rehabilitation to live better with dementia," *Geriatrics and Gerontology International*, vol. 18, no. 11, pp. 1529–1536, 2018.
- [10] J. Cerejeira, L. Lagarto, and E. B. Mukaetova-Ladinska, "Behavioral and psychological symptoms of dementia," *Frontiers in Neurology*, vol. 3, p. 73, 2012.
- [11] L. B. Gerlach and H. C. Kales, "Managing behavioral and psychological symptoms of dementia," *Psychiatric Clinics of North America*, vol. 41, no. 1, pp. 127–139, 2018.
- [12] Socialstyrelsen, "Nationella riktlinjer för vård och omsorg vid demenssjukdom: stöd för styrning och ledning [National guidelines for care and care in dementia: support for management and guidance]," 2017, <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/nationella-riktlinjer/2017-12-2.pdf>.
- [13] D. Edvardsson and A. Innes, "Measuring person-centered care: a critical comparative review of published tools," *The Gerontologist*, vol. 50, no. 6, pp. 834–846, 2010.
- [14] A. Barbosa, L. Sousa, M. Nolan, and D. Figueiredo, "Effects of person-centered care approaches to dementia care on staff: a systematic review," *American Journal of Alzheimer's Disease and Other Dementias*, vol. 30, no. 8, pp. 713–722, 2015.
- [15] L.-O. Dahlgren and M. Fallsberg, "Phenomenography as a qualitative approach in social pharmacy research," *Journal of Social and Administrative Pharmacy*, vol. 8, no. 4, pp. 150–156, 1991.
- [16] A. S. Terkelsen, J. V. Petersen, and H. K. Kristensen, "Mapping empirical experiences of Tom Kitwood's framework of

- person-centred care for persons with dementia in institutional settings. A scoping review,” *Scandinavian Journal of Caring Sciences*, vol. 34, no. 1, pp. 6–22, 2020.
- [17] I. Ekman, K. Swedberg, C. Taft et al., “Person-centered care--ready for prime time,” *European Journal of Cardiovascular Nursing*, vol. 10, no. 4, pp. 248–251, 2011.
- [18] B. Woods and P. Subramaniam, “Digital life storybooks for people with dementia living in care homes: an evaluation,” *Clinical Interventions in Aging*, vol. 11, pp. 1263–1276, 2016.
- [19] A. Cooney and E. O’Shea, “The impact of life story work on person-centred care for people with dementia living in long-stay care settings in Ireland,” *Dementia*, vol. 18, no. 7-8, pp. 2731–2746, 2019.
- [20] A. Cooney, A. Hunter, K. Murphy et al., “Seeing me through my memories’: a grounded theory study on using reminiscence with people with dementia living in long-term care,” *Journal of Clinical Nursing*, vol. 23, no. 23-24, pp. 3564–3574, 2014.
- [21] M. G. Austrom, C. A. Carvell, C. A. Alder, S. Gao, M. Boustani, and M. LaMantia, “Workforce development to provide person-centered care,” *Aging and Mental Health*, vol. 20, no. 8, pp. 781–792, 2016.
- [22] I. Ericsson, S. Kjellström, and I. Hellström, “Creating relationships with persons with moderate to severe dementia,” *Dementia*, vol. 12, no. 1, pp. 63–79, 2013.
- [23] S. K. Kim and M. Park, “Effectiveness of person-centered care on people with dementia: a systematic review and meta-analysis,” *Clinical Interventions in Aging*, vol. 12, pp. 381–397, 2017.
- [24] V. Lawrence, J. Fossey, C. Ballard, N. Ferreira, and J. Murray, “Helping staff to implement psychosocial interventions in care homes: augmenting existing practices and meeting needs for support,” *International Journal of Geriatric Psychiatry*, vol. 31, no. 3, pp. 284–293, 2016.
- [25] D. Edvardsson, P. O. Sandman, and B. Rasmussen, “Forecasting the ward climate: a study from a dementia care unit,” *Journal of Clinical Nursing*, vol. 21, no. 7-8, pp. 1136–114, 2012.
- [26] G. Bollig, E. Gjengedal, and J. H. Rosland, “Nothing to complain about? Residents’ and relatives’ views on a “good life” and ethical challenges in nursing homes,” *Nursing Ethics*, vol. 23, no. 2, pp. 142–153, 2016.
- [27] M. Ådnanes, L. Melby, J. Kaasbøll, and J. Kalseth, “Mental wellbeing among the oldest old, living in nursing home or at home,” *European Journal of Public Health*, vol. 29, 2019.
- [28] L. Istvandy, “Combining music and reminiscence therapy interventions for wellbeing in elderly populations: a systematic review,” *Complementary Therapies in Clinical Practice*, vol. 28, pp. 18–25, 2017.
- [29] I. Testad, A. Corbett, D. Aarsland et al., “The value of personalized psychosocial interventions to address behavioral and psychological symptoms in people with dementia living in care home settings: a systematic review,” *International Psychogeriatrics*, vol. 26, no. 7, pp. 1083–1098, 2014.
- [30] A. M. Rokstad, S. Vatne, K. Engedal, and G. Selbæk, “The role of leadership in the implementation of person-centred care using Dementia Care Mapping: a study in three nursing homes,” *Journal of Nursing Management*, vol. 23, no. 1, pp. 15–26, 2015.
- [31] L. Nordenfelt, “Hälsa, autonomi och livskvalitet: några grundläggande begrepp,” in *Värdighet I Vården Av Äldre Personer*, L. Nordenfelt, Ed., pp. 29–62, Studentlitteratur, Sweden, 2010.
- [32] U. H. Graneheim and B. Lundman, “Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness,” *Nurse Education Today*, vol. 24, no. 2, pp. 105–112, 2004.
- [33] D. F. Polit and C. T. Beck, *Nursing Research: Generating and Assessing Evidence for Nursing Practice*, Wolters Kluwer, Alphen aan den Rijn, Netherlands, 10 edition, 2017.