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Social death of older adults residing in nursing homes in Finland

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ABSTRACT

Social death refers to situations in which individuals become socially excluded from social interaction or are considered socially insignificant. Social death is about losing roles, relationships, and eventually identity in the eyes of others. When becoming a permanent resident in a nursing home, older adults face an increased risk of social death. However, empirical research on social death and its manifestations in nursing homes is still scarce. The aim of this study was to investigate the phenomenon of social death by interviewing family members (N = 19) of older people living in nursing homes in Finland. A theory-driven thematic analysis of family members' interviews revealed two cross-cutting themes that were linked to social death in nursing homes. We discovered that 1) the transition to a nursing home significantly narrowed the older adults' social environment and 2) dementia seemed to affect all aspects of older adults' social life and social agency negatively. Furthermore, four main mechanisms of social death in nursing homes were 1) losses associated with decline of physical and mental health, 2) loss of social identity, 3) isolation and lack of social connectedness, and 4) lack of quality of care. It seems that nursing home residents, especially those with advanced dementia, face social death because they are not seen as persons who are entitled to social roles and meaningful activities. Thus, there is an urgent need to improve the social connectedness of all older adults living in care facilities, with particular attention to those with memory loss. Based on these results, we provide checklists for nursing professionals and all citizens to restore the social value of older persons.

Introduction

Previous literature describes social death as occurring in situations in which individuals or certain groups of people become socially excluded (Brannelly, 2011; Králová, 2015; Sweeting & Gilhooly, 1997; Wesselmann & Williams, 2017). Socially dead people are considered unworthy or incapable of social interaction (Brannelly, 2011), which results in the loss of meaningful social connections and roles (Králová, 2015). Thus, it might be argued that to be socially dead is to be ignored and excluded, which threatens the fulfillment of fundamental needs such as belonging, self-esteem, control, and meaningful existence (Wesselmann & Williams, 2017, 236) in a self-perpetuating manner. It is noteworthy that social death is a *process* in which a person allegedly loses his or her capacity to interact with other people and thus loses social roles (Caswell & O'Connor, 2017). The process is not necessarily intentional; it could be caused by, for example, diseases affecting one's functional or communicational capacities. For example, Sweeting and Gilhooly (1997) discovered that family members taking care of close ones with severe dementia sometimes referred to them as “out of reach” or “as good as dead”.

Social death thus appears to result from disturbances in a person's or a group's social position. Social death is about losing roles, relations, and eventually identity in the eyes of others. Jana Králová (2015) has distinguished three types of social losses that, when two or three are present simultaneously, result in social death: a loss of social identity, a loss of social connectedness, and losses associated with disintegration of the body. When we consider the situation of older adults residing in nursing homes in light of Králová's theory, their risk of social death seems apparent.

Social death and cultural representations of nursing homes

Previous literature shows that being placed in a nursing home may negatively affect an older person's social position (Gilleard & Higgs, 2013, 2015; Pirhonen, Ojala, Lumme-Sandt, & Pietilä, 2016). According to Clive Seale (1998), being transferred into a nursing home strips older

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adults of their social identity to such an extent that he refers to it as a social funeral. Gilleard and Higgs (2015) highlight the cultural importance of self-determination as a qualifier of a person. Older adults move into nursing homes because of the loss in their functional abilities, which inevitably affects the prerequisites of being autonomous, and there is a stigma in being old and in need of help (Day & Hitchings, 2011). Pirhonen et al. (2016) found that community-dwelling older persons spoke about their age peers in nursing homes as 'ability others', stressing how those people had lost their autonomy due to poor functioning. Thus, in losing their bodily integrity, older persons transferring into nursing homes may risk their position as social equals. Previous research has also shown that older adults' contacts with friends, relatives, and neighbors do decrease significantly after transferring into a care facility (Port et al., 2001; Paque, Bastiaens, Van Bogaert, & Dilles, 2018); i.e., their social connectedness weakens. Thus, Králová's (2015) preconditions of social death (loss of social identity and connectedness combined with losses in bodily integrity) appear to be easily fulfilled in the case of older adults residing in nursing homes.

Erica Borgstrom (2015, 275–278) considers social death in end-of-life care as encompassing three aspects: "i) exclusion and isolation, ii) inequality, and iii) lack of dignity and communication". There is heuristic value in applying Borgstrom's idea to nursing homes. According to Borgstrom, social death is identified in people being gradually removed from mainstream society, resulting in isolation and loss of sense of being (see also Sinclair, Swan, & Pearson, 2007). Others see these people as excluded from mainstream society (Skye, Leedahl, & Chapin, 2018), yet previous literature also shows that older persons themselves often view a transfer from a private home to a nursing home as an 'end of the line', in which they become separated from the familiarities of home, the life they are accustomed to, and their long-lasting social ties (Drageset, 2004; Powers, 1995).

The second definer of social death in Borgstrom's (2015) study is inequality. What makes social death *social* is the fact that not all people are at risk of experiencing it; it concerns certain sub-groups of populations. This notion marked the very beginning of research into social death in the 1960s, when David Sudnow (1967) reported how dying patients' social status seemed to influence whether they were provided with proper end-of-life care or not. The same applies to older adults residing in nursing homes generally. As previously pointed out, Seale (1998) views a transfer to a nursing home as a social funeral, while Gilleard and Higgs (2010, 2013) consider loss of independence in old age as a cultural death. It seems that nursing home residents, as a subgroup, are at greater risk of social death than the older population in general.

Previous research has also shown that the quality of care provided in nursing homes is often insufficient. For example, nursing homes have been found to lack the prerequisites of proper end-of-life care (Seymour, Kumar, & Froggatt, 2011), medical care (Morin, Larocher, Texier, & Johnell, 2016), and mouth care (Jablonski et al., 2009). Furthermore, nursing home residents are at higher risk of suffering from malnutrition and dehydration than older adults in general (Paulis, Everink, Halfens, Lohrmann, & Schols, 2018; Shipman & Hooten, 2007). Hayes et al. (2014) anticipate that difficulties in communicating with a person increase the risk of social death. We also know that dementia, in particular, reduces communication from nursing staff to residents (Hayes et al., 2014), and that most nursing home residents in Finland have dementia due to progressive neurodegenerative disease (Remes, 2018). Bauer et al. (2016) showed that residents with poorer communication skills were more often prescribed antipsychotics when they needed analgesics and, thus, lacked proper care. As Jaber Gubrium (1997) has shown, sometimes there does not need to be communicational difficulties involved, but older persons' opinions may be left aside due to the staff's attitude of them knowing better. According to Borgstrom (2015), poor quality in care strips older persons of their dignity and is therefore a marker of social death. Regarding older adults residing in nursing homes, Borgstrom's (2015) preconditions of social death (exclusion, inequality, and loss of dignity) seem just as plausible as Králová's (2015).

Although nursing home residents appear to be at high risk of social death due to political, economic, and cultural issues (Diamond, 1992), empirical research on the matter is, surprisingly, lacking. Residents' social lives (or lack thereof) have frequently been studied (Gardiner, Laud, Heaton, & Gott, 2020; Pirhonen & Pietilä, 2018), as have social imaginaries of nursing homes (Gilleard & Higgs, 2017; Seale, 1998), yet we know practically nothing about everyday manifestations of social death in these settings. Our aim is to view the phenomenon through the eyes of residents' family members. Through a thematic analysis of their interviews, we depict the essential mechanisms of social death in nursing homes.

Data and method

Data

The data consists of 19 telephone interviews with family members of nursing home residents. The interviews' duration varied between 16 and 88 min, resulting in a total of 872 min of interview data. The data were audio recorded and transcribed verbatim (246 pages, 97,392 words). All of the nursing home residents in question had dementia, and twelve of them were still alive at the time of the interview. Seven of the interviewees were spouses of the resident, and twelve were their adult children. Seventeen of the interviewees were female.

The interviewees were recruited based on a prior COVID-19-related survey targeted at nursing home residents' family members (Pirhonen, Forma, & Pietilä, 2022). In the survey, participants were asked if they would be willing to give an additional interview about their experiences of nursing home care and, if so, to provide their phone numbers for that purpose. A limitation of this study is that the original survey used to recruit interviewees was conducted only in Finnish and therefore family members from linguistic and ethnic minorities were not reached. As language and attitudinal barriers reflect on social well-being, it would be important to design future studies in a more inclusive manner (see also Kröger, 2022). The interviews were conducted during March–May 2021, after the COVID-19 lockdown in nursing homes. In the interviews, family members' experiences regarding their close ones' care and well-being were broadly discussed. The COVID-19 lockdown was discussed, but a wider time perspective was also considered. The interviewees were asked to discuss the time when their close one initially entered the nursing home and to describe the situation there before COVID-19 affected everyday life. After ten interviews had been conducted, the quality and sufficiency of the data was preliminarily estimated; nine further interviews were subsequently carried out, resulting in a total of 19 interviews.

In this study, we used family members as respondents because we were interested in their perspective and because advanced dementia posed challenges for conducting a telephone interview with the nursing home residents. Firstly, acquiring the residents' consent to the interview would have been problematic due to their health and limitations of self-determination, as research ethics demand that participation is voluntary and the participants understand what they consent to. Secondly, it would have been unethical to interview residents with advanced dementia via telephone, as it is well known that cognitive impairment and decreased communicative abilities can make talking on the phone extremely difficult. Face-to-face interviews, on the other hand, had to be avoided in 2021 due to the Covid-19 pandemic. Nevertheless, we encourage scholars around the globe to involve people with advanced dementia in research whenever it is possible.

Ethical approval for the research was obtained from the Research Ethics Committee in the Humanities and Social and Behavioral Sciences at the University of Helsinki, and the Finnish ethical guidelines for research (Finnish National Board on Research Integrity, 2023) were closely observed. Participation in the study was voluntary. The participants received information about the research, the recording of the interviews, data protection, and anonymity prior to providing oral consent. The participants' consent was audio recorded before starting the interview. Pseudonyms are used to identify the participants in the extracts presented in this study. The presentation of the findings is guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.

Method

The interviews were analyzed using theory-driven thematic analysis (Braun & Clarke, 2006, 2019). First, the research team familiarized themselves with both the data and the previous theories of social death (see Introduction). Then, all the elements in the data that were connected to any aspect of social death were systematically coded using NVivo 12 Plus software. The coded passages of data could consist of one or more turns of talk that formed a continuous narrative, and several codes could be assigned to one passage. After the coding phase, themes were identified, defined, and grouped. In the final phase, the team constructed a thematic map of the findings and selected data extracts to illustrate the themes in more detail.

Findings

The findings of the analysis are presented as a thematic map in Fig. 1. As this map illustrates, there were two broad, cross-cutting themes with regard to social death in nursing homes. Firstly, as expected, the transition to a nursing home itself had narrowed the social environment of the residents (cf. Drageset, 2004; Powers, 1995). They were no longer able to pursue hobbies or visit places as they had before, and only a few of their previous social contacts visited them in the nursing home; mainly their spouse or adult children. In fact, in the data, it was common that only one person took on the role of contact person while the participation of other family members and friends was limited to occasional visits and phone calls. Secondly, all of the residents in question had dementia, and dementia seemed to affect all aspects of their social life and social agency negatively. Furthermore, we identified four main aspects of social death in nursing homes: 1) Losses associated with decline of physical and mental health, 2) Loss of social identity, 3) Isolation and lack of social connectedness, and 4) Lack of quality of care. As the majority of nursing home residents in Finland have dementia (Remes, 2018), the majority of nursing home residents can also be regarded as being at high risk of social death, since they can possibly be affected by all of the aspects of social death identified in this study. In the following sections, we will analyze each aspect in more detail.

Losses associated with decline of physical and mental health.

While Králová (2015) identified losses associated with disintegration of the body as an essential aspect of social death, Caswell and O'Connor (2017) highlighted the loss of interactional capacities. In our data, nursing home residents with dementia experienced varying degrees of losing both their physical and cognitive health along with their interactional capacities. Decline in functional and cognitive abilities could prevent the residents from using a phone or leaving their room without assistance, while decline in interactional capacities could make it difficult for them to hold a conversation or even produce speech. These types of changes naturally affected the quality of residents' interactions with others in many ways, as they challenged the social norms regarding communication. For example, Elli had trouble understanding her husband, Erkki:

> Elli (wife): *His speech has been so bad for so long.*
>
> Interviewer: *So you cannot- can you understand him?*
>
> Elli: *Well he speaks in a very quiet voice and then sometimes, it is utter nonsense. And he has had this problem for a long time, even when he was still at home, that he may say something but the words are all wrong, so I have to try and figure out what he means.*

Keeping contact with the resident demanded effort and adjusting on the part of family members and support from the nursing home staff. However, due to the complex challenges caused by advanced dementia, the support provided was often insufficient, as Inkeri reminisced:

> Inkeri (wife): *We call him, he can no longer answer the phone, he does not know how. He is very timid, he just cannot do that. So we call the nurses, when they can answer. They sometimes do not have the time, they are in a hurry. So then they call back, or I call my husband's phone, which is in his room. But often they leave my husband in the common space there, and it is noisy, so he cannot focus on the phone call. And he may forget that he is on the phone.*

While Inkeri's husband, Eino, had trouble using the phone and remembering that he was on the phone, others had difficulties with

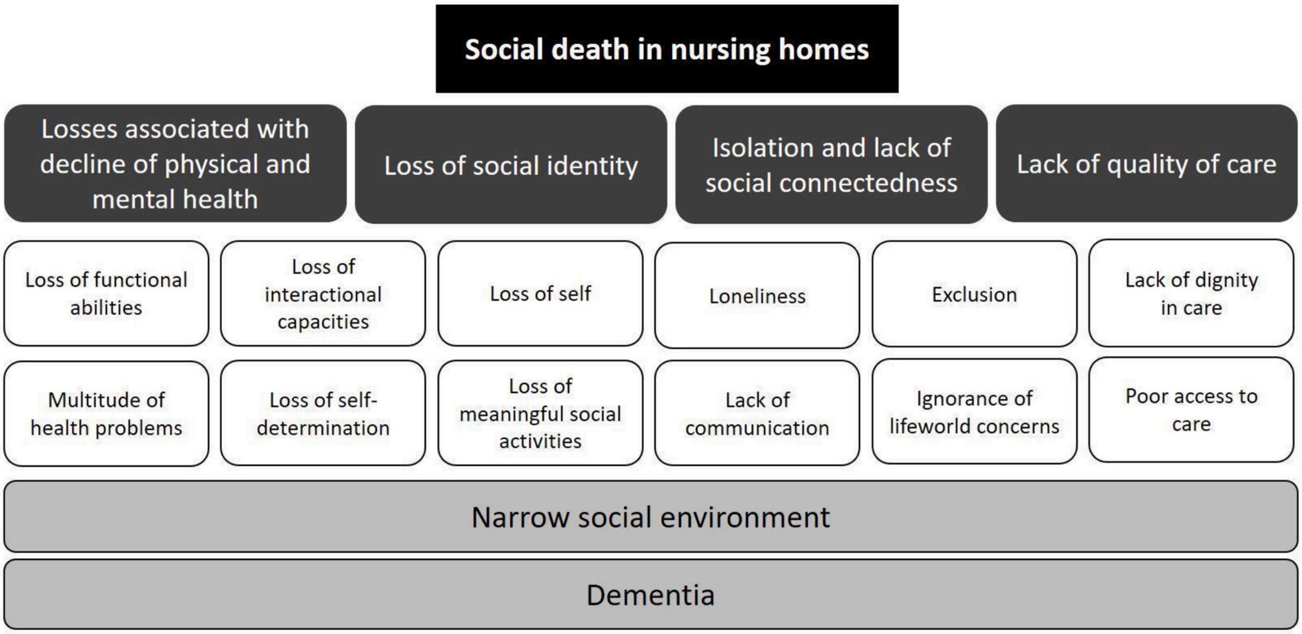

Fig. 1. Thematic map of social death in nursing homes.

hearing, holding the phone in their hand, or understanding the purpose of the phone. With advanced dementia, face-to-face interaction could also become difficult to maintain, and problems with cognitive abilities could also lead to the loss of self-determination.

In terms of health, another noteworthy feature was that nursing home residents often had other health issues. For example, in addition to dementia, Inkeri's husband had rheumatoid arthritis, chronic obstructive pulmonary disease, and anemia. This multitude of health concerns only highlighted the residents' status as persons who need care and assistance, who are therefore no longer social equals with their close ones and are also made more vulnerable to malpractice and neglect. We will address this in further detail in the section *Lack of quality of care*.

Loss of social identity

Loss of social identity has widely been acknowledged as a severe threat to wellbeing of people with dementia (Kitwood & Bredin, 1992; Kontos et al., 2018). Therefore it is not surprising that Králová (2015), identified loss of social identity as one of the main aspects of social death. In our study, on one hand, nursing home residents' loss of social identity was connected to the loss of self; on the other, to the loss of meaningful social activities. For family members, like Krista, seeing their close ones forgetting their own history, loved ones, and personal traits due to dementia was painful. However, care measures – especially medication – could also threaten the social identity of the care recipients, and could be just as hard for the family members, such as Elli, to witness.

> Krista (daughter): *…and I fear that she (mother) loses everything, loses herself and loses others, loses it all, and still exists, like that. (…) and she used to be so happy and all, and suddenly she changed completely. And it is terrible to watch her being so lost. She does not know anything, who she is, where she came from and where she is going.*

> Elli (wife): *There ((during an acute hospital visit)) they started to fill him with all kinds of medications and got him into a condition where he crawled on all fours on the floor and did not speak at all anymore. He crawled on the floor like a baby and ate all kinds of garbage he found there and- This is the condition they got him into.*

Krista's depiction of her mother resembles Sweeting and Gilhooly's (1997) description of being “out of reach”, while Elli's narrative of her husband's behavior on medication connects with Wesselmann and Williams's (2017) notions of losing one's self-esteem, control, and meaningful existence. Having a social relationship with a person who does not seem aware of their own nor others' identities was difficult for family members. Krista believed that other members of her family, as well as her mother's friends, had trouble dealing with the “weird, frightening” behavior caused by Alzheimer's disease. According to her sister, there was no “need” to visit their mother in the nursing home anymore. Some family members also seemed to take the changes caused by illness personally, as if they threatened their own social identity as well. For example, Johanna seemed hurt by her father Kari's inability to remember her life events:

> Johanna (daughter): *My history is kind of swept away. He (father) only remembers my first name and that I am his daughter, and some things here and there. But each time he is amazed: oh, I'm married, oh, I have a job, oh, that kind of a job. (laughter) Then five minutes pass, and he asks my surname again. So, sure it changes our relationship, when the knowledge disappears.*

The relationship between the resident and family members could become resentful, and family members could respond to tensions in the relationship or their own discomfort by reducing contact. Hence, the residents' connectedness could be curtailed by family members' social responses to dementia rather than dementia symptoms per se. We will explore the theme of social isolation in more depth in the following section.

Isolation and lack of social connectedness

The third aspect of social death in nursing homes identified in this study is isolation and lack of social connectedness, which Králová (2015) and Borgstrom (2015) also identified in their theories of social death. With regard to nursing home residents, however, both the environment and the residents' state of health weakened their social contacts with others in multiple ways. Firstly, as stated earlier, the loss of interactional capacities and the loss of social identity could make it hard for residents' family members to maintain social contact and experience connectedness with the them. Secondly, the transition to a nursing home could break up life-long partnerships. In the worst case, spouses were separated and moved into different care units despite their wishes and what was promised to them, making it impossible for them to be together. Thirdly, witnessing the residents' losses was emotionally difficult for their family members. For example, Tiina said that she had reduced contact with her parents in order to save herself from feeling bad:

> Tiina (daughter, both parents in a nursing home): *Now the nurses have told me that she (mother) is doing fine, but to us, she keeps on complaining that nothing is fine.*
>
> Interviewer: *How does that feel?*
>
> Tiina: *It feels unpleasant and therefore I- I have diminished ((keeping contact))- I don't call and I do not necessarily visit that often, because each visit just leaves me feeling bad, anda phone call can sometimes ruin my day.*

The staff members in nursing homes were typically occupied with care tasks and did not have a lot of time for socializing with the residents. Even family members who were satisfied with the quality of care acknowledged that living in a nursing home was lonely:

> Johanna (daughter): *The staff members treat the residents with warmth and care. So, I don't know if the residents really lack anything. But of course, the time they have for the resident is limited. Because there are many residents and some need more personal care like feeding and things like that. I guess they lack company. The family members can't be there all day, so it is lonely there.*

Some family members were concerned that the residents spent all their time alone in their rooms. The situation was most difficult for those who were unable to get up from their beds without help, like Riitta's mother Alli, who eventually spent over three years in her room:

> Riitta (daughter): *Some ((nurses)) say “oh, I have not seen her all day”. And when I ask “oh you haven't seen her, well, where might my mother be then?” they go “she is in her bed with the bed rail up.” So, they got permission for the bed rail about a year ago, and they have certainly used it. My mother has been kept in bed. A couple of months ago she got deep vein thrombosis in her leg from not being moved.*

As Riitta's narrative shows, isolation could have consequences not only for the residents' social well-being, but also for their physical health. Despite this, according to the interviews, nursing homes became even more isolating places after the COVID-19 pandemic due to changes in visiting policies (see also Paananen, Moore, Blomqvist, Kulmala, & Pirhonen, 2024). At the time of the interviews in spring 2021, there were still some social restrictions in place, and some nursing homes had ceased to use external services such as occupational therapists and activity coordinators in order to avoid “unnecessary” contacts that might spread infections.

Lack of quality of care

The final main theme of our study, *Lack of quality of care*, resonates with Borgstrom's (2015) notions that inequality and lack of dignity encompass social death in end-of-life. The interviewees' narratives highlighted that the care of older individuals was not seen as a priority in the healthcare system: access to long-term care in a nursing home was often far from safe and timely, and 12 out of 19 disclosed concerns about the quality of care. Some, like Mari, Riitta, and Inkeri, had made complaints about the care and had dealt with conflicts with healthcare professionals. Their narratives demonstrate that the family members' lifeworld concerns, i.e., their understandings of the residents' experiences of problems and events (see Mishler, 1984), are easy to ignore in the care system.

For example, Inkeri had asked the staff members to use larger diapers for her husband so that the diapers would not dig into his skin and make him tear them apart at night, but the staff members were worried that larger diapers might leak from the legs and denied her request. Riitta, in turn, had bought care supplies for the nursing home after noticing her mother's dry skin and bloody scalp, but her efforts did not result in improvement.

> Riitta (daughter): *When I got to see her again ((after the COVID-19 lockdown)) with my own eyes- I have never been delighted to see how they- how they do not take care of things, even though they have all kinds of materials and accessories in the cabinet. I brought a full bag to the entrance just a month before, the nurse came to take it because I could not be in contact. I brought all kinds of creams and whatnot, but they do not find the time to use them.*

On some occasions, however, the family members succeeded in making changes to the care. Inkeri was worried about her husband's medication after repeatedly finding him unconscious during the daytime. Since the nursing home staff failed to act, she decided to take him to a doctor by herself. After his medication was halved, Inkeri's husband's condition improved.

> Inkeri (wife): *For a long time, he had these kinds of attacks of unconsciousness. Sleep things, he was almost unconscious. I tried to wake him up and slapped his cheeks to wake him in the afternoon. He had slept for hours but they just let him be. I said, this is not normal, there must be something wrong with the medication or something. But they did not do anything about it. So I took him to the health center, booked a time and we went to check the medication.*
>
> Interviewer: *So you took him yourself?*
>
> Inkeri: *By myself, yes. And this doctor there said that the Alzheimer's medication was too strong- that it can cause precisely things like this. That it needs to be halved.*

For Inkeri, the staff's reluctance to take action in her husband's situation may seem pure negligence, yet there might be institutional conditions involved as well (see also Gubrium, 1997). Individual care workers are often bound to institutional instructions and practices. Recent literature on the nursing field reports lack of resources, tightening pace of work, and the personnel's increasing moral stress (Van Aerschot, Puthenparambil, Olakivi, & Kröger, 2022). Our interviewees' experiences may partly be explained by these factors, but, all in all, our data shows that through the eyes of family members, nursing home residents may not be seen as people who are entitled to comfort and meaningful activities. This suggests, that they have lost their position as social equals (cf. Gilleard & Higgs, 2015, 264–265), and their well-being depends partly on their closest family members' actions, persistence, and willingness to keep contact (see also Paananen et al., 2024).

Discussion

Since there is a lot of prior documentation about misrecognition of residents' person in nursing homes (Gubrium, 1997; Kitwood & Bredin, 1992; Kontos et al., 2018), our aim was to study whether prior theorizations of social death would be empirically applicable in nursing home residents. Based on previous theorizations of social death and a thematic analysis of family members' interviews, the risk of residents' social death seems plausible. We identified four main mechanisms of social death: 1) Losses associated with decline of physical and mental health, 2) Loss of social identity, 3) Isolation and lack of social connectedness, and 4) Lack of quality of care. Perhaps no single aspect is socially 'lethal' on its own, but the more these aspects occur simultaneously, the higher the risk of social death becomes (see also Králová, 2015). What is noteworthy is that the most common reason for needing round-the-clock care – that is, having advanced dementia – may expose a person to all four mechanisms of social death identified above. However, it is important to understand that social death is imposed from the outside and results from other people's actions, reactions, attitudes, and conceptions of valuable interaction and dignified care.

It seems that when it comes to the social death of nursing home residents, deterioration of physical health has social consequences. Dementia and comorbidities debilitate functional and communicational capabilities, which eventually affects an older person's self-determination to the extent that round-the-clock care is needed. At this point, we must understand that what happens next is not inevitable, but an outcome of socially constructed cultural representations. In the Finnish context, at least – and probably throughout the Western world – an older person entering a nursing home is at risk of losing their social value. It seems apparent why Seale (1998) chose to describe this as a social funeral; in the nursing home, the social aspect of a person's well-being becomes overrun by the needs of their deteriorating body and the operation of the organization. Ignoring residents' social needs can result in what we call "the death of sociality". Given the current arrangements in institutional care and construction of dementia in our social imaginary, people are doomed to be socially insignificant (Brannelly, 2011; Králová, 2015). If the quality of physiological care is also insufficient and the person is no longer seen as entitled to well-being and comfort, social death is actualized in its full meaning. People are then viewed as both socially and physically insignificant – in Sweeting and Gilhooly's (1997) words, 'as good as dead'. In such cases, social death may hasten physiological death. We trust that our results make a much needed empirical foray into a widely touted but only partly evidenced set of claims regarding social death and advanced dementia.

Our findings seem to combine Králová's (2015) and Borgstrom's (2015) prior tripartite conceptualizations of social death into a four-part checklist for good quality of life in nursing homes. Anyone working in a nursing home could always: 1) cherish the genuine person regardless of the various ways in which their body and mind might be deteriorating, 2) treat every resident as an equal member of the community, 3) encourage residents' friends and relatives to visit them and make them feel welcomed, and 4) fight for residents' right to receive the most dignified care available and act accordingly. The same checklist can also be applied to improve the societal position of nursing home residents. Each of us could: 1) consider whether we see nursing home residents as 'ability others' (Pirhonen et al., 2016) or as already socially buried (Seale, 1998), 2) find ways to keep residents connected with their neighborhood and wider society (for example by enabling leisure, political, and religious activities, etc.), 3) visit our relatives, friends, and acquaintances in nursing homes regularly, and 4) demand that our politicians take the needs of older adults more seriously and better finance the services required.

We acknowledge that lack of resources and workforce (Van Aerschot et al., 2022) as well as the current political economy of care provision make it difficult for care providers to reverse social death. As voters and taxpayers, we are jointly accountable for the fact that nursing professionals are not often able to do their job as well as they could. However, our study has provided empirical evidence regarding the risk factors and mechanisms of social death and advanced dementia that may help policy makers, care providers, and researchers to understand the phenomenon and provide better quality care in future. Finally, it must be noted that life in nursing homes was not entirely as gloomy as our findings may imply. Our aim was to study whether previous theorizations regarding the risk of social death would be applicable in nursing home residents, and so we concentrated on data describing malpractices and family members' worries. However, most of the interviewees also described positive aspects of nursing home care, and a couple of them perceived it to be almost flawless.

Limitations of the study

Regarding the interpretation of the results, it is important to acknowledge that family members' perspective to nursing home residents' care and well-being may be notably different from residents' own viewpoint. Previous studies have shown, for example, that family members' satisfaction ratings with nursing home care can be higher than the ratings given by residents (Castle, 2006). Family members can also project part of their own quality of life onto the person with dementia (Arons, Krabbe, Schölzel-Dorenbos, van der Wilt, & Olde Rikkert, 2013). In addition, family members tend to compare persons with dementia with how they used to be, whereas for the persons themselves, the relevant point of comparison is more likely their peers (Smith et al., 2005). Our results need to be interpreted bearing in mind these kinds of factors. On the other hand, for the ethical and practical reasons presented in the methodology section, our interest has been in family members' perceptions of residents' everyday life and care in nursing homes.

Conclusion

Our results show that nursing home residents face the risk of social death in many ways. Persistent negative cultural images manifest themselves in the everyday lives of the residents. In Finland, public funding of services for older adults has been subject to budget cuts for decades, and the future does not seem any brighter. This negative development reflects a lack of respect for old age and older adults. Many nursing home residents face the consequences of these cuts every day in the form of lack of activities and poor quality of care. However, social death is not irreversible in the way that physiological death is. The inhumanity may be reversed once we recognize the existence of social death and choose to fight against it. After over a quarter century of worrying and warning about nursing home residents' risk of social death, it is high time to take action.

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Ethics approval statement

Ethical approval for the research was applied from the Research Ethics Committee in the Humanities and Social and Behavioral Sciences.

Patient consent statement

The study did not involve patients.

Nursing home residents' family members were recruited in the interview study based on a prior survey. Participation in the study was voluntary. Before giving their consent orally, the participants received information about the research, recording of the interviews, data protection, and anonymity. The participants' consent was audio recorded before starting the interview.

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Submission declaration

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CRediT authorship contribution statement

Jenny Paananen: Writing – review & editing, Writing – original draft, Visualization, Methodology, Formal analysis. **Jenni Kulmala:** Writing – review & editing, Validation, Project administration, Funding acquisition. **Jari Pirhonen:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization.

Declaration of competing interest

The authors declare no conflicts of interest.

Data availability

Data not available. The data that has been used is confidential. Due to the sensitive nature of the questions asked in this study, informants were assured raw data will remain confidential and will not be shared.

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