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Human Rights and the Ways Relatives Interpret Participation for People with Dementia in Nursing Homes

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Abstract

The exercise of self-determination is a human right; however, for people with dementia (PWD), progressive physical and cognitive impairment negatively affects their decision-making processes. For PWD, it is often relatives who make such decisions. This qualitative study included interviews with sixteen relatives of PWD who live in nursing homes. Research questions are as follows: How do relatives understand the participation of PWD who live in nursing homes? How do co-researchers understand participation and the role of relatives? A co-researcher was consulted when the questions were designed. During the interviews with relatives, photos were used to stimulate discussion. Critical situations in nursing homes were discussed with relatives and later interpreted together with a co-researcher. The findings included an understanding of how relatives played a key role in PWD; however, relatives were concerned that PWD were unable to take part in decisions. In addition, relatives named ways that nursing homes opposed human rights, and the co-researchers also highlighted situations that conflicted with human rights. Classifying dementia as a disability at the policy level could strengthen the rights issues of PWD. The key findings of the study are essential for social workers arranging for placement of PWD in nursing homes.

Keywords Human rights · Dementia · Disability · Residential care · Autonomy

Introduction

Fundamental human rights include expressing one's opinion, getting the help one needs, and participating in community life (UN, 2006). Due to physical and cognitive impairments, certain population groups have difficulty obtaining these rights. One such group is persons with dementia (PWD) who live in nursing homes (Cahill, 2018; Steele et al., 2020). In this manuscript, we aim to critically examine the concept of self-determination for persons with dementia (PWD) from a theoretical perspective. In Sweden, stringent policy documents exist concerning self-determination for residents in nursing homes (Lindmark et al., 2022). However, in practical implementation, staff members often allow established routines to dictate their actions rather than prioritizing the preferences of the residents (Harnett, 2010). Additionally, there is considerable variation among different nursing homes in Sweden regarding their approaches to promoting resident self-determination.

Acknowledging the inherent challenges associated with self-determination for PWD, it is essential to recognize that most individuals require assistance from others to make decisions. Nevertheless, in Sweden, the majority of older individuals endeavor to remain in their own apartments for as long as possible. When assistance is needed, municipal home care services are provided. In cases of severe dementia where living at home becomes impractical, individuals may opt to transition to a nursing home. It is noteworthy that the decision to move into a nursing home rests with the older person. Whether for-profit or not-for-profit, all nursing homes are funded by the welfare system, with residents paying rent based on their income. Residents retain decision-making autonomy both in choosing to move into a nursing home and in managing their apartment within these facilities. The term "nursing homes" is employed to denote that residents lease an apartment and conduct their daily lives within the nursing home environment, aside from the care they receive (NBHW, 2017).

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Aware of the cross-national variations in self-determination for PWDs residing in nursing homes, we emphasize that Swedish nursing homes offer a substantial degree of autonomy to residents, even those with dementia. A scoping review incorporating articles from the USA, UK, Sweden, Canada, Australia, Germany, Israel, and the Netherlands underscores that self-determination is frequently characterized as an ethical dilemma when the resident's right to autonomy is discussed against the staff's duty to safeguard them from harm. The review concludes that an ongoing discourse among staff members is essential to navigate the complexities surrounding self-determination for PWD (Morris et al., 2021). Furthermore, cognitive difficulties can change over time, these residents may have problems expressing themselves and being listened to, and they need assistance in exercising their self-determination (Haugen et al., 2019). In this study, we problematize how relatives discuss and understand participation for persons with PWD living in Swedish nursing homes, in relation to human rights. This is important as relatives often represent the person with dementia. According to a review by Holmqvist et al. (2022), there are two crucial aspects of representing others: the balance between violating individual rights and protection and the relationship between the representative and the person being represented.

Human Rights

In accordance with the principles of the Swedish welfare system, the fundamental human rights of nursing home residents are considered paramount. Residents, regardless of their individual capabilities, are entitled to opportunities that facilitate self-determination. This includes individuals with severe dementia, who retain the right to self-determination. In light of this, it is incumbent upon the staff to adopt a rehabilitative approach, actively working towards improving the capabilities of the residents (Lindmark et al., 2022). The social model of disabilities focuses on structural and attitudinal barriers that limit people with disabilities from participating in society. This model means that the environment is an obstacle to these people's inclusion in society, fostering a negative image of the group through the use of stigmatizing language. Shakespeare et al. (2019) suggested that PWD are framed as disabled and thus included in the social model of disabilities. We are conscious that dementia is a progressive disease that limits the PWD's opportunities to make decisions. However, in this paper, we try to frame dementia as a disability in order to forward research and discussion of human rights related to the care of PWD. This paper will incorporate PWD by the UN Convention on Human Rights of Persons with Disabilities (UN, 2006), which stipulates civil, political, economic, and cultural rights. Moreover, persons with disabilities should be active agents in society, express views, and participate in culture, recreation, and leisure. Cahill (2018) applied the social model to PWD as a group having the right to be included in mainstream society and treated equally (Cahill, 2018; Steele et al., 2020). Furthermore, PWD were not involved in developing the CRPD, as were people with other disabilities. Although the Convention says nothing specifically about promoting the rights of PWD living in nursing homes, it could offer opportunities to conceptualize dementia as a disability and a human rights issue. PWD should therefore interact with staff trained in human rights and be part of society (Cahill, 2018; Steele et al., 2020; Swaffer, 2016). Moreover, caregivers may use "minimizing" tactics to deal with care recipients' claims, for example, trivializing their wishes and complaints in nursing homes (Harnett, 2010). Cahill (2018) has adapted the CRPD for nursing homes and PWD. Nursing home residents should have a right to a private sphere, be treated equally with dignity, be able to exercise self-determination, be protected from inhuman treatment, and be able to join in, for example, cultural and recreational activities. Furthermore, we note the following articles from the CRPD (2006): article 12, equal recognition before the law; article 14, liberty and security; article 15, freedom from torture or cruel, inhuman, or degrading treatment or punishment; article 17, protecting the integrity of the person; article 19, living independently and being included in the community; and article 30, participation in cultural life, recreation, leisure, and sport. We define dementia as a disability and have a particular focus on human rights according to the CRPD (2006), adapted for PWDs living in nursing homes. Autonomy, self-determination, and participation are different aspects of human rights that we will focus on in this study.

Autonomy and Self-Determination

According to Erlandsson (2014), policies governing the care of older people focus on the cost of care for society, in contrast to policies governing the care of younger people with disabilities, which emphasize their civil rights and opportunities to live the same lives as persons without disabilities. By applying a human rights perspective to PWD living in nursing homes, researchers can identify barriers to meaningful lives and social participation (Cahill, 2018). According to Haugen et al. (2019), PWDs depend on informal and formal caregivers for opportunities to be involved in decisions affecting their daily lives. Relatives, staff, and managers are spokespersons for PWD, supporting their decision-making in daily life while considering their right to self-determination. However, there are ethical dilemmas when a spokesperson makes decisions for persons with cognitive impairment. Caregivers must protect PWD from harm and simultaneously respect them as citizens with autonomy, as stipulated in the Swedish Social Services Act (Giertz et al., 2019; Nedlund & Taghizadeh Larsson, 2016; Thelin, 2021). Moreover, nobody in Swedish nursing homes is allowed to make decisions for PWD against their will. This entails problems for staff and relatives who need to decide on PWD due to their cognitive impairment.

Participation

Participation is similar to involvement and engagement and refers to how people can be involved in various situations. To improve the participation of excluded groups, there is a need to change societal norms and ensure that caring staff have an ethical compass that stipulates that participation is essential (Denvall & Iwarsson, 2022). According to the International Federation of Social Workers (IFSW, 2020), nursing home staff should promote older people's opportunities for decision-making at all societal levels and treat them with dignity. The Swedish Social Services Act also stipulates that individuals should be autonomous and exercise self-determination. Despite the lofty aspirations articulated in policy documents concerning human rights, there exist challenges in translating these ambitions into practical implementation. The actual circumstances on the ground reveal that involving PWD is more complex than outlined in policy documents (Ingard et al., 2023). Some situations may be subject to diverse interpretations. From a pragmatic standpoint, it could be argued that employing a strategy of "coaxing" is a conventional method for addressing problematic situations (Harnett, 2010). However, it is hard to involve PWD in decisions due to their cognitive impairments. PWD must sometimes be protected from harm while simultaneously being involved in decisions (Cahill, 2018; Holmqvist et al., 2022). Cahill (2018) wrote that nursing home staff sometimes use neuroleptics to reduce the behavioral nursing home staff due to their lack of knowledge and/or time to spend with residents. Moreover, Erlandsson (2014) shed light on policy document descriptions of how to care for older people who need support. The policy documents describe these persons as individuals that institutions should take care of with dignity. That is in contrast with the area of disability, where human rights have a prominent place. Relatives and staff think they can make decisions for PWD because they know them. The power dynamics also change if someone in a relationship is living with dementia, and relatives may confuse what is best for PWD and what is best for themselves. To facilitate the involvement of PWD in decisions affecting them, their caregivers must see them as capable of taking into account both the relationship and the context (Smebye et al., 2012). Nursing home residents' participation at the collective level is unusual, and there is little research on how residents gain power in decision-making in nursing homes. Furthermore, multiple factors affect PWD's opportunities to participate (Strøm & Slettebø, 2021).

Research Gap and Aim of Study

Altogether, most research on the self-determination of PWD from their relatives' perspective emphasizes the complexity of the situation. However, the literature says little about how their relatives talk about nursing home residents' opportunities for self-determination in light of a human rights perspective. For PWD, relatives often play an essential role. The relatives often become advocates who must interpret and try to meet the needs of PWD. The next of kin can be the people who know their loved ones best. However, this dependence on relatives can pose significant challenges: Is it certain that relatives understand what the PWD wants? Is there a risk of relatives taking over decision-making competence from the elderly and thus making it difficult for them to exercise their human rights? We accordingly designed this study of how relatives, who support PWD's decision-making, discussed the notion of participation, interpreting their responses in relation to human rights. As an additional perspective, we also used co-researchers to get feedback from persons with relatives in nursing homes. Furthermore, the co-researchers were trained in methods of user-focused monitoring (see "Method" section). Other actors mentioned in the article are relative supporters and contact persons. A relative supporter is a municipal worker who supports relatives with emotional demands concerning the PWD and provides education about the disease as well as more practical support (The National Board of Health and Welfare [NBHW], 2017). A contact person is a staff member who frequently deals with the resident, providing continuity for the resident and facilitating his/her care (NBHW, 2023) as well as communicating with the relative about the resident's situation (SOU, 2017). This study intends to problematize how relatives talk about participation by their relatives living in nursing homes, leading to the following main research question — "How do relatives understand participation by PWD who live in nursing homes?" — and this related secondary research question — "How do co-researchers understand participation according to the interviews with relatives?".

Swedish municipalities should facilitate for older people who need long-term care the opportunity to move into a nursing home. The municipalities are responsible for caring for older people; relatives do not have formal responsibilities for that. The nursing home should offer its residents a safe home, self-determination, and opportunities to be involved in the community. There must be sufficient nursing home staff throughout the day and night. Each resident should have a flat, and the staff must respect the residents' privacy (NBHW, 2016). In recent decades, Swedish nursing homes have experienced funding cuts, and care providers are expected to deliver the same care quality but with fewer economic resources. Moreover, fewer older people needing support are now able to move into nursing homes (Plesner, 2020). There are some essential tools, such as life stories, for involving relatives and residents in decisions in nursing homes. Relatives can provide a life story about who the resident was before he/she moved into the nursing home, so that staff can more easily support the resident (Demensförbundet, 2023).

Method

This study included sixteen interviews to capture the relatives' experiences and points of view regarding the participation of the PWD. We interviewed the relatives mostly at home but sometimes at the University or a café. There were two men (sons) and 14 women (daughters, friends, sisters, and three wives). The age of the informants was between 48 and 78 years old. Through interviews, it was possible to create follow-up questions, in the dialogue with relatives, and to find informative quotes. Figure 1 provides an overview of the different steps and actors that participated in the data collection.

Co-researchers

User involvement in research, for example, participation in developing the study design, research questions, and conclusions, is essential to ensure that the researcher focuses on the correct issues (Staniszewska et al., 2017). Furthermore, Glasby and Beresford (2006) stressed the necessity of benefiting from knowledge-based practice, from the wisdom of healthcare and social workers, and from the lived experience of service users. The knowledge of service users can be more relevant in some cases than traditional evidence-based knowledge.

According to Rapp et al. (1993), service users in social work areas can improve research by giving opportunities to adapt predetermined questions from the service users' point of view and letting service users discuss and interpret the data analysis. Flanagan (2020) highlighted the importance of involving service users in research and of co-producing research in social work. However, Borg (2009) argued that the researcher has interpretive precedence as to what constitutes essential knowledge. Bethell et al. (2018) found that involving PWD in research was common, but that few studies reported the impact of involving them in research.

User-Focused Monitoring

User-focused monitoring systematically gathers knowledge of user experiences for the organization's benefit. According to Jakobsson and Rosenberg (2008), persons with experiences of mental health problems or their relatives must perform user-focused monitoring. User-focused monitoring emphasizes the viewpoints of users (here called "co-researchers") and gives suggestions to improve care. These methods were developed in the 1990s in Great Britain and provide a basis for developing mental healthcare organizations in dialogue with user organizations. One co-researcher in this study was trained in user-focused monitoring, and the other worked for a user-led organization; both co-researchers have experienced having relatives in nursing homes. The co-researchers gave us input on our study, helping us take account of the relatives' points of view. The co-researchers also contributed relevant aspects when we discussed the results. We contacted the National Partnership for Mental Health, the umbrella organization of Swedish mental health user organizations, to contact the co-researchers. From the Partnership, we got the name of one person who had performed three studies using user-focused monitoring in nursing homes in Sweden. She read our interview guide and gave us feedback based on her experience of having a relative with dementia in a nursing home. The same person later took part in our analysis of the interview results and gave feedback from her perspective in a face-to-face meeting. Moreover, we also received feedback on the results from one co-researcher, through a virtual meeting.

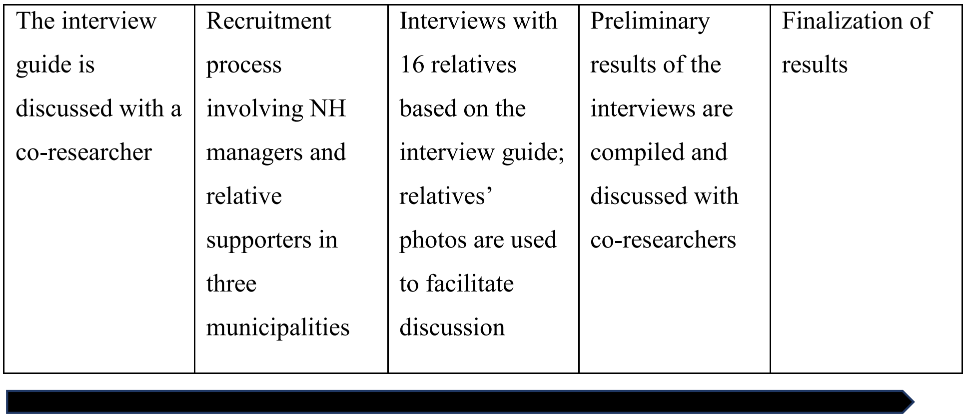

Fig. 1 The different steps of data collection

The interview guide is discussed with a co-researcher	Recruitment process involving NH managers and relative supporters in three municipalities	Interviews with 16 relatives based on the interview guide; relatives' photos are used to facilitate discussion	Preliminary results of the interviews are compiled and discussed with co-researchers	Finalization of results

Interviews

The interviews with relatives reflect their views of how their relatives, as PWD, could be involved in decisions regarding their daily life in nursing homes. We asked the relatives for their reasoning about this topic. Furthermore, we asked nursing home managers if they could invite relatives to participate in the interviews. We also contacted relative supporters, asking if they could help us recruit relatives for interviews. The transcribed semi-structured interviews lasted 1–1.5 h. Furthermore, using photos in the context of nursing homes can facilitate storytelling from the residents' perspective (Lood et al., 2023). The relatives brought their photos to the interviews.

Data Analysis

We used content analysis, according to Lindgren et al. (2020), with a particular focus on the human rights aspects of the results. We identified, condensed, and then coded the meaning units. Furthermore, we categorized the codes and assembled them into themes. The articles from the CRPD (UN, 2006) were indicative when we developed the themes. We investigated problematic situations described by the relatives, which we identified as violating the human rights of the target group. One author read all the transcribed interviews in full; the two other authors read parts of the transcripts; and all three authors discussed the themes used in the analysis.

Ethics

To avoid identifying any participants, we do not mention the names of the participating nursing homes or individuals. Participation was voluntary, and there was no undue pressure to participate. The study was approved by the Swedish Ethical Review Authority (Dnr 2021-00067).

Results

This section concerns relatives' reasoning about how their relatives, the PWD, participate in daily life in their nursing homes. Grounded in the transcribed interviews, the authors interpreted the interviews, formulating themes and relating them to selected articles of the CRPD (UN, 2006). The number after each quotation refers to one of the 16 informants included in the study. This section presents the findings from the interviews, thematically organized and related to the CRPD articles, and also includes comments from the co-researchers.

How Relatives' Reason About PWD Self-Determination: Article 12 "Respect the Rights, Will and Preferences of the Person", and Article 19 "Choices Equal to Others"

According to some relatives, self-determination was necessary even though the nursing home resident was living with dementia. PWD must experience making decisions regarding their daily lives and contributing to other persons' lives, so that they can feel significant and have a function in the nursing home. Furthermore, one participant commented that her mother was stubborn and that staff could not force her to do anything she did not want to do. Her mother mostly declined staff proposals because she suffered from anxiety and depression. That being the case, it was essential that the staff encourage her to participate in activities that would break her negative train of thought. According to some of the interviewed relatives, the PWD could not express their wishes, so the staff needed to know how the residents functioned prior to the progression of dementia. Moreover, involving PWD in decisions demands special efforts from staff, who need to understand and speak the same language as the residents:

> Well, she can't actively convey what she wants to do. She has gotten past that part. In the beginning, we talked about her and what she likes to do and stuff like that. It was probably more in the beginning, when there were a more stable staff group and more people who spoke Swedish … She can't convey that "Now I would like to go out into the yard and take a walk" – she cannot convey such things, but the staff must take the initiative. (no. 10).

Furthermore, the staff need to figure out what PWD want if they have no language. However, the PWD could be stubborn, and they have the right to decline suggestions. Sometimes the staff let the residents perform everyday tasks (e.g., washing dishes and making the bed) if that was in line with the nursing home's routines. In that case, they can experience self-determination in some way:

> Yes, but he'll have to keep messing around there. When he gets out of bed, they are completely fine to let him get on with making his own bed. And then if he would like to, if he carries the dishes away, he can stand by the tap and wash the dishes. (no. 15).

Some relatives also said that their relatives living with dementia could not make decisions due to their cognitive status. These relatives believed that the most important thing was that the staff treated PWD well and that they, as relatives, became involved in the decisions. According to some relatives, it was hard for PWD to achieve self-determination since this depended on the staff.

> I feel a little sad when I talk about this because, like, I guess no one has asked these kinds of questions either. You are in a hamster wheel in some ways, though, have been for many years thanks to mom. … Participation is important, but I think it has been difficult to achieve it. I've had to fight to get a bit of participation, like that. And so it's very personal, I feel … it feels a bit like leaving a child at preschool. (no. 16).

One relative took a photo with him to the interview, illustrating how a resident resisted life in the institution. The resident tore the nameplate off his door because he was angry about life in the nursing home. He could resist living in the nursing home through this symbolic action.

Coaxing: Article 17 "Respect for His or Her Integrity"

According to the relatives, the staff sometimes coaxed residents to convince them to take a shower; sometimes, the staff even asked relatives to convince the residents to take a shower:

> Yes, but not to decide over her head, but rather influence her so that it is a good decision. But my mother … we might have to convince her a little because the staff never force. I've never seen them do that … but they saw what she needed, but she didn't want any help. So then we had a little discussion, mother, and I – it's great that someone helps you when you have difficulty reaching the top of your head and doing laundry and such. And in the end she thought so too. (no. 3).

However, the relatives thought that residents were easier to handle if they had severe dementia.

Manipulating: Article 17 "Respect for His or Her Integrity"

The resident wanted to go home and told the staff that often. In that case, the relatives tried to manipulate the resident: they told her that she was soon coming home, not to upset her, because the nursing home, not her former residence, was now her home. In the following quotation, the relative lied so as not to upset the resident, telling her that she would soon have a new home:

> It's been a lot of work … We're selling the house, yes … but you're in the queue for an apartment via the housing company, so then we'll rent an apartment for you. (no. 6).

Demands to Involve PWD in Decisions

In sum, life stories could be an essential tool for the staff to learn who the residents were before they moved into nursing homes. However, some relatives did not use the opportunity to leave a life story with the staff. Furthermore, they did not think that the residents could be involved in developing plans for their lives in nursing homes due to their cognitive disabilities. Contact persons played an essential role in informing the relatives about the care situation. However, sometimes, the nursing homes did not inform relatives when they changed contact persons, and the relatives and residents could not select the contact persons. There were sometimes meetings for staff and relatives, which were an essential forum for relatives to complain and to get information about the nursing homes. However, it was rare for the staff to have meetings with the residents.

Life Story and Implementation Plan: Article 18 "to Obtain, Possess, and Utilize Documentation of Their Nationality or Other Documentation of Identification"

Some relatives left life stories telling the staff who the residents were as people. However, the relatives could also be afraid to leave staff these stories, in case the staff did not use them with concern for the residents' integrity:

> I started writing it and I talked to him. We haven't handed it in yet, and it was with the idea that I wanted to see what kind of staff were there and I'm thinking about what we would write in it. (no. 4).

Furthermore, some relatives believed that the staff did not read the life story, making it pointless to leave one:

> So I don't think all the staff have read it [i.e., the life story]. Not the ones who are working now, anyway. Possibly when she [i.e., the resident] was new there. And yes, the contact person read it, I know. And we have proven that it exists for whoever became the new contact person. Then I don't know, but I don't think all the staff read it. I find it hard to believe that they actually have the time. (no. 10).

Some relatives did not leave a life story because they found it pointless: They had already told the staff about the residents' lives before moving into the nursing home, and some had no idea and the relatives thought they could not do that due to their cognitive disabilities.

Contact Person: Article 19 "Support Services Including Personal Assistance Necessary to Support Living"

The relatives stressed that the residents each had a contact person who was more or less available to the relatives. If the relatives did not have good relations with the contact person, they would have fewer opportunities to influence the care. Moreover, some relatives said that the contact person did not do what they should for the residents, not taking care of the residents properly. Furthermore, the relatives and residents could not choose the contact person, and sometimes, the nursing homes even changed the contact person without telling the relatives:

> There is nothing wrong with the [contact] people. Nothing we want to change, but it's nothing that you can influence, and it can even be like … on a couple of occasions, whatever it is, there is a new note on the door and then there are two new people. (no.3).

A relative brought a photo to the interview that she got from the contact person, who wanted to inform her about what happened with her mother during the day. The photo showed her mother in a bad mood because the staff had forced her to shower. The relatives thought that this must be unpleasant for the resident. Still, it was the staff's choice to send her photos showing problematic conditions for the resident:

> Well, they sent this one on the app and then they wrote like this: "Greetings from K newly showered." And then I thought that it's probably not a funny situation. But then I thought that it was rather honest of them to send pictures in which she is not only laughing and smiling and happy. (no. 12).

User Involvement in the Organization of Nursing Home: Article 19, "Full Inclusion and Participation in the Community"

According to relatives, the nursing homes arranged meetings for relatives. Those meetings were crucial for involving relatives in the nursing homes, informing them of what happened, and letting them present criticisms. Some relatives had yet to hear about such meetings, but they wanted them because they wanted to influence the care the nursing homes provide.

Violations of Human Rights in Nursing Homes

In sum, some anecdotes that the relatives told go against articles in the CRPD (UN, 2006). For example, articles 19 and 30, about independence, societal inclusion, and participation, cannot be completely applied because the staff must follow residents outside the nursing home if they visit cultural events, for example. Furthermore, article 14, about liberty and security, cannot be completely applied because staff-enforced restrictions hinder residents from moving around in the building. Moreover, article 15 was contravened because some care situations could be deemed degrading, such as restrictions that limit residents' freedom of movement.

Inclusion in Society and Going Outside the Nursing Home: Article 30 "Participation in Cultural Life, Recreation, Leisure, and Sport," and Article 19, "Living Independently and Being Included in the Community"

According to the relatives, it was rare for staff to accompany residents outside the nursing home and help them take part in city activities such as drinking coffee or attending events. If the residents attended events outside the nursing home, relatives must accompany them; if not, they must live their daily lives indoors:

> Afternoon tea sometimes, so not an organized afternoon tea like this for the whole department, but I want to go myself somewhere … that possibility does not exist today. After all, it's a relative who makes it happen or a volunteer who does it … often it's the case that the person who perhaps needs it the most never gets the chance. (no.3).

Furthermore, relatives believed that the staff needed more time to accompany the residents on activities outside the nursing homes and that the staff had less time during the last year. There are nursing homes that hire buses to take residents on outings, but the residents cannot choose the destination, although they can choose not to go if they dislike the destination. The buses also tend to be small, so not all residents can go on the outings.

Article 15 "Freedom from Torture or Cruel, Inhuman, or Degrading Treatment or Punishment"

Some relatives believed that the residents experienced care-related visits, such as dental check-ups, as torture, because the PWD did not understand what was happening. It hurt, and one resident did not understand why he had to undergo this experience:

> Doing this to him was like abuse, and then I thought, wouldn't it be better to wait and see, because he didn't seem to be in any pain? … Because it felt like he was being abused. He didn't understand anything. He certainly wouldn't want to go to a dentist. (no. 2).

Degrading treatment annoyed some relatives and residents. For example, the residents did not appreciate restrictions that hindered them from walking around in the nursing home. The staff reacted to that behavior with more restrictions, such as locking the door to their flats. The residents did not like locked doors that hindered them from going out:

> She can still move, decide that now I don't want to be here, but now I want to go there. And instead they idiotically tried to fit her in. The more she screamed and sort of wanted out, away, the more they tried to shut her in. So they had the wrong attitude. (no. 7).

However, there is also a restriction in the form of psychotropic drugs that calm the residents and reduce disruptive behavior. The staff should help the residents with their mental health instead of just restricting their behavior with drugs;

> She has been mentally unwell. They've tried changing medications, but I've been thinking the whole time that it's not just the medications, it's also how you treat her that might be able to calm her down as well. (no. 16).

One resident was restricted by bed rails installed around her bed and did not appreciate being stuck in bed. The resident did not understand why she had to stay in bed with bed rails that hindered her from doing what she wanted.

Liberty and Security: Article 14 "Right to Liberty and Security of Person … That the Existence of a Disability Shall in No Case Justify a Deprivation of Liberty"

A relative talked about a nursing home where her relative had lived earlier. The staff of that home had confined her relative in her room, leaving her alone and isolated against her will. The staff did this without letting her relative know about the situation. In her loneliness, she fell on the floor. Later, the relative moved her to another nursing home:

> They didn't take good care of her … they had locked her in her room … because she yelled and screamed … it was Christmas Day … but you think about how many times this happened when no one knew about it, because in this case a friend happened to come to visit her and then the staff rushed to unlock the door … and there she was sitting on the floor because she couldn't even walk. (no. 7).

Furthermore, one relative spoke about how staff isolated a resident during mealtime because he disturbed others. Because of that, the resident had to sit and eat alone against his will. The relatives thought that his behavior was grounded in anxiety, which the staff met with isolation. The routine was that everyone sat in the dining room and ate, but not that one man because of his behavior:

> Well, because he started screaming a lot. And sometimes it was a lot, and then he was disturbing the other residents. And there was nothing to be done about it. I don't know what it was, because it could be a cry for help, or it could be anxiety. Then in the food situation, they then put him in another room, but he didn't like that. (no. 8).

The Co-researchers' Thoughts About the Results

According to the co-researchers, a PWD should be able to exercise self-determination depending on his/her capabilities. Co-researchers highlighted aspects of self-determination that indicated violations of human rights according to policy documents (Lindmark et al., 2022) and the CRPD (UN, 2006). An example of what the co-researchers thought was inhuman behavior was photos sent by a contact person to a relative. The nursing home resident did not like to shower, but the staff forced her to shower regardless. After the shower, the contact person sent a photo to the relative showing the resident in a bad mood because of the shower. The co-researchers believed that that behavior invaded the resident's privacy and contravened human rights principles. Moreover, the co-researchers thought that staff needed more education in meeting residents' needs and when to use restrictions and coaxing to handle the residents. The co-researchers also believed that providing life stories was important to give staff information about who the residents were before dementia. This includes knowing the culture residents grew up in. However, what was most important was that the staff should listen to the residents. The co-researchers also noted the importance of the organization of nursing home routines: routines need to support and facilitate PWD participation, and not the reverse.

Discussion

In this article, we problematize self-determination for PWD by asking how relatives view self-determination among their relatives in nursing homes. We connect the responses to a human rights discourse on disabilities. The study was guided by the question: How do relatives understand participation by PWD who live in nursing homes? Relatives emphasized their essential role of informing staff about the residents, in order to develop good relationships with staff. Furthermore, staff must be curious about who the residents were before moving into the nursing home. The photos used during the interviews were quite helpful in facilitating discussion of this with relatives. Some relatives believed that they had to make decisions for the residents due to their cognitive disability, and they seemed not to consider that the PWD can still have capabilities. Furthermore, as some relatives did not consider the PWD as adults with capabilities, they thought that staff could coax and manipulate the residents, for example, to agree to shower. However, we can also frame this as a realistic approach to get residents to shower. According to Smebye et al. (2012), relatives are sometimes confused about what is best for PWD and themselves. There is no simple right or wrong regarding self-determination, and it is challenging to balance self-determination and protection from harm (Morris et al., 2021). We can interpret the relatives' narratives as against CRPD (UN, 2006), and as coaxing and manipulation, specifically Article 17, concerning protecting integrity. Moreover, if relatives treat the PWD as having no capabilities to make decisions, that could be against the CRPD because PWD often still retain some capabilities (Smebye et al., 2012).

However, some other relatives believed that nursing home residents must gain the right to self-determination, which we interpret as gaining human rights, according to the CRPD (UN, 2006). Furthermore, some relatives identified examples of staff actions that reduced the residents' self-determination. The most common example was that residents could not socialize in the community outside their home which we interpreted as contravening articles 19 and 30, stipulating community inclusion and opportunities to join in cultural activities. According to Cahill (2018), efforts to include PWD in the CRPD would contribute to PWD being included in society. In addition, the staff focus in dealing with PWD was on care and protection rather than on participation in daily life and cultural activities in society (cf. Cahill, 2018; Steele et al., 2019, 2020). Therefore, for PWD to gain self-determination, how staff and relatives think about their capabilities is crucial. Moreover, staff also used restrictions, for example, requiring a resident to sit and eat alone against his will due to his behavior, which disturbed the other residents. It took considerable work for staff to handle a resident with disruptive behavior. The staff handled such behavior by imposing restrictions, such as not allowing the PWD to sit and eat with others, which we interpret as an example of degrading treatment and punishment (Article 15). Institutional arrangements affect the daily life in nursing homes and limit the opportunities to promote residents' human rights. As we interpret it, examples of human rights infringements include the residents' limited options to take part in life outside the nursing home and the restriction on residents whose behavior disturbs other residents and the institutional routines. However, it is hard for the staff to work according to the high ambitions stipulated in Swedish policy documents regarding human rights. According to Harnett (2010), there are challenges to implementing the visions of policy documents (which have high ambitions regarding human rights) in daily life in nursing homes. Moreover, the staff follow local institutional routines in managing the daily life of the residents, which may limit residents' opportunities to participate (Alftberg, 2021). How relatives discuss and problematize participation could affect how the residents are involved in decisions simply because they need support from relatives and staff to make decisions regarding their daily lives. Both staff and relatives must understand how to involve residents (Strøm & Slettebø, 2021). Steele et al. (2019) shed light on the importance of nursing home residents having the right to self-determination — surely, PWDs deserve social justice and not just care. After talking with the co-researcher, we interpreted actions such as sending a photo of a resident in an exposed situation as actually contravening human rights according to the CRPD (UN, 2006), Article 15, regarding degrading treatment, and Article 17, regarding personal integrity. The co-researcher's view was an eye-opener for us and forced us to see the inhumanity of sending photos to relatives. According to Cahill (2018), PWD still retain their personalities and can respond to stimuli even though they do not speak, and staff need more education about dementia. The co-researcher also stressed the importance of well-educated staff who can meet residents' needs. Moreover, the residents must have privacy, including not being observed by others.

Concluding Remarks and Implications for Social Work

As relatives are often spokespersons for residents, how they understand participation by PWD is essential. How the relatives identified situations limiting the residents' self-determination in nursing homes relates to how they understood the PWD's rights to participate in their daily lives. As residents' spokespersons, the relatives can also identify when nursing homes do not facilitate the residents' participation. Moreover, staff in an organization must follow routines that steer how they do their daily work, sometimes going against the staff members' individual wishes — for example, nursing home staff did not have flexible routines or sufficient time allowing them to accompany the residents to activities outside the nursing home. However, if relative supporters work with nursing home staff, they can help the staff to facilitate residents' participation and, by extension, uphold their human rights (UN, 2006). Similarly, the co-researchers contributed to this study by making the authors conscious of aspects that contravened human rights, when they read the interview results.

Moreover, classifying dementia as a disability at the policy level could strengthen the rights of PWD (Shakespeare et al., 2019). With the human rights approach incorporated in, for example, policy documents, it becomes easier to emphasize PWD as having rights, even though they live in nursing homes. Human rights related to PWD must be respected, and social workers can play a role in developing policies that support them (Kusmaul et al., 2017). Social workers can strengthen older people's right to be accorded full human rights, not just treated according to a needs-based approach (Cox & Pardasani, 2017). The following key ideas emerged from the study's findings: how relatives viewed the participation of their next of kin with dementia as important and how nursing home routines could sometimes prevent the residents from participating. Furthermore, classifying dementia as a disability could strengthen a rights perspective. The co-researchers identified situations in which nursing homes risk implementing procedures that are not in accordance with human rights. Finally, social workers could influence nursing home policies and help secure participation routines that include paying more attention directly to the resident.

Limitations

We asked the managers to help us recruit relatives to interview. To reduce selection bias due to the managers acting as gatekeepers, we also contacted relative supporters in two municipalities; they suggested the names of more relatives to interview.

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Declarations

Conflict of Interest The authors declare no competing interests.

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