Dignity, dependence and relational autonomy for older people living in nursing home

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Abstract:

Dignity is a core concept in nursing care. In earlier theories on dignity, close links have been drawn between dignity and autonomy, and autonomy has been closely related to independence. These traditional understandings of dignity and autonomy may be challenged when an individual moves into a nursing home. Our findings show that negative views about dependence, institutional frames and structures in the nursing home, and the attitudes and actions of health care personnel may diminish independence and lead to a lack of autonomy. Each of these areas can be experienced as a serious threat to the residents' dignity. Findings are interpreted and discussed in the light of a theory of relational autonomy, which represents an alternative to the traditional individualstic understanding of dignity and autonomy.

Keywords: dependence, interdependence, dignity, nursing home, relational autonomy.

Introduction

Dignity is a central concern in care and in medical ethics (Andorno, 2009; Milton, 2008). The International Council of Nurses Code of Ethics declares that "[i]nherent in nursing is a respect for human rights, including cultural rights, the right to life and choice, to dignity and to be treated with respect" (ICN, 2012, p 1). But dignity is also a vague and contested concept. Macklin describes dignity as a useless concept. She thinks that the concept of dignity means no more than respecting a person's autonomy (Macklin, 2003) while Pinker claims that it is a 'squishy and subjective' notion (Pinker, 2008).

In contrast to these critiques, we think dignity is an important concept in clarifying how residents in nursing homes may experience the quality of the care they receive. People living in nursing homes are often dependent on others to have their needs met. We need knowledge about what these residents themselves experience as maintaining or infringing their dignity in this vulnerable situation.

The relation between dignity and autonomy Previous research on dignity emphasizes the importance of respecting the patients' autonomy, integrity and independence (Franklin, Ternestedt, & Nordenfelt, 2006; Hall, Longhurst, & Higginson, 2009; Harrefors, Sävenstedt, & Axelsson, 2009; Randers & Mattiasson, 2004; Stabell & Lindström, 2003; Woolhead, Calnan, Dieppe, & Tadd, 2004). Research also shows that nursing home residents may find it humiliating when nurses do not respect their integrity and their need for independence (Stabell & Lindström, 2003). Woolhead et al. (2004) found that older people relate dignity to self-esteem, trust, equality, autonomy, independence and control. According to Hall et al. (2009) residents living in nursing homes may feel that their dignity is at stake when they lose

their physical functions and hence their independence. What this earlier research in nursing homes shows is that dignity is closely related to autonomy and to having control in one's life.

Our findings confirm that there is a relation between experiences of dependence, autonomy and dignity. However, dignity has not been considered in the light of a relational approach to autonomy. We believe relational autonomy may help us to understand the links between dignity and experiences of dependence and autonomy.

Relational autonomy. Theories on relational autonomy can be seen as a critique of the traditional understanding of autonomy which emphasizes the independent, rational, free and self-governing individual (Sherwin & Winsby 2011). Most residents in nursing homes can no longer live up to the ideal of the independent, free and competent decision maker, so traditional views of autonomy do not fit. By contrast, relational autonomy takes the view that all individuals are interdependent and socially embedded and that autonomy depends on social relationships and the institutional and socio-cultural context in which we live in (Mackenzie & Stoljar, 2000). This is a view of autonomy which takes the situation of nursing home residents seriously. In relational autonomy, dependence and frailty are not seen as something to avoid. It is not the dependence or vulnerability which threaten a person's autonomy and dignity, but how that person is treated as a dependent and vulnerable individual, and how the socio-cultural context and institutional structures in a nursing home may undermine the person's opportunities to exercise autonomy. According to the theory of relational autonomy, we have an obligation to respect the autonomy of the residents in nursing homes and to help them live in accordance with their will and their values. Respecting the autonomy, here means to respect the right to make significant decisions regarding everydaylife when living in a nursing home. This means that we should support the residents in nursing homes, so that they may be able to live their life in accordance to their will, their wishes and values.

By approaching dignity and dependence from the perspective of relational autonomy, we will offer a broader understanding of how to maintain the autonomy and dignity of residents living in nursing homes.

Aim

The aim of this article is to present and discuss some findings on how older people in nursing home experience dignity related to dependence and autonomy and how their dignity may be promoted.

Design and method

The study was qualitative and based on a hermeneutic approach (Kvale & Brinkmann, 2009). According to the philosophy of hermeneutics, we always interpret the world in the light of our pre-understanding. With a hermeneutic approach, the knowledge building may be seen as a circle where new knowledge melts together with previous knowledge (Gadamer, 2004). The pre-understandings influence both the interview guides and the interviews conducted by the researchers. Our pre-understanding in this study is built on the researchers' different experiences of caring for older people, clinical nursing and research as well as on earlier theories and research about dignity.

Participants and research context

Twenty eight residents were included from six different nursing homes; two nursing homes in Sweden, one nursing home in Denmark and three nursing homes in Norway. Care for older people is organized quite similiarly and nursing home care is a part of public services in all of the Scandiavian countries. The nursing home wards where the residents lived were general wards, and the nursing home wards housed 15 to 30 residents. Most of the residents had their own private room, but in one of the Norwegian nursing homes, the residents had to share a room with another resident. Four of the nursing homes were in large cities, while two of the nursing homes were in smaller cities.

To be included in the interviews, the residents were supposed to live in a nursing home have the capacity to give their own written consent to participation and not suffer any cognitive impairment.

There were seven men and twenty one women, aged 62–103. The interviews were conducted in the nursing home where the residents lived.

Qualitative research interviews

The interviewers used an interview guide that built on the research questions, but the questions were open-ended to gather rich answers. An example of an open question was, "How did you experience moving into the nursing home?" Questions guided by the research questions focused on what the residents experienced as a dignified life and how life in the nursing home could affect their experiences of dignity.

The interviews were conducted by the researchers in the project, taped and transcribed verbatim. Each interview lasted from 40 to 70 minutes.

Analysis and interpretation

The interviews were read by all of the authors in the research group, and the authors met several times to discuss the interpretation of interviews and the findings with each other. Following a hermeneutic interpretative approach, our pre-understanding was important in the analysis (Gadamer, 2004).

The analyses followed Kvale's (2009) three steps analysis. These three steps start with selfunderstanding, continue with common sense, and end up with a theoretical level (Kvale & Brinkmann, 2009). The interviews were read several times to get an overall view of the material. Sub-themes that emerged were written down and abstracted to theoretical themes.

Research ethical considerations

The study was approved by an independent Committee for Medical Research Ethics in the respective countries and also authorized by Norwegain Social Science Data Services (NSD).

All of the participants signed an informed consent form. They were also informed that they could withdraw from the study at any time, without any reason, and that a withdrawal would not have any consequences.

Results

Moving into a nursing home may represent a great change in a person's life. What seemed to be common to almost all of the residents was the fact that moving into the nursing home was experienced as a threat to their dignity. This was related to experiences of becoming dependent on others, to lack of time and resources in the unit and to lack of freedom, but it was also related to the attitudes of health care personnel.

Experiences of being dependent as a threat to autonomy and dignity

The residents experienced being dependent differently. Some of the participants said that it did not bother them and that it was natural to become more dependent on others when one got older. *"You may become dependent on others too one day,"* one of the participants said to the interviewer. Some of the residents also expressed how good it was to get the help they needed when they were dependent.

Resident A (woman): I enjoy being cared for. It's not humiliating. No, I'm not ashamed about that. I'm OK with that

But many of the residents talked about how humiliating it felt to lose control over their body and let others do things for them that they were not able to manage by themselves anymore. This was experienced as a threat to their dignity. As one of the residents expressed it: Resident B (woman): Yes, I need help for everything. My dignity was not prepared for that. I think it's difficult to be dependent on others, when one has to go to the toilet ... and when going to bed.

One woman also told about how she felt when getting help to take a shower from carers who were young and healthy:

Resident C (woman): It's not very funny to get help to shower. You know, I could have been a grandmother to those who care for us. And you have to take off your clothes and stand naked in the shower.

Another resident told about how she experienced moving into the nursing home and becoming dependent on others, and described it as a big change in her life:

Resident D (woman): It has been a big transition for me, to move in here, from being totally independent and living in my own house and deciding over my things, and now sitting in a wheelchair because I cannot walk or stand up.

The transition from being independent and living in her own house to sitting in a wheelchair and moving into a nursing home was experienced as a threat to her dignity. She felt that she could not do anything by herself anymore.

These findings show that the residents relate dignity to independence and that they may experience being dependent as a threat to their dignity.

How the system and institutional frames may be experienced as threats to autonomy and dignity

According to our findings, institutional frames such as lack of time and resources could make the residents even more dependent, and could therefore be experienced as threats to their dignity. These factors could decide when residents would get help from the professionals or from whom they would get the help. In many residents were totally dependent on the priorities of the health care workers. The participants told how they had to be patient and wait to get help to get up in the morning or for toileting, and how little time the care workers had. They often did not know when they could get the help they needed. Some of the participants thought this was a resource problem, that there should have been more personnel at work.

Resident E (woman): Sometimes we have to sit and wait for a long time, to get help. We are many people, and the carers are few.

Resident F (man): Nobody seems to have time to anything. There is a lot of waiting, for example to get up in the morning

Resident G (woman): It's just that there are too few of them.

Resident H (woman): They are so gentle, very gentle, but unfortunately they have too little time. "

That they had to be patient and wait to get the help they needed shows that the residents not only lost control over their bodies; they also lost control over their time. They were in many ways left to the institutional frames, routines, and resources available. This unpredictability and loss of control demonstrates how the residents are totally dependent on the system in the nursing home or the system that controls the nursing home from the outside. The system outside may be the authorities who are responsible for the resource allocation. Our findings demonstrate that it is, to a large extent, the system and not the residents who live inside the system that controls the residents' lives.

These findings also demonstrate how institutional frames may affect the residents' opportunities to make autonomous decisions in their everyday lives.

Some of the residents also mentioned the importance of having the same carers who knew them to help them every day. As one of the residents said:

Resident I (woman): It is very difficult, when there are new carers. And you have to explain how you want it all the time. It would have been nice to have a permanent stable staff.

Because of the strict routines and lack of resources they could not decide when to get up in the morning or when to eat their meals. Our findings show that when one does not have the opportunity to make one's own decisions, one loses control and power, and this may be experienced as a threat to one's dignity.

Autonomy and dignity at stake in the care-relationship

Most of the residents described the healthcare personnel as kind and helpful. They thought that the health professionals did the best they could do with the resources they had, and some felt that they had to excuse the carers for having too little time for the residents. Being dependent on help was not experienced as a threat to their dignity when they felt that they were cared for in a good way. As one of the ladies said:

Resident J (woman): I need help for everything...almost everything. That doesn't bother me. They are very nice and good at helping me, yes they are. I think they treat me in a good way, when they help me.

But some of the participants also told of humiliating situations, where the health care personnel were rude, impolite and paternalistic. As one of the participants said:

Resident K (woman): (...) Three times have they told me that they are not my slaves when I've been asking for help. Twice when I've been asking for help for my stomy, and once when I asked them if they could help me folding up my quilt." Another resident was asked, "Do you think this is a hotel?" when she asked for help.

How they experienced their dignity being under threat was also related to a feeling of losing their freedom in the nursing home. This feeling of losing their freedom became obvious when participants described how the workers overruled the residents in the day-to-day care. They felt that they lost their ability to make their own decisions, as the example below shows:

Resident L (man): They [the health care workers; our comment] don't want me to buy an electric wheelchair. I've got the money, but they don't want me to buy it. They're afraid that I will move around with it inside the building, but that's not the reason I want it. I want it so I can get out. At present I cannot even get to the churchyard with flowers.

The feeling of losing their freedom was related to the experience of being captive in the nursing home. They felt that they were "locked in" in the nursing home. The doors were not locked in these nursing home wards, but the residents were dependent on help from the carers to get out, and it was the carers who decided when they could go out.

Resident M (man): (...) I think to myself that I should be a free man, but I'm not free. The decisions that are taken depend on what they decide, not what I decide. If I get my clothes on and want to go out, I'm not allowed to go out. "You have to stay inside," they say. They say that if I want to go out, I need to have someone with me or I can't go. That's how it is. They think I'm too weak. And I can agree that I was weak when I moved into that other place. But there are never any devils that will accompany me out. Never. If you let me tell you what I think ... Rudeness, impoliteness, and paternalistic attitudes described by the residents demonstrate the asymmetric relationship between the residents and the care workers. When residents are dependent on others, disrespect from the helper may be experienced as a serious threat to the residents' dignity.

Discussion

What our findings show, is that dignity may come into play at different levels in the residents' lives, a cultural level, an organizational or system level and a relational level. The cultural level is Western society where independence is viewed as a core value related to dignity. The system level may be understood as the institutional frames and routines and the social or relational level is the "lowest" level, where the patient meets the care-givers. The term *relational autonomy* may cover all these levels, and may help us to understand the relation between dignity and autonomy at these three levels.

Cultural prejudices against dependence - and a relational view of autonomy

The Western cultural setting, where the study was situated, is to a great degree affected by liberal traditions which goes back to the Age of Enlightenment and modernity, with Immanuel Kant as one of the dominant thinkers. Kant related dignity to a person's autonomy, reason and free will (Banerjee et al., 2006). The traditional understanding of autonomy also builds on this liberal ideology (Sherwin & Winsby, 2011). The contrast between the independent lives the residents experienced outside the institution and life inside the institution where they are totally dependent on others, becomes more obvious in a society where the ideal is the young, independent, healthy and productive person, and where autonomy, as independence and freedom, seems to be the fundamental value (Agich, 2003; Angus & Reeve, 2006; Charlotte Delmar, 2012; Vetlesen, 2001). Our findings show how becoming dependent is experienced as a threat to dignity. These findings, we think, reflect the negative view towards dependence

in society as whole. Sherwin and Winsby (2011) claim that older people may internalize negative beliefs and attitudes from the wider society, and this may result in a diminished sense of self-worth. When independence seems to be the highest goal, it may feel like a burden to become old and dependent and not able to manage one's life independently (Vetlesen, 2009). Vetlesen calls this tendency in the society "pathological", a tendency that may lead to more suffering, aversion and pain (Vetlesen, 2009). If we take a relational perspective on autonomy, this negative view of dependence and old age leads to discrimination and oppression, which may again lead to a reduced sense of self-worth (Sherwin & Winsby, 2011). Sherwin and Winsby (2011) also state that people who are oppressed may "internalize some of the social biases attached to their group". Our findings support this idea. Instead of defining dependence in negative terms, we could see it as the common foundation for all human beings, as we become human beings through interaction with others (C. Delmar et al., 2006; Vetlesen, 2001). We are born dependent, and we are dependent on others to a greater or lesser degree throughout life. A relational approach to autonomy acknowledges dependence in positive terms, but it also acknowledges that dependence may lead to harm if the dependence is not valued and protected in social relations and context.

Dignity and institutional frames from the perspective of a relational autonomy

Our findings showed that institutional and organizational frames also affected the residents' experiences of autonomy and their dignity. Organizational frames, such as time and resources, may increase or decrease the residents' autonomy and their opportunities to live the life they want to live. A relational perspective on autonomy supports the assumption that both the social context and institutional frames and structures may reduce a person's ability to live the life he or she wants to live. We argue that the institutional frames may lead to even more dependence.

Several of the participants talked about how little time the carers had for them, and how they had to wait for the help they needed. The participants did not feel that they could influence the institutional resources or other frames in the nursing homes, and this was experienced as a threat to their autonomy and dignity. Other studies have also found that lack of resources may be a threat to the residents' autonomy and hence their dignity (Jakobsen & Sorlie, 2010; Kilcoyne & Dowling, 2007). The fact that resources are scarce in nursing home care in Norway is also documented in previous research (Førde, Pedersen, Nortvedt, & Aasland, 2006; Tønnessen, Nortvedt, & Førde, 2011). Resources are something that neither the staff nor the residents can control. It is a part of a structure, or a system that both groups may feel they cannot influence or control.

Other frames that are difficult for the personnel or the residents to control are the environmental facilities in the nursing home, such as the architecture. If residents do not have their own bathrooms, or if it is difficult to get out of the nursing home, residents' ability to take a shower or to get out of the nursing home whenever they want may be restricted. If they have to share a room with another resident, this may lead to less privacy for the residents.

Institutional environments may be oppressive and lead to unjustified dependence, restricting autonomy (Kittay, 2011). These frames include daily routines in the nursing homes. Routines and activities often provide little space for the residents to make their own choices (Sherwin & Winsby, 2011). When the residents still lived in their own homes, their lives were not restricted by institutional routines. They could decide when they wanted to get up in the morning, or when to eat breakfast. After moving into the nursing home they did not always know when they would be able to get up in the morning, or if the care worker had time to help them with a shower. According to Thorsen (2003), predictability and having control over time are important if residents are to experience having power in their lives. If time and

routines are not predictable, and if residents feel they are losing control over their daily lives, this may be experienced as a threat to dignity (Franklin et al., 2006; Thorsen, 2003).

However, environments can also facilitate residents' autonomy. There are organizational frames that staff can control. As health care workers we have an obligation to promote the residents' autonomy by adjusting the environment, so that residents are enabled to live their life in line with their interests and values.

If we take a relational perspective on autonomy, we argue that society and politicians have a responsibility to ensure that resources are allocated so that older people living in nursing homes can live their lives in line with their will and wishes. This is also supported by Sherwin and Winsby (2011).

Dignity and the care relationship from the perspective of relational autonomy

Thorsen (2003) claims that care and how the care is experienced have to be understood relationally. Dignity is also a relational concept, and always involves a relationship (Frank, 2004). From a relational perspective, the care relationship is of great importance in protecting and enhancing the autonomy and hence the dignity of frail old people. According to our findings, residents can experience the relationship with carers as a threat to their dignity. The resident is even more vulnerable when he or she cannot decide who gives them help, they just have to receive whatever or whoever they get and are dependent on the carers' attitudes towards them (Held, 1995). As carers we are responsible for protecting the vulnerable person's dignity (Frank 2004). The relationship between the helper and the dependent person is fundamentally an asymmetric relationship, in which the helper has the power (E. Rundqvist & Lindström, 2006). This power may be used in a good way, in a dignifying way, but the power may also be abused and lead to infantilization, which may be experienced as a threat to the dignity of the one who receives the help (Ewa Rundqvist, 2004; E. Rundqvist & Lindström, 2006; Thorsen, 2003). According to Rundqvist, we should give authority to the

patients by confirming them. If the patient cannot be given authority, the nurse should employ her authority to ease the suffering of the patient (Ewa Rundqvist, 2004). This is also in line with the idea of a relational autonomy (Sherwin & Winsby 2011). If the nurse does not give authority to the patient in the relationship, this may lead to violation of dignity.

Mann, in his taxonomy of dignity-violation, describes how attitudes may affect the dignity of a person. He describes not being seen or heard and violations of personal space as threats to the person's dignity (Mann, 1998). As our findings show, residents living in nursing homes may experience all these types of threat in the care-relationship. This result is also supported by findings from interviews with family members on how they experience the care for their loved ones in nursing homes (Nåden et al., 2013). Their loved one may be seen as a number within a group, the resident group. Their personal space may be violated every day when the care workers help the old and frail person with daily care, which is often of an intimate character. Not being heard was also described by our participants, and may be a threat to dignity and autonomy in the care-relationship.

These findings show how vulnerable the care-relationship is, and how dependent one is as a care receiver on who delivers the care.

Limitations

One of the limitations in this study was that all the participants had a Scandinavian background and that the study only took place in Scandinavian nursing homes. As the traditional understanding of autonomy to a great degree builds on a Western tradition and philosophy, it could have been interesting to investigate how dignity and old age is understood and experienced among older people with non-Western backgrounds living in Scandinavian nursing homes. It could also be interesting to investigate nursing homes or residential living for older people in non-Western cultures.

Another limitation was that this study only included individual who did not have any kind of cognitive impairment. In nursing homes in Norway we know that approximately 80% of the residents suffer from cognitive impairment (Selbæk, Kirkevold, & Engedal, 2007). This may be the same in other Scandinavian countries, since nursing homes in these countries tend to be similar. This means that residents representing the majority of the residents living in nursing homes were not included in this study.

Conclusion

According to our findings a person's dignity related to dignity may be at threat at different levels. Our findings demonstrate that there is a relation between experiences of being dependent, autonomy and dignity. According to the idea of relational autonomy we have to look into all three levels to maintain the residents'autonomy and dignity. We should not merely focus on what happens in the care- relationship,but we also have to take seriously how cultural and organizational aspects may affect experiences of dignity.

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Conflicting of interests

The authors declare that there is no conflict of interest.

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