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“They are different now” – biographical continuity and disruption in nursing home settings

Tove Harnett & Håkan Jönson

Keywords: ageism, biographical approach, disability studies, long-term care

Introduction

Research on nursing home care has identified routines and institutionalization as problems (Reed & Payton, 1997; Ziemba, Perry, Takahashi, & Algase, 2009) and person centeredness as part of the solution. Broad goals express that older people in nursing homes should be able to live “as normal and unconstrained a life as possible” (Kane & Kane, 2001:121) and “receive support to maintain interests and habits” (2009/10:SOU18). While similar goals have been prominent within disability policies, a notable difference concerns comparisons that are used to establish what is a normal life. Eldercare policies emphasize person centeredness and biographical continuity within the context of care. Disability policies emphasize the right to be able to live like “others”, a comparison that invokes contexts and categories that are external to disability and care (Jönson & Taghizadeh Larsson, 2009; Erlandsson, 2014).

In this article we will investigate the translation of policies on personalized nursing home care into practice and use a “disability lens” (Jönson & Harnett, 2016) to highlight weaknesses inherent in the goal of biographical continuity. Research on biographical

continuity in eldercare has so far paid insufficient attention to what it means to “maintain interest and habits” for nursing home residents with multiple impairments and diseases. What aspects from before should be taken into account? Are some conditions regarded as just causes for abandoning these goals? By introducing a disability lens we point towards the possibility of using new kinds of comparisons and goals regarding living conditions for people in nursing home settings.

The aim of this article is twofold, 1) to examine how goals to personalize nursing home care through biographical continuity are discussed by persons directly involved as residents, their relatives, staff and managers of nursing homes and 2) to use a “disability lens” to introduce alternatives to biographical continuity as means to counter institutionalization. Through the use of an “Equal Rights Framework” that is inspired by disability models of Scandinavia, we will demonstrate that the focus on personhood that has been used to fight institutional models may in fact play into an ageist dynamics.

Biographical continuity in nursing home settings

Research on nursing home care is vast and ranges from studies on residents’ wellbeing and quality of life (Garland, Oyabu, & Gipson, 1989; Kane, 2003; Zimmerman et al., 2005), to studies on care work and the conditions of care workers (Fjær & Vabø, 2013; Juthberg, Eriksson, Norberg, & Sundin, 2010; Pekkarinen, Sinervo, Perälä, & Elovainio, 2004). Several studies have described life in the nursing home in terms of inflexible routines (Persson & Wästerfors, 2009), loss of identity (Ryvicker, 2009), lowering of self-esteem and reduced sense of personhood (Scourfield, 2007). Consequently a large body of research has aimed at replacing task centered and depersonalizing care arrangements with approaches that focus on the personhood and biographical continuity (McCormack & McCance, 2006).

Theoretically, goals to maintain residents' identity and habits are expressed in continuity theory (Atchley, 1999) and are central in approaches such as the person-centered care paradigm (Kitwood, 1997; McCormack & McCance, 2006), culture change (Corazzini et al., 2015), relationship-centered care (Nolan, Davies, Brown, Keady, & Nolan, 2004) and in life history approaches (Villar & Serrat, 2017; Edvardsson, Fetherstonhaugh, & Nay, 2010; McKeown, Clarke, & Repper, 2006; Surr, 2006).

The strength of a personalizing approach is obvious; the fact that people are different and have unique life histories and unique habits and interests becomes a fundament of care. This traditional way of countering institutionalization has been successful, but the application of a "disability lens" reveals an inherent weakness. Traditional approaches that focus on personalization tend to frame rights in relation to personhood *within* the context of care. Goals, such as to enable residents to live according to their identity and be like "themselves", refer to personal characteristics that are difficult to transform into rights. The obvious risk is that increased frailty and adjustment to the context of care are regarded as "natural" changes caused by the aging process and reasons for not maintaining established habits and interests (Jönson & Harnett, 2016). A "disability lens" makes evident a tendency to use internal, rather than external, comparisons in eldercare. It is thus possible to reveal a dichotomy of institutionalization versus personalization and investigate other types of comparisons – external to the context of care – that may improve the welfare of older persons with extensive support needs.

Swedish nursing home care

In this article we use the internationally established concept of *nursing homes* to emphasize that the type of residential care discussed represents the highest level of care available

outside the medical hospital ward. Residential care facilities in Sweden are formally labelled *special housing for older people*, and care services are covered by Sweden's Social Services Act. Aging-in-place, i.e. a preference to provide home-based care, has been the leading principle of Swedish eldercare since the 1950s, and for reasons of cost, the general threshold for moving into a care facility has been raised during the last few decades. As a result, those moving into residential care now have massive care needs and the majority have dementia (National Board of Health and Welfare, 2014). The responsibility for nursing homes was moved from the health care sector to municipal social services in 1992, and thus *from a medical model to a social care model*. The Social Services Act was based on the idea that older people in need of care should "as far as possible be able to be like others and have a situation similar to others" (Prop. 1979/80:1, p.212). To achieve this goal, municipalities were urged to focus on providing home care and making care facilities homelike (Lundgren, 2000; Szebehely & Trydegård, 2012). Facilities are no longer referred to as institutions and there have been efforts to introduce amenities that are typical of regular apartments. With very few exceptions, nursing home residents have private rooms with an en-suite bathroom and a kitchenette. In policy documents, residents are referred to as tenants and their private rooms are formally regarded as rental apartments, even if they are located in a corridor of a former traditional institution. The type of individualized small-scale (avoiding ward-like arrangements) care that is described in efforts to introduce a "culture change" (McCormack et al., 2008) constitutes mainstream nursing homes in Sweden. The relatively good living conditions in Swedish nursing homes (in terms of physical environment, privacy and social activities) provide a specific context for ambitions about maintaining interests and habits. For instance, in a Swedish nursing home the facility will in itself serve to maintain certain habits of residents: They furnish their apartments with private furniture, they are allowed to

smoke inside their apartments, they have a private bathroom and they can (often) bring their pets.

Method

The data for the study was collected within the research project “Improving everyday conditions by reconceptualizing eldercare through the lens of disability policies”. One aim of the project was to investigate tensions inherent in efforts to provide personalized care in collective settings like residential care facilities. The present article was based on 20 interviews at four nursing homes located in two medium-sized (100 000 inhabitants) Swedish municipalities. Twelve interviews were conducted in the form of focus groups or pairs, and eight were conducted individually (all four managers and four of the residents). In total we interviewed 46 persons: 19 residents, six family members, four managers and 17 staff members. A detailed description of sampling and methodology is described in Harnett and Jönson (2014). The project was approved by the regional ethics review board in Lund (Dnr 2013/349).

Theoretical approach and analytical framework

In the article we will use a constructionist approach and regard phenomena like biography, needs, age, illness and impairments as sociological topics to be studied, rather than given facts or causes for a particular arrangement (Bodily, 1994).

In order to question ideas that are often taken for granted in eldercare and analyze the way normality and rights are constructed through comparisons, we used a framework that is inspired by disability policies (Jönson & Harnett, 2016). The framework, called the “the Equal Rights Framework”, is based on the Scandinavian normalization principle and its claim that (younger) persons with impairments should be provided with living conditions that are as similar as possible as those of other members of society.

The framework that we have developed consists of three types of interdependent comparisons/references: context-centered, category-centered and personhood-centered, that may be internally oriented to care and impairment or externally oriented to comparisons outside care and impairment (Figure 1). For a detailed description see Jönson and Harnett (2016). A resident in a nursing home who wants to have a daily shower based on the fact that “I used to have a daily shower before moving here” uses an external reference to personhood. A care worker who states that “you are in a nursing home now and others here shower once a week, so you will have to adapt to the way we do it here” uses internally references to context and category. The argument “it’s normal for any person to have a daily shower so that should apply to me” is an externally oriented reference to category.

Figure 1. An equal rights framework for persons in need of support and care

Type of references	Internally oriented – care and impairment	Externally oriented – society in general
Context-centered	The contexts of care or impairment	Other contexts invoked as comparison

Category-centered	Other care users or categories relating to care or impairment	Other categories invoked as comparison
Personhood-centered	The unique person in relation to care or impairment	Other aspects of the unique person invoked as comparison

Leaning heavily on external references, disability policies have focused on the right of persons with impairments to education, work, independent living and a normal family life similar to that of “others” in society (Nirje, 1992).

In eldercare, however, external categories are used to less extent. There is a strong tendency to define normality and justice in relation to comparisons between residents and to explain limitations as caused by the aging body rather than the organization of support (Jönson & Harnett, 2016). Some externally oriented references to context-category have been successfully used to improve the rights of residents in Swedish nursing homes, for instance the shift to a social model where residents are formally regarded as tenants (category) in apartments (context) rather than patients in wards. Still, thought models and comparisons used to argue for social rights are drastically different between disability policies and eldercare policies, making it relevant to use a “disability lens” to investigate how a normal life is constructed in nursing home care.

In this study, the Equal Rights Framework is used to investigate the tension between internally and externally oriented references to *personhood* in discussions on what kind of life a nursing home should enable its residents to live. In the framework, a focus on a person’s current habits and wishes at the care facility– which may be different from before –

constitute *internally oriented references to personhood*. Interviewees sometimes described this in terms of who a person “had become since moving into the nursing home”. This reasoning is drastically different from aims to maintain a person’s previously established interests and habits, which represent *externally oriented references to personhood*. Inevitably, personhood within the care facility is affected by the context of care, but to what extent this is natural and good may be disputed.

Analytical procedure

Interviewees were asked to elaborate on two main questions: What is the meaning of individualization/personalization in the nursing home? What does it mean to live a normal life in a nursing home?

Both authors read the transcribed interviews and the analytical framework was used to identify relevant themes according to the process of *directed content analysis* (Hsieh & Shannon, 2005). During the analysis we posed questions to the data derived from the interpretive framework: “What aspects in residents’ lives are presented as important to achieve biographical continuity?”, “What references are used in claims about the need to maintain habits and interests?” and “What conditions are regarded as relevant to justify the infringement of biographical continuity?” During a second stage, the first author coded data selectively, based on the themes identified. Codes were continuously discussed and redefined during the second phase. The first coding revealed that interviewees tended to position their statements on biographical continuity as ways of defending personhood under threat or attack. Following this finding, our discussion will devote particular attention to the

way interviewees invoked different rhetorical contexts when arguing for standpoints on the topic of maintaining habits and interests (cf. Billig, 1996; Ibarra & Kitsuse, 1993).

Results

All interviewees embraced the official aim that nursing home care should be *personalized* and that everyday life should be adapted to individual needs and preferences. The question of what to define as *normal* posed a challenge, in particular in interviews with residents, and some argued that it was not possible to live a normal life in the nursing home. Biographical continuity was primarily mentioned by managers, staff and relatives, whereas residents mostly spoke from their own present position and emphasized their care needs and their expressions of will. Managers, staff and relatives spoke about residents in general and included people with dementia or other types of cognitive impairments in their reasoning.

Aims to achieve biographical continuity were expressed through talking about maintenance of residents' habits and interests. The analysis revealed that biographical continuity was framed in two very different ways: either through comparisons to residents' previous lives *outside* the context of care, or through comparisons to residents' lives *in relation to the present context of care and impairment*. These ways of contextualizing biography will be referred to as "external life referencing" and "internal care referencing".

A typical example of external life referencing was to point to an older person's *previous* habits, such as going on daily walks, and claim that the person should be able to continue with this when staying at the facility. This external referencing was usually also described as ways of providing personalized care. A typical example of internal care referencing was to

point to an older person's *current care needs and frailty* and argue that adjustment to the person "here and now" was the way of providing personalized care. In contexts where internal care referencing was invoked, actions to maintain residents' previous habits could be accused of representing a static view of residents and an inability to admit that people change.

External life referencing: They should be able to live like before

During interviews, biographical references to life outside the nursing home were frequently used to define personal needs. External life referencing was used to challenge traditional ideas where residents should adjust to institutional routines. In this way, external references served as a counter-rhetoric (Ibarra & Kitsuse, 1993) through which interviewees provided information about residents' "real" selves, which could be anything from food preferences to hobbies, personality or clothes. Information about the past was frequently used to back up claims about biographical continuity, for instance when relatives David and Cecilia talked about how the staff should be better at investigating who the resident really is. Cecilia specified the direction of this investigation:

And who are they? Who are they? I mean, that doesn't come from nowhere. When they come here they have lived a life, a long life, before. I think that might be of some interest to know. What have they done and what are their interests and how can that be dealt with? I think that is the ideal.

David remembered that when his mother moved into the facility, the staff did some sort of mapping of her interests for an action plan, but this had not been followed up or taken seriously. Both interviewees provided examples of activities that could be based on their mothers' established interests, skills and personalities, but "They don't do any of that," concluded Cecilia bitterly.

A more optimistic view of the maintenance of residents' interests and habits was expressed by managers and staff, who often structured their reasoning on a *rhetoric of similarity*. The rhetoric of similarity was based on an idea that people should have equal rights to maintain certain habits and interests, even if they live in a care facility. Within this rhetoric, interviewees used claims about entitlement and presented motives and solutions for care arrangements based on similarities between residents now and before.

Statements based on the rhetoric of similarity typically involved descriptions of a resident and his or her unique habits or interests: "We have a woman..." This was followed by an account on how the staff had acted to satisfy these particular needs and finished with an evaluation of how these actions had aligned with the identity or improved the resident's quality of life. Entitlement to special arrangements, based on perceived similarity between before and now, were central components in this rhetoric. In one group interview, a staff member described a man who had always gone for daily walks, but due to the risk of falls, some of the staff members had insisted on walking behind him when he went out. According to the staff, the man found this shadowing disturbing and he stopped going out as the situation no longer resembled his established walking habit. A decision was made to accept the risk the man exposed himself to and he was provided with an electronic key card that allowed him to enter and exit the building according to his wishes. When the staff talked about this situation, they emphasized that the man's right to maintain his walking habits was more important than avoidance of falls. Without the external life referencing as grounds for this claim, the staff might have insisted on escorting the man for safety reasons.

A prominent feature was that staff members described residents' habits as odd, hazardous or morally dubious, but still as something that they strived to maintain. Below is an example

of how external life referencing is used when a staff member described the importance of maintaining a care user's odd clothing habits:

We have a woman from the countryside. Always lived in a bohemian way. Always lived for her pets. She wears her old knitted jumpers that she has had for 20 or 25 years. We can find that very abnormal, I mean, it is not normal to walk around in clothes with holes in them. And she is a bit of a lone wolf and doesn't like to join in with activities. But that is who she is! (Jenny, nursing assistant)

By categorizing the woman's habits as "abnormal", Jenny formulated the case to be about showing particular sensitivity to the established identity of the resident. Through these kinds of claims, staff members emphasized efforts to personalize care, by presenting how they not only enabled residents to maintain ordinary habits, but also enabled them to maintain habits that were strange or hazardous.

When interviewees were asked to elaborate on how to define individualized care, a common type of statement referred to the critical situation when a person moved into the nursing home. Showing awareness of risks that care users were treated as a group, managers and staff argued that when a person was admitted to nursing home care, the facility should adapt to the individual and not the other way around. This position was clarified in statements based on negations of what residents should *not* have to do, for instance *not* having to change morning routines:

Just because I have to move into a nursing home I should not have to change my morning routines and get up earlier just because I have moved here. If I want to sleep late I can do so. (Nancy, Manager)

Another manager, Marianne, developed a similar claim into a description that emphasized the similarity between the nursing home and the regular apartment:

Interviewer: I wonder what you think about what individualized care means when a person lives in a nursing home?

Marianne: For me, when you move to a nursing home you just move to a new apartment. I will just change my place of living. I should be able to do the things I have done before, if I want, can to and have

the energy. It is only me as an individual who should decide if I should keep on playing canasta and bridge and watching hockey games or the local football team or whatever it may be. I am the one in charge of my decisions and the staff should only be a helping hand so I can do what I want to do. One should be able to continue with the life one has lived before, that is how I look at it. (Marianne, Manager)

In her statement, Marianne introduced an *external life referencing* where the goal of the nursing home is to mimic life in ordinary housing. This comparison was strengthened by mentioning activities that the nursing home should enable a new resident to maintain. The description of the nursing home as a “place of living” served as a contextualization cue, where nursing homes are places where people live ordinary lives, as opposed to places where people receive care. The nursing home was described as a place where people can “do the things they have done before” and even attend ice hockey and football games.

Research on the aesthetics of nursing homes has shown that managers and staff members who embrace the idea that a nursing home should be “homelike”, tend to define this characteristic in opposition to “institution like”, as a set of binary oppositions: Cozy vs sterile, natural vs artificial, self-determination, freedom of choice and integrity vs authority and discipline (Lundgren, 2000). A similar rhetoric was present in our interviews, and was developed in stories of a previous historical situation where interests and habits would not have been acknowledged. Through their statements, staff and managers presented a counter image, according to which nursing homes are no longer institutions and a culture change has been profound. Part of this image was also staff members who did not impose their own preferences onto residents, such as this comment about clothing:

If you want to wear two jumpers, you wear two jumpers. We will not take one off. We would have done that in the past. Then we would have taken a jumper off and talked to her (--). But, if I do that, I do more harm than good and attend to myself rather than the individual. (Linda, nursing assistant)

Linda's statement illustrates staff members' use of negations in talk about maintaining biographical continuity. Staff will *not* force residents to go to bed at a certain time and they will *not* take an extra jumper off. These kinds of statements must be understood in terms of the opinion they are opposing (Billig, 1996), i.e. as situated in a context when residents had to adjust to certain rules and routines. But even though Linda claimed that residents are allowed to wear two jumpers, she did not claim that *any* kind of habits should be maintained. Rather, her statement represented a culture change and contrast to the culture of the past. In this sense, statements about enabling residents to maintain certain habits, such as how to dress and when to sleep, carried a symbolic meaning: Nursing homes are *not* total institutions and residents are *not* patients who have to adjust to institutional order.

Our suggestion is that the frequent reference to the intolerant past may provide an understanding of the description of manager Marianne in the previous quote: When moving into a nursing home "you just move to a new apartment" and you should be able to "keep on playing canasta and bridge and watching hockey games". This description could be seen as extreme and peculiar based on the fact that, for most people, a move to a nursing home constitutes a dramatic shift in living conditions that does not equal moving to just any apartment. But if the statement is understood in terms of the context it is opposing, comparisons to apartments and talk about hockey games primarily serve to establish the nursing home as something other than a total institution.

Internal care referencing: They become different

In her description of what residents should be able to continue to do when moving into a nursing home, manager Marianne inserted an important reservation: If you “can, want to and have the energy”. When elaborating on the issue of normality, she commented on expectations that the baby-boomer generation would demand activities of a different kind than care users of the present, but concluded that this would probably not be the case:

[--] because when we move in here we will not have the energy to go on golf tours and spa tours or experience things or so on when we are 80, 85, 90, because that's about the age that you are when moving into a nursing home today.

Marianne's claim above is based on internal care referencing, according to which people's age and frailty make it impossible to maintain their previous interests and habits. This kind of internal reference to frailty was frequently added as reservations to the aim of biographical continuity. It was suggested that illness, age and frailty make residents incomparable to their previous selves and since they were no longer the same as they used to be, it was presented as logical to not make efforts to maintain their previous lifestyles. Notably, some staff members and managers commented on the increasingly raised threshold for entering a care facility: “You know in nursing homes nowadays they are so ill, compared to how it used to be... in my opinion... they are very ill when entering here.”

Descriptions of how residents changed concerned personality, taste for food and habits, and the causes of these changes, were described as dementia, impairments, medications or the process of aging. During a group interview, a staff member, Steven, referred to such aspects as “limitations” to take into account and argued that “You can't just equate things, and no matter how much you want to be able to do what you did at home when you come here... there are other obstacles... because they are much worse now.” These kinds of statements

were part of a rhetoric on change, according to which residents had changed so much from their previous selves that it was logical to disrupt, rather than maintain, previous lifestyle and habits.

Arguments based on a rhetoric on change focused on residents' frailty and illustrate the weakness in personhood centered comparisons for establishing social rights and rights to normal living conditions for older people. Our analysis shows that age tends to be portrayed as a natural explanation for illness and impairments and as something that makes older people incomparable to who they once were. The rhetoric on change illustrates inherent weaknesses in using aims about biographical continuity. By looking at disability policies and their aims of living like "others", it is evident that "me/us versus them" comparisons are more robust and less likely to be challenged by claims that a person is getting older and weaker than before. To regard illness and impairments as being caused by aging has also been shown to be crucial in the reasoning of older persons themselves (Levin & Levin, 1980; Coupland & Coupland, 1993; Bodily, 1994). In our data comparisons to others, for instance other citizens or other pensioners, were not the main way of defining normality. Instead, biographical comparisons in terms of "now versus then" were common, but emphasized difference, which was particularly prominent when the residents described how age and frailty made them incomparable to their previous selves. This is illustrated by an extract from an interview with two residents called Betty and Denise:

Interviewer: But if you were to compare with something, to say what is normal when living in a nursing home, what would you compare with then?

Betty: No, with what you manage.

Interviewer: What you manage?

Betty: It's not like before, when you lived at home and could walk.

Interviewer: No.

Betty: Now you sit, you almost don't get out or do anything.

Interviewer: You sit and almost don't get out.

Denise: No, no, so it's quite boring I think.

Betty: Since you end up in this wheelchair.

Interviewer: No

Betty: So there is not much you can do, there is really not.

Denise: But it's the disease that causes... that you can't live a normal life.

When elaborating on the issue of normality, Denise continued to argue that "It's the disease that prohibits you from living a normal life... it's your own body that limits you, different things that you can't manage, and then you must try to manage and accept that." Through this kind of internal care referencing, residents portrayed themselves and their bodies as fundamentally different from before. Instead of talking about what kind of support they would need to maintain habits and interests from their previous lives, residents frequently invoked references to the internal care context and described their frail bodies as logical causes of disruptions of biographical continuity. Disease, impairments, medications and the process of aging were described as the reason for not being able to live a normal life and for not being able to uphold established interests and habits. Acceptance was thus important, but not only in relation to bodily changes but also to a situation that was perceived as boring and socially poor. This way of lowering expectations has previously been commented by Kane and Kane (2005:52) as "a propensity to accept less, and hence to demand less" among older persons with impairments. In contrast to younger persons, older persons with impairments "seem to view decline as an inevitable consequence of aging that must be borne with equanimity" according to Kane and Kane (2005:52). The use of internal references provides an explanation for this phenomenon.

The social meaning of the rhetoric on change was about opposing a static view of older people. Hence, arguments about *not* maintaining residents' habits were also arguments about acknowledging change and decline. Managers and staff members stressed that the action plan that was written when a resident entered a facility had to be adjusted in order to

follow how the individual changed. They also described these kinds of adjustments as frequently resulting in disagreements with relatives who had a more static view of residents. Staff members' and managers' statements included descriptions of how residents changed through the progression of illness and aging. These descriptions were the foundation for a rhetoric on *denial of change*, invoked when talking about relatives' inability to accept that residents changed and declined whilst living at the facility. This rhetoric was built upon internally oriented references to residents' personhood, i.e. to who they had become since moving into the nursing home. As noted previously, interviewees tended to mention a combination of differences relating to illness, aging and medication:

Relatives may say that he or she [the resident] likes that food, but the food does not taste the same as before, as a result of the process of aging. Those who are not as ill as those with dementia, they take morphine and are in pain and so on. That affects... They can't live like before, they are more tired, the food does not taste like before. (Patty, nursing assistant)

When referring to unrealistic expectations among relatives, managers and staff members used comments like "They [relatives] look further back to compare how it was before" and "You can't take what they did ten or 20 years ago [as a reference for normality]" or "Things that applied four years ago [have changed] – some live here for a long time".

The argument that relatives deny change are well-known and could be seen as a matter of regarding identity as a process that changes depending on time and circumstances rather than a static object that should be maintained and reproduced (Wellin & Jaffe, 2004). From the perspective of relatives, changes of established habits among nursing home residents are sometimes regarded as institutional molding, and if they are perceived to be in conflict with the identity of the resident they may even be labelled as nursing home abuse (Harnett & Jönson, 2010). In this article, we would like to draw attention to the way that attempts among relatives to invoke biographical continuity may encounter an established rhetoric on

the denial of change. Our point is not to argue that the position of managers and staff is wrong, but to show the weakness of external references to personhood. The person in residential care is in many cases not perceived to be the same as before, and there are rhetorical tools available for countering claims about the need to uphold established interests and habits.

Discussion

In international comparison, Swedish nursing home care is considered to be of a high standard, and accordingly ambitions for care were high at the facilities we studied. The findings revealed a strong consensus among interviewees on the importance of making care and everyday life in the nursing home personalized and based on “needs” and “preferences”. In line with this aim, external life referencing emphasized the importance of biographical continuity and the maintenance of residents’ established interests and habits. This referencing was developed in opposition to the idea that residents should adapt to the nursing home as a total institution. Although not specifically mentioned, central aspects of the person centered care paradigm (Kitwood, 1997; McCormack & McCance, 2006) were well integrated in care, as it was described.

Striving for biographical continuity based on references to “external life” was questioned by references to residents’ “internal care needs”. Claims based on internal care referencing emphasized change and were developed in opposition to a static view of residents’ personhood. Brought together, these two positions reflect the complex and ambiguous nature of nursing home care. Even though the two positions justified completely different care arrangements, both *external life referencing* and *internal care referencing* appeared as ways of personalizing care and protecting the personhood from different forms of unwanted

influences. In the framework, this rhetorical battle for personalization could be illustrated in the form of an L, where the vertical arrow upwards (marked A) represents claims that proposed changes of personhood reflect institutional molding and the horizontal arrow (marked B) represents claims that proposed continuity of the personhood represents a static view and the denial (among relatives) of change. Comparisons that referred to other contexts and categorizations were mentioned, for instance in comments that residents move to “apartments”, but seemed to be placed outside the central tension that the debate on personhood established.

Figure 2.

Type of reference	Internally oriented – care and impairment	Externally oriented – society in general
Context-centered	The contexts of care or impairment	Other contexts invoked as comparison
Category-centered	Other care users or categories relating to care or impairment	Other categories invoked as comparison
Personhood-centered	The unique person in relation to care or impairment	Other aspects of the unique person invoked as comparison

Our suggestion is that a stronger focus on references to categories and contexts outside care and impairment could balance the present tension and act to improve the everyday life of nursing home residents. Such references could invoke categories like other *citizens*, other

pensioners, other women/men, other couples, other persons of the same religion, other vegetarians, etcetera. A mission for researchers, policy-makers, social movements and those directly involved in eldercare is to identify relevant references that could complement the biographical approach and become an integrated part of personalization.

It could be argued that the type of dismissal of biographical continuity that was present in our interviews mirrored the simple fact that residents became increasingly frail during their stay at the nursing home. This would however draw attention away from the ways in which the system of care enables or disables residents. Within disability studies, researchers have argued that a dominant “medical model” has constructed disability as intrinsic to the body of the individual, thus diverting attention from the barriers that society sets up for persons with different functional capacities (Brisenden, 1986). An alternative social model that has been developed by activists and researchers stresses the role of society as disabling or enabling (Oliver, 1996).

In relation to our study, the use of a disability lens reveals that an equivalent to the medical model was used to explain why it was not possible to maintain certain activities. Age and the process of aging were used as justifications for biographical irrelevance, and disease and impairment were regarded as *causes* of not being able to live a normal life. Bytheway (1995) has argued that the existence of obvious age differences between people makes ageism the most difficult form of discrimination to detect and combat. A similar argument can be pursued in relation to the *aging process* and the passing of time. While references to age, frailty and changes in personality and preferences reflect attempts to acknowledge the realities of growing old, they may also act as *techniques of neutralization* (Sykes & Matza, 1957) in relation to biographical goals, and as justifications of ageism (Levin & Levin, 1980).

People who acquire impairments during the period of old age, as it is socially defined, are perceived to “age into” impairments and support needs. It appears logical to compare the present situation of being impaired or ill with a previous situation of being non-impaired, and to conclude that the passing of time reflects the process of normal or pathological aging. In Figure 2, this reflects the idea that arrow B points towards a past that is no longer relevant. The presence of age as a natural explanation for illness and impairment is manifested in “me now versus me then” comparisons that prohibit the use of “me versus them” comparisons (or “us versus them” when articulated by a social movement) of the type that has been prominent in disability policies. As has been shown in this article, claims for biographical continuity and other forms of personhood-centered references may in fact divert attention from the way society enables or disables older persons in need of support to live like *others*.

Using a disability lens – some conclusions

Swedish eldercare stands out as one of the best in the world in terms of resources, levels of staffing and quality of care (OECD, 2013), and given the personalized approach that was evident in our study one might argue that there is little room for improvement. What needs to be noted is that research on persons who age *with* support in form of personal assistance (a support form that is mainly used by younger persons and not possible to receive if help needs appear after the age of 65) reveal opportunities to live a type of life that is beyond the horizon of imagination within nursing home care (Hellström & Taghizadeh Larsson, in press). What traditional person-centered care approaches have in common is a focus on the present context of care as the relevant setting for comparisons. In Kitwood’s research (1997), “personhood” is viewed as a product of a caregiving relationship, not as a yardstick for

enabling people to live the same kind of life as before. Even though there are certain overlaps between the notions of personhood and citizenship, there are also important differences, for instance that citizenship focus on social rights and participation in society (Twine, 1994). Also approaches such as relationship centered care, use the present care situation as outset for comparisons by focusing on the sense of belonging and security *within the context of care* (Nolan et al. 2004). The use of a disability lens sheds light on fundamental differences in disability and eldercare research, policies and practices. In eldercare research personal identities and belongings are invoked for the purpose of improving feelings of wellbeing among individuals, not for establishing rights or for arguing that the entire system of care needs to be rearranged.

Research on living conditions for persons who have aged *with* impairments shows that *ability* is largely a matter of which supportive environments are provided by society. In a study on older persons aging with impairments, Taghizadeh Larsson (2013) describes a 65-year-old Swedish woman, Ann-Marie, diagnosed with MS in her 20s and unable to move her arms and legs. With support from personal assistants she was enabled to attend artistic activities (painting with her mouth), participate in gymnastics and travel to Denmark, Spain and Iceland. Despite severe impairments, Ann-Marie's living conditions of were dramatically different compared to those offered to people living in nursing homes, as was the horizon of expectations. While the nursing home residents interviewed in this study tended to demand and receive less with reference to their impairments, Hellström and Taghizadeh Larsson (in press) have shown that older persons with dementia who age at home *with* massive support from personal assistants may come much closer to living a normal life. Not until such

examples are brought in as comparisons is it possible to question the present organization of eldercare.

To conclude, this study shows that despite the fact that disease and impairments were the very reason for admission to nursing home care, the residents' frailty was seen as the main obstacle to maintaining previous habits and interests. What using a disability lens reveals is that this way of regarding impairment among older persons as natural limitations constitutes a form of ageism that is difficult to detect and combat. It is deeply rooted in our understanding of the aging process as the natural cause of differences between then and now.

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