

Ageing, dementia and the future – ambivalent futurework in rehabilitation-focused dementia care

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Abstract

Due to its goal-orientation, rehabilitation may be considered a future-oriented practice. As rehabilitation is increasingly recognized as contributing to dementia care it is important to explore how rehabilitation corresponds with the future orientation of older people with dementia.

The aim of this study was to explore the futurework of home-dwelling people with mild to moderate dementia in the context of rehabilitation-focused municipal dementia care, that is, their thinking and practices regarding their future and how these correspond with institutionalized practices.

The study was conducted as a case-study inspired by the methodology of Institutional Ethnography (IE). The study setting was two Danish municipalities sampled as a paradigmatic case. Eight older people living with early-stage dementia (mean age: 78 years, age range: 65–91) were strategically sampled and each interviewed recurrently within a period of six through 15 months. In total, 29 interviews were completed. An abductive analysis was subsequently conducted based on these interviews.

Findings included three dimensions of futurework: Extending the present state into the near future; avoiding being confronted with an anticipated future; and adjusting to decline and preparing for

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future losses. Based on these findings, a notion of ‘ambivalent futurework’ is suggested. The futurework of older people did not always correspond with the institutional arrangements in a rehabilitation-focused dementia care. Findings show that the institutional arrangements in dementia care may support as well as challenge the futurework of the participants. Paying attention to the ambivalences of older people living with dementia and recognizing the ambivalent futurework may be essential in rehabilitation-focused dementia care.

Keywords

rehabilitation, future, institutional ethnography, dementia, future outlook

Background

According to the World Health Organization, more than 30 million people across the world live with a dementia condition, and in the light of globally improved life expectancy this number is expected to increase further (WHO, 2017). An individual may now live for more than 20 years following a dementia diagnosis, though the average life expectancy is estimated to be between 7 and 10 years (Brodaty et al., 2012).

Dementia is a clinical syndrome characterized by a progressive cognitive decline that interferes with the ability to perform daily activities (Buss et al., 2012). Impairments appear from the early stages and cause restrictions in everyday functioning and social life (Buss et al., 2012). More recently, dementia has been considered a disability (Gove et al., 2017) and within the last two decades a rehabilitative approach to dementia care has been increasingly acknowledged (Clare, 2008, 2017; Downs et al., 2008; Downs et al., 2006).

Rehabilitation constitutes a core recommendation in the recent World Health Organization Global Action Plan for the Public Health Response to Dementia (WHO, 2017). In the field of dementia, as well as in general, rehabilitation is proposed in order to sustain the right of people with a disability to attain and maintain maximum independence, and to maintain or enhance their functioning, social engagement, and social participation (Bryden, 2002; Clare, 2017). In Denmark, rehabilitation is recommended in national clinical guidelines (Sundhedsstyrelsen, 2013). According to a national survey, 83% of Danish municipalities have included rehabilitation in dementia policy documents (Thuesen et al., 2018). Yet, both internationally and in Denmark, the principles and practices of rehabilitation in connection with dementia are still very heterogeneous (Cations et al., 2017; Kroll & Naue, 2011; Ravn et al., 2019). Likewise, studies report substantial confusion among health professionals regarding what the concept of rehabilitation entails, and how to implement rehabilitation in dementia care in a meaningful way (Cations et al., 2020; Thuesen et al., 2018).

Rehabilitation in connection with dementia has been defined as a genuinely person-centred approach (Clare, 2017; Thuesen et al., 2020). This includes an individualized, goal-oriented approach that entails working with people to achieve the goals that are important to them (Clare et al., 2010; Thivierge et al., 2014; Thuesen et al., 2020), and collaboratively developing positive prospects, goals and plans for the future (Brueggen et al., 2017; Thuesen et al., 2020). Rehabilitation goals have been defined as “a future state that is desired and/or expected” (Levack et al., 2015, p. 9) and rehabilitation may thus be considered a future-oriented practice. Rehabilitation literature has addressed temporality as an issue in rehabilitation, connecting the past and present of the patient with a possible future state (Mattingly, 1998; Papadimitriou & Stone, 2011) and revealing a plurality of possible futures (Mattingly, 1998). According to Pikkarainen et al. (2015), who are working in the field of gerontological rehabilitation, a future orientation per se is defining for most rehabilitation

practice: rehabilitation being about moving from the present into the future, towards concrete rehabilitation goals. Other recent research on rehabilitation older age supports the idea of rehabilitation as a future-oriented practice. Rehabilitation in older age has been associated with continuity (Thuesen et al., 2021), life-long development (Bødker, 2019), maintaining independence and self-reliance in daily living (Legg et al., 2016) and potentiality, which refers to expressing that which does not currently exist, but may come into being in the future (Bødker, 2019; Papadimitriou & Stone, 2011). The future orientation of rehabilitation practice highlights the need to explore how rehabilitation corresponds with the future orientation of people taking part in rehabilitation. Finding different temporal orientations in a sample of older rehabilitants, Pikkarainen et al. (2015) state that in terms of ageing, person-centred rehabilitation should take into consideration the temporal orientation of older adults. And yet, aspects of future orientation have not been explored and discussed within rehabilitation research in the field of dementia.

There is an increasing body of knowledge concerning the future outlook of people living with dementia. In anthropological research, Gjødsbøl and Svendsen (2019) suggest that being diagnosed with dementia constitutes a prophecy of the inevitable future discontinuity of personhood and life. Likewise, neuropsychological research has dealt with impairments in imagination and future thinking in dementia (Schacter et al., 2017; Strikwerda-Brown et al., 2019). One hypothesis in neurobiological literature suggests that people living with dementia are not able to imagine their future circumstances (Ashworth, 2020) due to anosognosia (unawareness of a disease or deficit, rooted in cerebral physiology) or (early) impaired executive function (de Boer et al., 2012). Research on the future outlook of people living with dementia suggests other explanations. Recently, future outlook, as well as strategies for managing a changing future with dementia, have been explored in several studies. Some research is motivated by a clinical and political demand for future planning in dementia (advance care planning and decision-making), which makes thinking of the future imperative when living with dementia (Bijlsma, 2017; De Boer et al., 2012; Roenhorst, 2016). Other research is motivated by an ambition to understand the experience and coping strategies of people with dementia and their relatives in managing an uncertain future with dementia (Ashworth, 2020; Heaton et al., 2020; Hellström & Torres, 2016). Overall, these studies reveal different future outlooks and strategies. The study by De Boer et al (2012) shows an overall tendency within the group to live on a day-to-day basis and avoid worrying about the future. Moreover, they find that people with dementia might express the hope that things might remain the way they are, or for their memory problems to improve (spontaneously or by medication) (De Boer et al., 2012). These findings agree with those published by Hellström and Torres (2016) - in terms of sustaining hope and taking each day as it comes. Although not representing the majority of the study group, some participants in Hellström and Torres' study (2016) regarded the future positively. However, participants also described the 'here and now' in ways that involve the gloomy future they dread as a reference point. They operated with a 'not yet' horizon; however, the 'not yet' parameters seemed to shift with the progression of the disease. The idea of people with dementia having a future outlook of limited duration and involving an endpoint is also proposed by De Witt et al. (2010). Ashworth (2020) found that participants managed their changing futures by focusing on positive information and taking '1 day at a time'. They avoided contemplating things too far ahead in time as a way of managing their uncertain future. Heaton et al. (2020) found that the temporal orientation of people with dementia living alone was primarily characterized by two distinct coping strategies. One strategy involved holding on to the present and seemingly stretching it into the future, while the other strategy was of a more anticipatory nature, such as actively stopping a future threat from emerging and responding to possible future transformative events (Heaton et al., 2020). However, the majority of the studies about future outlook pointed out that most people with dementia paid little attention to

future planning and were not inclined to look too far ahead (Ashworth, 2020; De Boer et al., 2012; Heaton et al., 2020; Hellström & Torres, 2016). These observations may challenge current policy and practice: several studies stressed the need to reconsider future planning policies such as advance care planning and the role of advance directives in the early stages of dementia (Ashworth, 2020; De Boer et al., 2012; Heaton et al., 2020). Ashworth (2020) conclude that “policy which encourages future planning should consider its utility and explore ways of helping people to plan, whilst focusing on daily living” (Ashworth, 2020, p. 1647).

Future outlook in terms of future time perspectives has also been explored in humanistic and sociological gerontological research, i.e. in studies of ageing and time in older people without dementia (Baars & Visser, 2007; Carstensen, 2009; Dittmann-Kohli, 2007). Dittmann-Kohli (2007) has explored the temporal references in the construction of self-identity and their gradual change throughout a life span. The author focuses in particular on an existential time perspective and finds that time awareness grows with chronological age. According to Dittmann-Kohli (2007), the study of subjective time experience must encompass the social representations and cultural models adopted by individuals as a cognitive framework for experience. Future time perspectives have also been explored by Shifflett (1987), who found that age was negatively correlated with understandings of the future as open, and positively associated with the future as limited. Young adults exhibited significantly greater ambiguity towards the future than older adults.

Inspired by Institutional Ethnography (IE), the present study will focus on the future orientation of older people with dementia in terms futurework. Institutional Ethnography was developed by the Canadian sociologist Dorothy Smith in the 1980's as an approach to investigating the institutional framing of ordinary people's everyday lives (Smith, 2005). 'Work' is a key concept in IE, expanding the ordinary usage of the term. According to IE, the everyday life perspective should be approached by focusing on 'work' as the doings of people in their everyday life. How people reorganize their everyday lives under conditions of dementia can consequently be perceived as work. Exploring work entails approaching everyday experience as located and embodied, and furthermore how work is organized by legislation, administrative regulations and practices, professional philosophies, etc. (Smith, 1987). In IE, the concept of 'work' includes anything or everything people do that is intended, involves time and effort, and is done in a particular time and place under definite local conditions (Campbell et al., 2006). Institutional Ethnography draws on people's experiential – and diverging – knowledge of their work. According to Dorothy Smith, “the concept of work represents the participants as active and, from this point of view, we can begin to see them as encountering and working with and within health care institutions that are implicit in their accounts.” (Campbell et al., 2006, p. 7).

George W. Smith has further developed IE's concept of work by introducing the term 'lifework' in a study involving people living with AIDS (G. W. Smith et al., 2006). With inspiration from the work of both Dorothy and George Smith we introduce the term 'futurework' as an analytical tool to access the future perspectives of people living with dementia. People who are diagnosed with dementia may have to revise their lives and expectations and reconsider what the future holds, and rehabilitation-focused developments in dementia care provide a new institutional framing of the everyday lives and temporal orientations of people with dementia.

To our knowledge the futurework, or future orientation, of people living with dementia in relation to rehabilitation services has not previously been explored. The concept of futurework did not guide the study from the start but came up in a preliminary analysis, as elaborated on in the methods section.

This study aims to explore the futurework of home-dwelling older people with mild to moderate dementia in the context of a rehabilitation-focused municipal dementia care; that is, exploring their

thinking and practices regarding their future and how this corresponds with institutionalized practices.

Methods

The study was conducted as a case study inspired by the methodology of IE. The empirical end analytical focus in IE is the relation between institution and everyday life. Institutional Ethnography has been used in previous studies in the field of dementia (Høgsbro & Burholt, 2015; Øydgard, 2018) in studies of professional practice and experiences of relatives to people living with dementia, respectively. To our knowledge, this is the first time IE has been used in studies focusing on the work of people with dementia.

This study is part of an IE that includes interviews with old people with dementia and with professional workers, the observation of rehabilitative activities, and document analysis. In this paper, only data from interviews with old people are included. Findings from the remaining part of the IE are reported in another paper. While this paper addresses the everyday work of people living with dementia and how it relates to rehabilitation-focused dementia care, the other paper focuses more broadly on the organizational narratives in this dementia care (Graff et al., forthcoming).

Study setting

The study setting consisted of two Danish municipalities sampled as paradigmatic cases, meaning cases of metaphorical and prototypical value (Flyvbjerg, 2006). A paradigmatic case promotes validity and generalizability by the strategic selection of cases and transparent descriptions, so that readers may recognize and identify with the case (Flyvbjerg, 2010). The cases (two municipalities) were selected because in terms of political and practical priorities they represented a setting with a particular focus on rehabilitation, according to a national survey on rehabilitation services in Danish municipalities (Thuesen et al., 2018). After conducting focus group interviews with professional workers engaged in dementia care and rehabilitation, and local members of the Alzheimer's Society (NGO-representatives), two municipalities were included. They represent a large and a medium-sized municipality in the Danish context. In this case, rehabilitation may be implemented in the form of specific services, such as group-based exercise or reablement, assistive devices, and other activities guided by a rehabilitative philosophy. The institutional setting is described by Graff et al., (forthcoming).

Participants

Eight older people (mean age: 78 years, age range: 65–91 years) were strategically sampled to include information-rich cases (Green & Thorogood, 2018). Participants were identified by health care professionals from the two municipalities. To be included in the study, participants had to be ≥ 65 years and newly diagnosed with either Alzheimer's Disease, vascular or mixed dementia. The stage of dementia had to be mild to moderate, as evaluated by the health care professionals. To obtain maximum variation (Green & Thorogood, 2018), the health care professionals were encouraged to look for participants who had either accepted or declined rehabilitative activities, participants who were either married or living alone, and participants either with experience or (due to declining faculties) no experience of different kinds of rehabilitative activities at home or at a centre facility.

The participants are presented in [table 1](#). Five women and three men were selected to participate in the study. Six of the participants were married. The elapsed time from diagnosis to the initiation of the study ranged from 0.5 to 2.5 years. Participants had experience of, or had been invited to participate in, rehabilitative activities including physical training, home-based reablement, information about living a life with dementia, and social activities. Following a broad concept of rehabilitation, ([Marshall, 2004](#)), activities were considered as ‘rehabilitative’ if they were focused on enabling people with dementia to participate in everyday life.

Generation of data

Eight older people were interviewed repeatedly within six to 15 months. A total of 29 15–45 min interviews were conducted with the study participants and their relatives. By distributing the interviews over time, we were able to explore the lived experience of dementia, corresponding to the varying manifestations of dementia over time. Moreover, we were able to observe a variety of different institutional responses.

The semi-structured interviews were guided by questions focusing on what participants do in their everyday lives and to what extent they take part in institutional arrangements. In line with [Dorothy Smith \(2002\)](#), interviews focused on the concrete activities of the participants’ everyday lives, asking what they did and what they thought about it. Participants were interviewed with reference to a standard day, with questions revolving around the work they did related to different stages throughout such a standard day. Moreover, they were interviewed about their experiences of taking part in, or being invited to take part in, rehabilitative activities. Inspired by [McCoy \(2008\)](#), we were alert to correspondences as well as disjunctures between their everyday work and institutional factors, expressed as critique or resistance to institutional responses, for example, regarding future planning and rehabilitative strategies. Spouses took part in most interviews, though we aimed to limit their active participation in the interviews to some extent, in order to prioritize the narratives of the people with dementia. To do this, we sought to conduct interviews with the participants alone. However, this was not always possible, and at some interviews other relatives besides the spouses were present. In one participant’s case, the interviews were so heavily dominated by the perspectives of the relatives that it was decided to conduct only three interview rounds, whereas in the other cases four to five interviews were completed.

Table 1. Participants.

Person no	Name (anonymized)	Age	Sex (M/F)	Marital status	Diagnosis (according to referring staff)	Time since diagnosis at first interview
1	John	82	M	Married	Alzheimer	1,5 years
2	Carol	65	F	Married	Alzheimer	2 years
3	Kitty	80	F	Married	Alzheimer	2,5 years
4	Kurt	91	M	Widowed and divorced	Vascular dementia	2 years
5	Jim	74	M	Married	Alzheimer	2 years
6	Inge	84	F	Married	Alzheimer	1 month
7	Helle	72	F	Widowed	Alzheimer	0,5 years
8	Ulrika	79	F	Married	Alzheimer	2 years

Both authors completed interviews. The first author (JTH) interviewed four people (John, Carol, Kitty, and Kurt) in municipality A and the second author (LG) interviewed four people (Jim, Inge, Helle, and Ulrika) in municipality B. The interviews were conducted according to recommendations for interviewing people with dementia (Cridland et al., 2016; Hellström et al., 2007), i.e., interviews were guided by a short interview guide and questions aimed to be clear and concrete (McKillop & Wilkinson, 2004). All interview sessions were tape-recorded and subsequently transcribed verbatim by a student assistant.

Ethical considerations

All participants gave their informed consent to participating in the study prior to participation. Participation was voluntary and anonymous. As informed consent is a delicate issue in interviewing people with dementia, consent was preceded by clear written and oral information, as recommended by Cubit (2010). As participants were interviewed repeatedly over a long period of time, formal (written) consent was confirmed after 1 year, as suggested by Ashworth (2020). Moreover, consent was verbally revisited in each interview.

The study complied with ethical principles for medical research as described in the Helsinki Declaration, and with the practices of the Danish National Committee on Health Research Ethics (National Videnskabetisk Komité, 2017). In Denmark, this kind of research does not require approval from an ethics committee; however, the study was approved by the Legal services at University of Southern Denmark (RIO) on behalf of the Danish Data Protection Agency (file number 2015-57-0008).

Analysis

The analysis was conducted based upon Timmerman and Tavory's guidance for abductive analysis. Abduction "refers to a creative inferential process aimed at producing new hypotheses and theories based on surprising research evidence" (Timmermans & Tavory, 2012: p. 167). An abductive analytical approach rests on the cultivation of surprising empirical findings against a background of multiple existing theories and through systematic methodological analysis (Timmermans & Tavory, 2012).

After the first round of interviews, we initially conducted an open coding guided by the concept of 'work'. Timmermans and Tavory (2012) suggest primary analyses as sites for fostering abductive reasoning as an integrated element in gathering data. In subsequent interviews, ideas were tested based on the preliminary analysis: the focus of participants on the 'here and now' situation, expectations about change over time (we noticed that participants were reflecting on their own dementia-related change or absence of change from one meeting to another), and a possible avoidance of thinking about the future. After all the interviews were completed, we conducted another open coding manually and tested different ways of structuring concepts and ideas. Abduction signifies a continuous process of conjecturing about the world that is shaped by the solutions a researcher has 'ready-to-hand' (Timmermans & Tavory, 2012: p. 172). Inspired by humanistic gerontology on time and future time perspectives (e.g., Baars & Visser, 2007; Dittmann-Kohli, 2007), the concept of 'futurework' evolved as a structuring dimension and motivated a search for literature on dementia and future outlook/future orientation. The final analysis was conducted in NVivo-software.

An abductive analysis is attentive to unexpected findings (Timmermans & Tavory, 2012). To facilitate de-familiarization we involved a user panel in the discussion of our ideas and findings. The

user panel included five people living with dementia (early stages) (described in [Thuesen, 2020](#)). To challenge our preconception about what a good life may be for people with dementia, we discussed with the user panel the ideas of human flourishing developed by [Nussbaum \(1992\)](#). This strengthened our focus on futurework. [Timmermans and Tavory \(2012\)](#) point out the importance of “deductively checking novel explanations with new data to test theoretical robustness” ([Timmermans & Tavory, 2012](#): p. 175). To test a preliminary idea about ambivalence inspired from cultural gerontology ([Baars, 2014](#)), we discussed contradictory findings with the user panel. This supported the idea of ambivalence, which will be introduced in the discussion.

Findings

The findings section includes three different aspects of futurework. They represent aspects of work in which rehabilitative practices correspond with the work done by the older people, and aspects of work in which they do not.

Extending the present state into the near future

Dementia affects the future outlook of people suffering from it. Participants took up these challenges differently, yet their work always implied some kind of effort to hold on to the present and stretch it into the future as described by [Heaton et al. \(2020\)](#). Active efforts to maintain living as usual were encountered throughout the data. One strategy encountered was to preserve the rhythms and routines of everyday life. The everyday lives of some participants were highly structured by routines determining who should carry out what activities, and when. Routines seemed to provide people with dementia with a feeling of continuity and helped them make the near future predictable. [Hellström and Torres \(2016\)](#) found that continuing former, or sometimes new, activities might be one way to create feelings of continuity in the earlier stages of the dementia disease.

Routines were supposed to be supported by compensatory services helping people with dementia to keep on performing their daily activities. Dementia counsellors advised families with dementia to apply to the municipality for cleaning help, so that more time could be spent doing other more pleasurable activities. Some participants embraced this suggestion, while others focused on maintaining their routines by continuing to perform these mundane daily activities. One woman was offered rehabilitative support at home, which included training in how to carry on being able to take the bus and how to keep on doing household work in collaboration with the care assistant. This support seemed to have a positive effect:

Helle: “I’m not walking around all depressed anymore”

Interviewer: “Is that how you felt in the beginning?”

Helle: “Yes I think so - Yes, a little rattled, I would say, but then it was nice that (an occupational therapist) came (...) She just taught me to use the bus and so on, to discover my options” (Helle, 1)

So, though routines could be supported by the municipal dementia care service, some participants might also experience such services, including the rehabilitative services, as disruptive. Some participants experienced taking part in training activities, for example, as time consuming, interrupting the natural rhythm of everyday life. One participant used this argument to decline the offer of time-limited professionally led training activities, preferring activities at a private fitness centre. He

recognized that the time-limited offer in itself might be the better option, but he did not want to give up his place in the more permanent fitness centre activity in exchange for a time-limited training activity. Another participant declined to take part in an institutionalized exercise programme and instead chose to take part in social exercise activities in the local community for as long as she could:

(talking about being physically active in local community activities): “I think it’s nice and I don’t want to do without it at all, as long as I can ride a bike. I hope I can keep on doing it for many years to come. The good thing is that I can attend everything else afterwards... I think it’s very necessary to keep alive those .. what’s it called now, what should I say (relationships?)... Those I know and those who know what it’s like for me.”(Carol, 3)

Terms like ‘as long as I can’ were often used by participants. As reported by [Hellström and Torres \(2016\)](#), such terms may indicate a feeling of continuity with an endpoint. A feeling of continuity was also pursued when participants took up new activities to restore functional capabilities. Participants talked about the importance of being active and taking part in physical, social and cognitive activities and exercise. One participant reported that after he had begun to participate in physical activity, he managed much better in his everyday activities. “It keeps it all straight” (*John, 3*). To some participants, doing exercise seemed more of a duty, predominantly performed for health purposes, echoing an emerging narrative of physical activity as healthy and preventing the development of dementia, as described in the literature ([Forbes et al., 2008](#)). Doing exercise was offered as a way of actively preserving a life situation in which continuity was challenged, so that in this way exercise might foster the hope of such preservation. Even so, the hope was fragile and statements about these aspects seemed rather ambiguous:

“She (the physiotherapist) felt (...) that it was a good idea that I sort of did some exercise training, because people believe that this might slow the development of dementia” (Helle, 1)

Participants found maintaining cognitive functioning to be a problem. When experiencing impaired cognitive function (e.g., impairments related to memory, concentration, language, problem solving) participants made use of restorative as well as compensatory measures. These measures were initiated by people themselves, or by relatives, or were sometimes suggested by the professionals. Most participants were aware of the existence of municipal showrooms and test rooms for assistive devices and technical equipment. Though none of them had experience of testing publicly provided devices, they still thought that it might be a potentially helpful measure in the future. In the majority of cases, most of them declined or postponed the use of publicly offered technical aids, and preferred sticking to old habits and routines – as long as they could. Doing crosswords, for example, was legitimated in terms of sticking to routines and in order to keep the brain active, in an effort to control and manage dementia symptoms. Using specially adapted smartphones was legitimated by a wish to maintain daily activities, to keep in touch and to structure daily activities. A few participants, like Jim, hoped to improve their cognitive functioning:

“This is probably more training, but then that’s the way it should be, there is training because it’s like a computer where you’ve taken ... the memory, you have thrown it away, and that’s how I feel, it’s gone what came out of there, and it won’t start working again. All I can do is try to see and take it up again and get it noted in here (in the brain), so you have a hope - it doesn’t come quick but it moves forward, and I think I can get something good out of it” (Jim, 3)

This quotation displays a variety of futurework in terms of preservation, representing the hope of preservation, using a restorative approach for maintenance and continuity. Still, it also illustrates the ambivalence which characterized all participants when talking about their hopes and possibilities in terms of improving or maintaining the current state – that is, extending the present state into the future by continuing daily routines, or by taking up new activities. As noted in several studies (De Witt et al., 2010; Heaton et al., 2020; Hellström & Torres, 2016), the present – the here and now – represents a limited duration with an endpoint. This aligns with the observations of Dittmann-Kohli (2007), who states that continuity in old age is a limited continuity, a certain duration that is expected to end within a limited horizon, referring to the presence of change within a certain period.

In summary, older people with dementia tend to extend the present state into the near future, actively striving for preservation and continuity within a limited space of time. Rehabilitation may support preservation and continuity, but institutional arrangements may also destabilize people by temporarily disturbing the routines of everyday life.

Avoiding being confronted with an anticipated future

The material exposed another aspect of futurework, namely actively keeping the anticipated future with dementia at a distance by avoiding people and places associated with dementia. This should not be interpreted as unawareness or non-acceptance of the dementia diagnosis. All participants in this study said that they were aware that they were suffering from a condition of a progressive nature involving increasingly severe cognitive decline until death – unless they died from something else. One participant (Kurt) stated that his type of dementia was the “slowly killing one”. Apprehensiveness about being confronted with dementia experiences may also be considered to be one aspect of actively avoiding thinking about the future, as described by Ashworth (2020), De Boer et al (2012) and Hellström and Torres (2016).

Several participants were either cautious about - or simply rejected - taking part in courses, self-help groups and other activities aimed at persons with dementia, as they did not want to be reminded of how their illness might develop. One woman explained why she withdrew from a course for people who were newly diagnosed with dementia. She was seated beside another woman with dementia and noticed how this woman when talking jumped back and forth and was incoherent in her train of thought. “I can do without it, because then I would be ashamed on behalf of my intelligence” (Inge, 4). One man, Kurt, was reflecting on whether he should continue to go to the day care centre, as the other participants there were more severely affected than him:

So they sit in there, half asleep and that... I say to myself: “Kurt, will you be like that? (...) It’s scary to me. Actually, I shouldn’t go in there. (...) Because I get to see all the worst problems.” (Kurt, 2)

Other participants alluded to information or activities in the local Alzheimer’s Society, which was usually suggested by the dementia counsellor. John avoids reading material from the Alzheimer’s Association:

Interviewer: “Such thoughts, would you rather keep them away?”

John: “I really think so. You have to admit it, true enough, but it’s not something to think too much about. Because I can’t do anything, it just comes on so gently. (...) Then you think about it (when others get bad). But you also have to be careful not to go nuts (...) We have to take life as it comes. It’s actually going quite well, I think.” (John, 2).

So, some participants tried to avoid meeting other people with dementia, though this strategy might conflict with institutionalized services and activities. Moreover, the strategy seemed to change over time. In the case of one man, who at first refused to take part in social activities for people with dementia, things changed as his dementia grew more severe and he ended up joining a day care centre where he became attached to some of the other members:

“It’s the way it is, it’s people who, like myself, are a little beside themselves sometimes, but I think it’s been fun for some of the time”. (Jim, 4)

Hellström and Torres (2016) note that the ways people with dementia refer to the ‘here and now’, and to the future, seem to be conditioned by where they are in terms of their illness. The above example may illustrate this notion: as his dementia got more severe, he was more likely to accept meeting people “like myself”, quoting De Boer et al. (2012): “*resigning himself to this future*”.

In summary, people with dementia may attempt to avoid being confronted with an anticipated future that involves being more severely affected by the disease. This reaction may conflict with collectively organized rehabilitative activities and activities, in which confrontation with other people with dementia is unavoidable.

Adjusting to decline and preparing for future losses

Being diagnosed with dementia may be a life-altering event, but not all participants experienced it that way. Participants reported difficulties with physical as well as cognitive functioning, including structuring their everyday activities. Quite often, the problems caused by dementia could not be separated from problems caused by other diseases or general age-related impairment and decline.

As previously described, some participants handled such challenges by extending the present state into the near future or by avoiding being confronted with an anticipated future state as a severely affected patient. However, findings also suggested that older people living with dementia positively adjust to decline and actively prepare for future losses.

Adjusting to decline may be motivated by distress, if people cannot carry out their preferred activities anymore. Several accounts supported this interpretation. Participants stopped using the computer; they stopped driving or taking the bus, as they were either not able to find their way, or were afraid that they could not complete normal tasks associated with taking the bus, such as paying. Others gave up on using mobile phones, as they felt embarrassed by making too many erroneous phone calls. Feeling a loss of control may be painful and shameful to people with dementia (Aldridge et al., 2019). Several participants stated that if you are not able to express yourself properly then you might as well say nothing (“then you should just shut up” (Carol, 3)). According to one participant, one may “feel like an idiot standing there and not being able to name a bird or something”. She refrained from meeting friends because she was afraid of acting or appearing stupid due to dementia (Inge, 4). Thus, some adjustments were negatively motivated. Other participants tried to express more positive qualities connected with adjusting to decline, while accounting for adjusting to decline as an active choice. Terms like ‘*I don’t bother*’, ‘*I don’t want to*’, ‘*I’m not interested anymore*’, or ‘*I’m getting tired of doing this and that*’ were widely encountered across interviews and may indicate disengagement as a choice. One participant stopped communicating in larger gatherings and said that she did not like talking that much anymore, but she experienced a lot of things by just listening (Carol, 1). Another woman said quite bluntly that when she was not able to drive anymore she just handed in her driver’s licence (Inge, 2).

While some examples of adjustment and disengagement (such as stopping driving) seemed to be socially acceptable, other examples seemed rather problematic. To reject exercise, assistive devices or social activities were not completely acceptable examples of adjustment in rehabilitative dementia care. Being active and taking part in institutionalized activities seemed to be regarded as the right behaviour by health professionals. This made it difficult for some participants to make choices of their own, if these choices did not correspond with the narrative of being active. It was suggested to one woman, Kitty, that she should attend a day care centre. At first, she refused, but the following excerpt indicates that she doubted whether she was allowed to decide for herself:

I was against it right at the beginning and I was angry ... I said you shouldn't suggest such a thing to me, I want to decide for myself. But then I went and thought, yes you might as well try just once and see if there's something in it. Then I said so I'd come... So I started going to (the day centre), as they said, it's no use sitting rooted at home and not coming out among people. So it was like - (my husband) and I - it was sort of thrust onto me as if by an invisible hand, I can't say what happened. But it's as if it was an invisible hand that pushed me..."(Kitty, 2)

After having been to the day care centre a few times, she actually liked it and she continued to go there. "So in the end I wanted to go there. And there were others who were just like me" (Kitty, 3). Yet, she kept on saying that 'they' (her husband, the staff) should not decide what she should do.

When accounting for withdrawing from specific activities, participants quite often spoke about it as if they had passed a developmental threshold: "*I am past it*"; "*It [is] just not for me anymore*"; "*Now was the time to quit (committee work)*". Such utterances seem to express that aspect of futurework as disengagement, as previously described; what [Dittmann-Kohli \(2007\)](#) describes as a descending position on a life-line. Participants also mirrored this descending position as age appropriate ([Neugarten et al., 1965](#)); that is, age appropriate in terms of what constitutes the right time to perform, or withdraw from, specific activities.

"When you say that we are slower, I say that you should expect that, I will soon be 84." (John, 4).

"That's how it is, we have reached an age where we are more in the group (of having problems with remembering)." (Jim, 2).

The idea of age norms and age appropriateness was described by [Neugarten et al \(1965\)](#) half a century ago. Such norms were identified in all participants, permeating the findings. When reflecting on symptoms and accounting for not being able to continue life as before, participants referred to age. They seemed to closely associate ageing with dementia, and symptoms might indeed be explainable by age as well as by dementia. For instance, it was pointed out that being slow or forgetful was quite normal at their age. Such explanations are well known in the literature on people's experience of dementia and on future outlook: [De Boer et al. \(2012\)](#) describe how people with dementia lower their expectations with age, and in the study by [Hellström and Torres \(2016\)](#) participants use age as an explanation for having dementia. That may be why not all participants seem to consider being diagnosed with dementia as such a life-altering event. This aligns with the perspectives of older people without dementia. [Dittmann-Kohli \(2007\)](#) states that older people's future expectations include cognitive decline. Inge talked repeatedly about being diagnosed with dementia in old age as less life-altering than if she had been younger at diagnosis:

“But you know what, I have one very, very big advantage. I only just found out now and I’ll be 85 at Christmas. The point is, you see, I might die many times over before dying of it (dementia)“ (Inge, 1).

“We have the advantage that it is at a very early stage and at a late age, I will be 85 at Christmas. So you see I have time to die before”(Inge, 2).

“I walk around with the hope that now I will be 85 and I’m having a reasonable time now and I hope I’m dead before I become. . . . because I do not want to leave the safe surroundings I have (to go, for example, to a nursing home)“ (Inge, 3).

Several participants expressed the hope that they would die from old age before their dementia got severe. For the old, the finitude of life is an existential condition, and most participants, in particular the oldest, talked about death as a natural aspect of life. This finding corresponds to the findings of [Dittmann-Kohli’s \(2007\)](#) and [Heaton et al. \(2020\)](#). Participants noted that their future life trajectory was shortening and that the end of life was not that far away. One participant concluded that she and her husband “*have nothing more to wish for*” (*Ulrika, 3*). Participants seemed to be more anxious about the disease getting more severe than about death. This aligns with the findings of [Dittmann-Kohli \(2007\)](#) concerning older people who are not affected by dementia.

Age appropriateness implies age-specific rights and obligations ([Neugarten et al., 1965](#)). Participants seemed to be expressing the right to reject taking part in rehabilitative activities. As for the woman cited below, who got angry when a home care assistant encouraged her to wash her own hair:

“I went crazy (...) she could help me instead of just sitting around being lazy (...) Of course, I want to do it and I don’t want to be sick. So I would like to do it myself, but it’s about getting your arms up and getting your hair washed properly. It can be a bit difficult (...) young people should not come and order others about like a king”. (*Kitty, 2*).

Another example: Kurt refused to take part in training activities by referring to his advanced age. He said that at the age of 92 he had lived long enough, but it he felt that the therapist wanted him to continue living:

“The only thought in her head was that I should live as long as possible. And I’m not interested in that. It completely doesn’t matter. (...) But would you believe it, they don’t use that kind of language - quite the contrary”. (*Kurt, 2*).

The attitudes of some older people and the views of rehabilitative professional practice somehow seemed to conflict. On the one hand, our participants seemed to associate dementia in old age with an age-based right to resign and to get compensatory help and support, while on the other hand, resigning to old age was not fully recognized institutionally as a legitimate strategy, and seemed to conflict with the sort of institutional narrative about rehabilitation and continuity illustrated above.

Other institutional arrangements, however, seemed to correspond with the narrative of dementia as decline and loss of autonomy. People with dementia were advised to fill out a legal document pertaining to their ‘future power of attorney’, so that their spouse or another close relative would be able to act on their behalf when they were no longer able to act as legal subjects. Participants were talking about this procedure in a matter-of-fact kind of way, and referred to it as something they should definitely do if they had not already filled out the document. Planning for a future with severe

dementia in terms of taking such legal steps seemed to be considered not as something discouraging, but as an important action about taking care of each other in the future.

Another example of institutional arrangement is planning for future care accommodation. Several participants had signed an application for a care home. In the case of one of the participants, there were doubts whether or not she was still to be considered a legal subject. As her husband remarked, it was ‘about time’ (for her to sign an application):

“It should be done while Kitty is still in her right mind. The state administrator was in doubt as to whether he would permit it, but then Kitty came up with a very relevant answer, and so it happened.” (Kitty’s spouse, 3).

To other participants, moving into a care home seemed too far ahead to them, but it was still something that they had in mind, though representing a gloomy future prospective:

Inge: “Neither of us wanted to go to a nursing home ever.”

Spouse: “But now we have to take the disease into account”. (Inge, 1).

In summary, futurework may imply adjusting to decline and preparing for future losses. While respondents may consider this a legitimate and appropriate strategy, it conflicts with the narrative of rehabilitation in dementia care. It corresponds, however, with other institutional arrangements in dementia care, such as a future power of attorney.

Discussion

This study analysed the futurework of older people with dementia who are taking part in, or rejecting, rehabilitative activities. Findings included three dimensions of futurework: extending the present state into the near future; avoiding being confronted with an anticipated future involving being more severely affected by dementia; and adjusting to decline and preparing for future losses. However, the futurework of older people does not always correspond with the institutional arrangements in rehabilitation-focused dementia care.

The three dimensions of the futurework of older people with dementia may seem contradictory. Such a contradiction may be interpreted as interpersonal differences, as suggested by [Pikkarainen et al. \(2015\)](#). It seemed, however, not to be the case in this study. Of course, interpersonal differences were present in the futurework of older people with dementia; however, differences appeared intra-individually as well. This hypothesis was supported by the user panel, as previously mentioned in the methods section. The user panel reflected on contradictory findings from the interviews and supported the idea of ambivalence. As an example, when invited to reflect on the contradictory statements: “I would like to try new things if they can improve my daily life”, versus “I just need to have peace and quiet daily life”, one user panel member stated that he agreed 60% with the first statement and 40% with the latter ([Thuesen, 2020](#)).

The findings are supported by other research on future outlooks and future time perspectives from the field of dementia as well as from gerontology. Gerontological studies and perspectives were included to suggest that understandings and experiences that have previously been exclusively associated with dementia may apply just as well to the ageing experience. Therefore, our discussion will include gerontological perspectives.

Ambivalence is an important topic in ageing – including lived ambivalence as well as ambivalence as an analytical concept (Baars, 2014; Jolanki et al., 2000). When thinking about old age, either-or dichotomies are commonly encountered (Baars, 2014; Thuesen et al., 2021), such as narratives of decline versus age-defying narratives of success and independency (Baars, 2017), third age versus fourth age, and continuity versus change (Grenier, 2012). Approaching the study of ageing (including dementia in old age) in terms of ambivalence undercuts these dichotomies. According to a cultural gerontologist, Outi Jolanki et al. (2000), ambivalence is rooted in older people's minds, talking about old age as a choice as well as a necessity. In dementia, our findings suggest that ambivalence may also include ambivalent futurework. In terms of futurework, ambivalence can be illustrated by the fact of extending the present state into the near future and avoiding being confronted with an anticipated future with severe dementia, while at the same time facing this future perspective. According to Dittmann-Kohli (2007), many older people desire preservation of the status quo, maintenance and continuity. They may fear the future in terms of a lack of physical and cognitive functioning and a loss of autonomy and independence, and therefore refuse or decline to answer questions about their future and possible decline. "There seems to be a certain resistance to visualizing existentially disastrous states in one's future life." (Dittmann-Kohli, 2007, p. 111). When it comes to dementia, ambivalence may become more marked due to uncertain future prospects. As stated by Hellström and Torres (2016), dementia is associated with numerous negative connotations and is one of the diseases that most people seem to fear. However, lived ambivalence may be considered an integrated aspect of ageing. Quoting Baars (2017), ageing is about *Learning to Live a Finite Life*. According to Baars this includes balancing the recognition of vulnerabilities and limitations with the creativity and fulfilment that are inherent in finite life. Older people, and the professionals whose job it is help them, must learn to balance control with the acceptance of its limits. This is what Baars (2017) calls the interhuman condition of ageing, which is characterized not only by its shared vulnerability, but also by the strengths of its humane responses.

Researchers point to the sociality of these existential considerations. By introducing the phrase 'interhuman condition' Baars (2017) points to the constitutive importance of others in our lives. This social embeddedness is a constitutive context in which individual autonomy can be fostered, supported, or crushed. According to Dittmann-Kohli (2007), future life perspectives are based on cultural models of the life course. Social representations or cultural models are adopted by individuals as a cognitive framework that may give rise to positive or negative ideas and concerns for the self. In this study, the futurework of older people with dementia is explored as socially embedded in relation to the institutional arrangements in community dementia care. Findings show that the institutional arrangements in dementia care may support as well as challenge the futurework of the participants. In the introduction, we stated that rehabilitation practices may support a linear future orientation towards goals of improvement or maintenance. Some of the present findings support such a view. Futurework in terms of extending the present state into the near future is about continuity and a few participants in the study do hope for improvement. This hope for improvement, however, is in itself somewhat ambiguous and seems to add to personal ambivalence, since the same individuals also perform futurework to avoid the future and adjust to decline. A future-oriented rehabilitation practice may even conflict with other dimensions in the futurework of older people with dementia. Rehabilitation may support strategies of preservation and continuity, but institutional arrangements may also destabilize life situations by temporarily disturbing the routines of everyday life. Collectively organized rehabilitative activities may conflict with futurework in terms of avoiding being confronted with an anticipated future as a more severely affected patient. Finally, the narrative of rehabilitation may conflict with the futurework in terms of adjusting to decline and preparing for future losses. However, a rehabilitative approach does not stand alone in dementia

care, but rather contributes to it as an additional perspective and approach (Graff et al., *forthcoming*). This may add to the opportunities for people living with dementia, but also to the ambivalence of ageing with dementia, by adding to the plurality of ways to manage everyday life and a future with dementia; by adding a plurality of possible futures. Paying attention to the ambivalences of older people living with dementia and recognizing the ambivalence of futurework seems to be an important strategy in rehabilitation-focused dementia care.

Due to its design, this study may have some limitations. Though the two cases were strategically selected as paradigmatic examples of 'rehabilitation-focused dementia care', the heterogeneity of rehabilitative activities was considerable. A case representing a specific rehabilitation programme might have provided a more homogenous case. Yet, as many studies stress, the heterogeneity implicit in what may be considered as rehabilitation in dementia care (Cations et al, 2017; Kroll & Naue, 2011; Ravn et al, 2019) means that we consider heterogeneity to be defining for current rehabilitation-focused dementia care. This claim is further developed in another paper from the current study (Graff et al., *forthcoming*).

The interview participants were strategically sampled to include information-rich cases. Though the number of participants was fairly limited, we did experience data saturation due to the repeated nature of the interview design and rich narratives of the participants, and we consider the conclusion to be within the scope of what can be legitimately derived from the empirical data, the qualitative design and other research. Interviewing people living with dementia poses some methodological and ethical challenges due to the potentially compromised cognitive functioning the participants are struggling with. However, we designed the study to overcome these challenges. Samsi and Manthorpe (2020) have reviewed the literature on interviewing people living with dementia. They state that time, setting, the relation to the interviewer and the way questions are posed are important contextual factors. Conducting more than one interview is valuable. People with dementia may need time and space to decide what to say and how to express it (Samsi & Manthorpe, 2020). By conducting several interviews with the same person over an extended timeline, we provided the opportunity for respondents to unfold and elaborate on their thoughts and perspectives. In each interview we gave a small summary of the previous interview. Moreover, repeating the interviews gave us time to develop a trusting relationship, as suggested by Samsi and Manthorpe (2020). Interviews were conducted in the participants' homes, which provided a safe and familiar context. Though we tried to get the perspectives of the individuals living with dementia, relatives were quite often present and active in the interview and may have influenced what was said. However, we do not consider the accounts of the people living with dementia less true than if relatives had not been present.

Conclusion

The study explored the futurework of older people living with dementia in the context of rehabilitation-focused dementia care. Three dimensions of futurework were suggested which may seem contradictory: extending the present state into the near future; avoiding being confronted with an anticipated future seen as more severely affected by dementia; and adjusting to decline and preparing for future losses.

At the same time we have suggested that rather than considering these three dimensions as contradictory, they should be seen as aspects of the ambivalences of the ageing experience. It is suggested that rehabilitation-focused dementia care may add to these ambivalences by adding to the plurality of ways to manage everyday life and future. Providers of rehabilitation should be attentive to these ambivalences.

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