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Organizational narratives in rehabilitation-focused dementia care – Negotiating identities, interventions and personhood

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Abstract

Background: Rehabilitation is increasingly being introduced in dementia care but studies highlight extensive heterogeneity in practices, conceptual confusion and divergent perceptions of its relevance across care organizations and national contexts. As this have implications for development of dementia care as well as for people with dementia's access to care it is important to study the organizational narratives and practices in rehabilitation-oriented dementia care organizations.

Methods: The study build on qualitative interviews (individual and group interviews) with health professionals (N = 26) engaged with dementia care and rehabilitation in two Danish municipalities. The interviews were conducted in 2018–2019. The empirical data was analyzed using abductive analysis and theory-based narrative analysis, using Loseke's conceptualizations of and approach to analyzing formula stories.

Findings: Four dominant organizational narratives were constructed from the data. Each narrative produced a specific organizational narrative of client identity: the active participant in individualized

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rehabilitation, the inactive individual benefitting from enhanced social environments, the disengaging self and the vulnerable self.

Conclusion: Introducing rehabilitation in dementia care may amplify the organizational polyphonic and provide a plurality of organizational identities each expressing different perceptions of personhood and agency for people with dementia. The organizational narratives were negotiated within a specific structural context where national regulation and dominant discourses on economic challenges and ageing gave precedence to some narratives more than others. In Danish elder care, the first narrative is the most influential but risks excluding people with dementia. Instead, rehabilitation in dementia care is positioned within a social and relational perspective, which may silence important discussion of agency and resistance.

Keywords

Rehabilitation, reablement, elder care, health professionals, dementia care, organizational narratives, formula stories, personhood, agency, out-patient rehabilitation

Introduction

Dementia is one of the primary causes of disability worldwide while increasingly also being considered as disability in itself (Gove et al., 2017; World Health Organization, 2017). The emergence of a dialectical understanding of dementia has paved the way for introducing rehabilitation in dementia care (Downs et al., 2006; Gove et al., 2017), both as a type of intervention and as a general approach to care (Ravn et al., 2019). Research on rehabilitation for people with dementia has shown promising results, whether post fracture (e.g. Allen et al., 2012; McGilton et al., 2013; Mitchell et al., 2016; Seitz et al., 2016) or with dementia as the action diagnosis (Bahar-Fuchs et al., 2013; Clare et al., 2010; Clare et al., 2019; Ravn et al., 2019; Thivierge et al., 2014; Øksnebjerg et al., 2020). Despite the increasing focus, both Danish and International studies show widespread heterogeneity in clinicians' perceptions of the relevance of rehabilitation in dementia care (Cations et al., 2020; Kroll & Naue, 2010; McGilton et al., 2021; Ravn et al., 2019; Thuesen et al., 2018). Some clinicians find rehabilitation pointless due to of the progressive nature of dementia and difficult to define meaningful outcomes when the user has dementia (Cations et al., 2020; Kroll & Naue, 2010). Other reservations concerns clinicians' expectation that people with dementia have difficulties participating in goal-setting or following directions as well as concerns related to use of resources (Cations et al., 2020; Isbel & Jamieson, 2017; McFarlanen et al., 2017; McGilton et al., 2021; Thuesen et al., 2018).

Organizational narratives

The divergent perspectives on rehabilitation in dementia care have implications for people with dementia who risk being routinely excluded from some rehabilitation programs due to assumptions about their cognitive abilities (Isbel & Jamieson, 2017; Kjellberg et al., 2013; Mitchell et al., 2016). Hence, how health professionals and care organizations understand and define people with dementia have consequences for their access to and experiences in dementia care. In other welfare areas than dementia care, studies have highlighted how organizational narratives about clients have real and lived consequences. As Järvinen describes it in relation to treatment of drug users in Denmark:

The way people are categorised sets the guidelines for how organisations will treat them, what services they will receive or be denied, what goals professionals will set for working with the clients and what means will be used to reach these goals. (Järvinen, 2014, p.12)

Organizational narratives of identity inform and shape service provision by providing images of the organization's 'typical' client, which justify the organization of services and the interventions needed to help this particular client with his or hers particular problem (Loseke, 2007). Understandings of clients and needs are shaped by social, cultural and institutional contexts (Selseng, 2018). Therefore, different organizations catering to the same type of clients, for instance people who are blind (Scott, 1985) or have substance abuse problems (Selseng, 2018) 'offer very different services in very different ways' (Loseke, 2007, p.671) depending on the organizations' specific image of their typical clients. By making the typical client visible and thus defining who are eligible for what, organizational narratives not only shape the services, though; like the institutional identities defined in social policies they also 'shape the social world and its inhabitants' life chances' (Loseke, 2007, p.667). The narratives are linked to the professionals' expectations of their clients – e.g. as unreliable or vulnerable - and thus how clients will be met, what will be expected of them and which type of services they will be offered. By defining the traits one must show to be perceived as a legitimate member of the organizational narrative (Loseke, 2001), the narratives shape the criteria for inclusion and exclusion and enable certain type of behaviors and actions while restricting others. A number of studies have shown how clients have to adapt to the organizational narrative of the 'typical client' in order to be eligible for assistance or avoid punishment (e.g. Andersen, 2015; Gubrium & Holstein, 2001; Loseke, 2001; 2007; 2012; Miller, 2001). Loseke (2001) for instance shows how women to receive the services of a shelter for battered women must present themselves in a way that make them believable according to the shelter's image of a 'battered woman'.

Importantly, not all clients fit or wish to fit into the typified organizational narratives of identity but may instead attempt to challenge or resist them (Järvinen, 2014; Järvinen & Andersen, 2009; Loseke, 2001, 2012). As Järvinen & Andersen (2009) show in their studies of drug treatment, though, this might have repercussions in terms of not receiving any services or of being pressured into accepting an unwanted type of intervention. This way, some organizational narratives might create 'self-fulfilling prophecies' (Järvinen & Andersen, 2009, p.870), pressuring clients to adapt to unwanted organizational identities.

As organizational narratives thus shape both care practices and life possibilities, we find it highly relevant to examine them in dementia care organizations. Hence, the aim of this article is to explore organizational narratives in local rehabilitation-focused dementia care organizations. To our knowledge there are no published studies of organizational narratives in dementia care organizations and local dementia care services are in general an under-researched area (Rahja & Thuesen, 2023). This article thus aims to contribute to the existing body of literature with novel theoretical as well as empirical knowledge of interest for both researchers and practitioners.

Methods

Setting

In Denmark, health- and social care is publicly financed, predominantly free of charge and given based on needs. Local governments, the municipalities, are responsible for the majority of primary health- and eldercare services, such as home care, home nursing care, physical rehabilitation and preventive measures. People with dementia have access to the same services as people without

dementia. However, a number of local services are targeted people with dementia, for instance specific exercise groups and day centres and individually assigned dementia coordinators.

Rehabilitation is written into national dementia policies and -guidelines (Sundheds-og Ældreministeriet, 2016; Sundhedsstyrelsen, 2016b) but without binding recommendations for local practice. On the local level the concept of rehabilitation is widespread in both dementia policies and dementia care but with variations in local conceptualizations and practices. Rehabilitation for home-dwelling people with mild to moderate dementia primarily consist of group based exercise, ADL training - mainly in the form of home care reablement or individual training by therapist, day centres with various activities and other activities guided by a rehabilitative care approach (Thuesen et al., 2018). Since 2015 it has been mandatory for the municipalities to offer short-term reablement interventions to people applying for home care to improve their functional ability in order to make them as independent of care as possible and improve their quality of life. People with dementia are specified as a target group for reablement in national guidelines (Sundhedsstyrelsen, 2016a) but in practice, not all municipalities include them systematically (Sundhedsstyrelsen, 2022).

The study was conducted in two municipalities selected due to being particularly focused on rehabilitation in local dementia care (Thuesen et al., 2018). The municipalities were sampled as a paradigmatic case, which are cases that prominently feature general characteristics of the domain being studied and promote generalizability and validity by being recognizable for an audience (Flyvbjerg, 2006, p.230). Municipality A is one of Denmark's larger municipalities with more than 100.000 inhabitants, while municipality B with less than 50.000 inhabitants is just below average size. While the two municipalities are similar in regards to types of services provided, corresponding to the services mentioned above, they differ in their organization. Municipality A has an interdisciplinary organization of care services. Home care, reablement, home nursing care and rehabilitation are delivered by teams consisting of home care professionals (mostly trained nursing assistants), registered nurses and physio- and occupational therapists. Dementia coordinators are also organized within an interdisciplinary team with social educators. Municipality B has a more traditional organization with health and care services organized in separate departments for home care, home nursing care and training and rehabilitation. Home care reablement is delivered by an interdisciplinary team consisting of nursing assistants, registered nurses and therapists. In line with national policies and municipal practice in general, the two case municipalities emphasize a broad understanding of rehabilitation as both rehabilitative interventions and -activities and as a general approach to care. The broad understanding is shared by this study. To reduce the risk of conceptual ambiguity, we elucidate the types of rehabilitation when relevant throughout the article.

Participants

26 health professionals from the two municipalities participated in interviews. 24 participants were recruited by the municipalities based on our recommendations regarding their job positions and engagement with dementia care and rehabilitation. Two participants were recruited by the authors after observational studies of practice and based on the same criteria regarding proximity to and experience with dementia care and rehabilitation.

All participants were women except one. The majority (one-third) were trained nurses followed by occupational and physiotherapists. A minority were trained nursing assistants (2) or social educators (2). They primarily held positions as needs assessors or dementia coordinators, while a minor group were employed as therapists or nursing assistants in interdisciplinary home care or reablement teams. Three participants held managerial positions: as team leader of the dementia coordinators, manager of a care department specialized in people with cognitive decline and

a manager of a dementia clinic. The majority of participants had between five and 25 years of experience in the field of dementia care and only three had less than 3 years' experience.

Interviews

The interviews were conducted between August 2018 and September 2019 in person at the organization sites by either the first author (municipality B), the last author (municipality A) or by both (three interviews). The analysis builds on five group interviews and six individual interviews with health professionals as well as on notes from more informal conversations with managers and staff. In municipality A we conducted one group interview with needs assessors and one group interview with dementia coordinators as well as five individual interviews with managers, therapists and a dementia coordinator. In municipality B we conducted three group interviews: one with needs assessors, one with dementia coordinators and one with members of the reablement team. We also conducted a single individual interview with a dementia coordinator.

The interviews followed a semi-structured interview-guide with open-ended questions in order to encourage reflections and meaning-making of practice and allow us to follow themes of particular interest (Brinkman, 2013). The interviews were recorded and transcribed verbatim. Quotes from the interviews were translated into English by the first author and are used as illustrative examples of the content of each narrative.

Analysis

The analysis of the empirical data was conducted following principles of abductive analysis, with data collection and analysis taking place concurrently and the analysis and development of themes were guided by existing theory. Repeated readings, codings and re-codings of the interview transcripts and the subsequent sorting of codes into groups led to the construction of themes emerging across the interviews (Thompson, 2022; Timmermans & Tavory, 2012). To promote credibility, the first and last author together coded the material, constructed and discussed themes and did the initial analysis (Patton, 1999). Final analysis was conducted by all three authors in unison.

Abductive analysis 'rest on a cultivation of anomalous and surprising empirical findings against a background of multiple existing sociological theories and through systematic methodological analysis' (Timmermans & Tavory, 2012, p.169). In this study, experiencing in the early data collection stage that access to rehabilitation for people with dementia was given on for us unclear grounds and that the informants did not agree on the relevance of rehabilitation in dementia care was one such surprising finding, not least due to the two municipalities being identified as forerunners in implementing rehabilitation in dementia care. In the subsequent interviews we therefore aimed at seeking clarification (Thomson, 2022) but without finding sufficient answers here or in the existing literature on rehabilitation and dementia. What we did encounter were a multitude of perspectives on the subject at hand within and across our case organizations. Taking inspiration from the literature on organizational narratives (e.g. Gubrium & Holstein, 2001; Järvinen, 2014; Loseke, 2007) and organizational narrative polyphony (Eaves & Walton, 2013; Pedersen, 2005; Pedersen & Humle, 2016) we proceeded with theory-based narrative analysis to identify and analyze each theme. To focus on the content and distinctions of each theme we applied Donileen R. Loseke's concept of formula stories (e.g. Loseke, 2001, 2007, 2012), which led to our analytical construction of four distinct organizational narratives. Loseke's approach was chosen because it offers methodological approaches to analyzing the content of organizational narratives, such as categorizing explicit

descriptions of characters and unpacking the system of ideas and preconceptions that the stories build on (Loseke, 2012). Loseke defines formula stories as ‘narratives of typical actors engaging in typical behaviors within typical plots leading to expectable moral evaluations’ (Loseke, 2007, p.664). Formula stories thus contain a plot and distinctive characters and become predictable and recognizable by drawing on specific systems of ideas ‘in ways that reflect how audience members understand the world’ (Loseke, 2012, p.253). In welfare organizations, formula stories appear as organizational narratives of identity informing service provision by making the client visible (Loseke, 2007). In organizational narratives, formula stories thus represents specific client identities or -categories as well as represent the typical practice in the organizations. Formula stories often reflect widespread social norms and values but are also continuously negotiated and challenged by divergent perspectives of the subject at hand (Loseke, 2007), which might result in organizational narrative polyphony (Eaves & Walton, 2013; Pedersen, 2005; Pedersen & Humle, 2016).

Ethical considerations

All participants provided informed written consent to participate. 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). 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).

Findings

Four organizational narratives were constructed from the data material, each produced a specific organizational narrative of client identity: the active participant in rehabilitation, the inactive person benefitting from enhanced social environments, the disengaging self and the vulnerable self. The key narrative, which the other narratives in many ways referred to was the first. This was both due to our focus on the subject in the interviews but mainly due to the narrative’s criteria for being a legitimate client being the most disagreed on subject in the interviews.

The active participant in individualized rehabilitation

The plot of the first organizational narrative is that individualized and goal-oriented rehabilitation can assist people in optimizing their functioning. In this narrative, rehabilitation was aimed at improving people’s everyday lives at home, as illustrated in this quote from a therapist working primarily with home care reablement:

We are sent to the home to see if we can help the person getting back to these everyday activities, which they have previously been very enthusiastic about doing themselves, and with getting more self-reliant in their everyday life. (Health professional, municipality A)

Goal setting was described as an essential tool in rehabilitation to target and individualize the interventions and involve care users. The emphasis on goal setting was present across the interviews, as in this description of a typical rehabilitative intervention in home care from a therapist from the other municipality:

Ideally, we have a start-up visit together with one of the home care staff. Then we make a plan for the intervention, find out what the person is motivated for and what parts of the training should come first, what the goals are and agreeing on how to proceed. And then at some point in the future we evaluate to find out how things are proceeding. Should we focus on new goals? Have we even reached the first goals? What will it take to reach the goals? (Health professional, municipality B)

The organizational identity produced by this narrative is that of a person who actively engages in becoming more self-sufficient again by participating in goal setting and work towards reaching the goals. The narrative refers to ideas well-known within the context of rehabilitation about activation, goal-setting and individualization. The narrative also draws on certain preconceptions about ageing and impairment referring to theories of successful ageing. Within this system of ideas, impairment in old age can be explained by extrinsic and modifiable factors and can therefore be changed by supporting the individual's active efforts. An important component in this is the idea of continuity – continuing with preferred activities and active engagements also in old age as exemplified in the first quote (Downs et al., 2006; Rowe & Kahn, 1987, 1997; Thuesen et al., 2021).

In the interviews, we encountered opposing perspectives related to the narrative's image of the typical client. According to interviewees from both organizations, the importance of active participation in goal setting was disagreed upon. While some health professionals perceived the ability to set goals yourself as a requirement for access to rehabilitation, others highlighted how it was possible to involve people with dementia in goal setting in other ways, e.g. drawing on their relatives or knowledge of their preferences.

Another subject of disagreement related to what should be the aim of rehabilitation. In several interviews a preventive aim was highlighted as especially relevant within dementia care, where rehabilitation could be a measure to prevent or delay further loss of functioning:

Rehabilitation in dementia care is that you maintain the skills they have, and then you remedy the decline in functioning by supplementing, so that you support the things they can still do. This way we keep them on each level of functioning longer than we would have otherwise. (Health professional, municipality B)

The view of rehabilitation as prevention was challenged, however, and other interviewees instead argued that the aim of rehabilitation was self-sufficiency and that rehabilitation therefore should be targeted people with physical functional decline:

It makes more sense because there is the possibility to terminate a lot more interventions because the users can become self-sufficient much faster, since it is only for a short period that they need assistance. Because it is something that can be rehabilitated. (Health professional, municipality A)

In this perspective, rehabilitation should be targeted those who had potential for developing their functioning and become self-sufficient again, because this would reduce the period of needing care and also reducing public spending on care provision. Both the expectation of active involvement in goal setting and the arguments for the aim of self-sufficiency would accordingly make it difficult for some people with dementia to live up to the narrative's criteria for inclusion, as they were not perceived capable of assuming this particular organizational identity (Loseke, 2007).

The inactive individual benefitting from enhanced social environments

The plot of the second narrative concerns how dementia as disability is malleable through stimulating social environments. An enriched environment coupled with a benign social psychology may facilitate the maintenance of function for a period of time or even some regeneration (Clare, 2008; Downs et al., 2006). This plot thus adds a social environment perspective to rehabilitation in dementia care.

In the interviews, interventions encompassing socializing elements such as day centres, where older adults can spend time socializing and participating in activities, were emphasized as important rehabilitative intervention for people with mild to moderate dementia. When asked to describe what made day centres so beneficial interviewees listed a multi-faceted range of benefits as exemplified here by a needs assessor:

Talking about prevention and exercise and rehabilitation, then they highly benefit from being out among other people, being active, walking from the car to the café, and they get to go on trips and they have to socialize. All that it entails to do so have been shown by science to be really important to maintain. When they stay at home and do not get out and only see one person that is not very good for their disease. You can create a more meaningful life for them and for their relatives while a lot of good follows from the activities at the centres. It simply is a really good intervention. (Health professional, municipality B)

Across interviews health professionals highlighted how collective physical activities and socializing had a positive influence on people with dementia's cognition. In the interviews it was emphasized that the underlying issue causing a need for enhanced social environments were not inadequate or negative social interactions with e.g. a spouse but inactivity. Therefore a combination of enhanced social environments and physical activities were emphasized:

We especially want for them to keep physically active so that they do not sit too much in the chair. Because we think that it is better for many things, also their cognition. And there is also something about the social, that you have a need for something social, like getting to talk about old days, which are some of the things of which there is evidence. (Health professional, municipality A)

As opposed to the first narrative, the aim of the activities in this narrative related to the social dimensions of people's life and their activity levels. Enhancing the social environment was thus presented both as a means and as a multi-faceted aim. The organizational narrative of identity produced by this is that of a person with dementia who due to inactivity will benefit from enhanced social environments and increased activity levels. The characterization builds on an optimistic perspective of dementia symptoms as something malleable, on the possibility to intervene and on a view of people with dementia as someone who should still be active, social and live meaningful lives despite their disability. In contrast to the first narrative's focus on individual optimization, though, this narrative emphasizes the social dimension of life.

The narrative's focus on enhanced social environments refers to ideas relating to person-centered care. Person-centered dementia care builds on Tom Kitwood's dialectical view of dementia, which 'sees the experience of living with dementia to be the result of a dialectical interplay between neurological impairment (or brain disease) and psychosocial factors [...] with particular emphasis on the social context' (Downs et al., 2006, p.244). Within this perspective, the social environment has an effect on neurological impairment and on individual personhood (Downs et al., 2006; Kitwood, 1997).

This makes supportive social interactions and environments focusing on strengthening the user's personhood essential.

The disengaging self

The third organizational narrative concerns how some people as they age have a natural wish to disengage from active life, which should be recognized:

For some people, the goal can be to get the best out of what is, "and can't we just please be left alone". ... I think that for many old people maybe this is a way to handle the situation. And then we are back at these old ways of thinking or models of how you cope with getting old. (Health professional, municipality A)

Conceptualizing disengagement as a coping mechanism was repeated by other informants arguing that not only ageing but also being affected by dementia could make people want to disengage. Withdrawal was not only presented as a coping mechanism, though, but as an active choice. Asked whether people always accepted activating interventions, some informants described how some people rejected interventions such as home care rehabilitation, being content to be able to manage their life this way and thus rejecting the offer to optimize their functioning. This way, the plot presents a person going through a natural health- or age-related process of withdrawal from active life, producing the organizational narrative of identity of the naturally disengaging person.

The plot's coherence depends on preexisting understandings of the ideas of disengagement. According to disengagement theory (Cumming & Henry, 1961), a desire to retire or disengage from social life and personal relationships is a natural way of coping with getting old. While the disengagement theory has long been abandoned by scholars based on its scientific shortcomings, it is still present as a social-gerontological narrative (Katz, 1996), exemplified by its direct reference in the quote above.

Yet, some informants discussed whether withdrawal from (rehabilitative) activities should be considered an aspect of natural disengagement or an aspect of pathology and consequently, whether they should recognize and support or challenge a disengaging behavior. The following excerpt is from a dialogue between three health professionals in one of the interviews:

Sometimes we are only thinking of what is best for them, instead of what they think or want themselves. It is really often that our goals are different from theirs (Health professional 1, municipality A)

But something happens with your priorities when you are in that situation and are being affected by something which is on-going. Maybe you are being totally real when saying "please leave me alone, I just want to sit here." We are not always good at listening to that, but that is because something is happening... (Health professional 2, municipality A)

Yes, something happens in the brain that makes you want to stay at home and be left alone. (Health professional 3, municipality A)

The vulnerable self

The excerpt above illustrates an ongoing professional discussion of care, representing a tension between the disengagement narrative and a narrative of professional knowledge and responsibility, suggested here as the fourth narrative. The plot of this narrative is that due to cognitive decline, some

people with dementia cannot always place the right decisions, which necessitates that health professionals take on a role as a 'surrogate decision-maker' (Sulmasy & Snyder, 2010). This may legitimize pressuring people with dementia to take part in e.g. rehabilitative activities even if they decline. The health professionals' knowledge of dementia and cognitive difficulties were thus presented as an argument for not considering people's preferences as much as they normally would. The question of whether or when this was acceptable was presented as a dilemma but one closely connected to the progressive nature of dementia. The obligation to involve and respect the wishes of people with dementia thus changed in terms of importance with the trajectory of dementia: 'But when we reach some point into the phase of moderate dementia, then we also have another obligation and that is "the duty of care"' (Health professional, municipality A).

This narrative thus legitimizes the use of soft paternalism (Fischer & Lotz, 2014), making decisions for people in order to protect and help them (Sulmasy & Snyder, 2010). The organizational narrative of identity produced by this story is that of a person with dementia who is incapable of performing their own choices and thus is vulnerable and needs others to make them for him/her. Therefore, it is also a character with reduced agency. The coherence of this plot is related to preexisting ideas about diminished cognitive abilities and subsequent loss of agency in people with dementia (Boyle, 2014; Grenier et al., 2017; Naue, 2008) and on ideas stemming from care theory emphasizing health professionals' obligation to care for people not capable of caring for themselves (Martinsen, 2006). Likewise, we propose that it also refers to the ethics of palliative care regarding frail and dying people having a right to be cared for with no further obligations (Saunders, 2003).

Discussion

Organizational narrative polyphony

We have analyzed organizational narratives occurring in interviews with health professionals about rehabilitation in dementia care using Loseke's concept of formula stories. We have presented four organizational narratives each producing a specific organizational client identity: the active participant in individualized rehabilitation, the inactive person benefitting from enhanced social environments, the disengaging self and the vulnerable self. The narratives as we have presented them here are our analytical construction. In practice, they are simultaneously present in on-going negotiations between individuals, groups and organizational settings and not as distinct as we make them out to be here. Organizational narratives are not just articulations; they have real and lived consequences (Järvinen & Andersen, 2009; Loseke, 2007; Selseng, 2018). They shape and legitimize organizational practices and clients have to adapt to the organizational narrative identity in order to be seen as a legitimate member in the organizational narrative (Gubrium & Holstein, 2001; Loseke, 2001, 2007, 2012). The pluralism of narratives we found in this study contrasts Loseke's own studies, which mostly concerns smaller and more clearly defined organizations such as shelters for women (Loseke, 2001), where a single dominant formula story inform service provision. We suggest that the pluralism of narratives found in this study reflect the complexity of and interdisciplinarity in the public dementia care organization we studied. As new approaches are introduced in dementia care, a plurality of voices, discourses, practices and narratives may be simultaneously present and negotiated in and around the organizations (Pedersen & Humle, 2016). Adding to the complexity, rehabilitation is being implemented in dementia care without yet being fully integrated in practice, causing us to be attentive to a more polyphonic organization (Eaves & Walton, 2013; Pedersen, 2005; Pedersen & Humle, 2016).

The discussion includes two parts: The first taps into the pending discussion on personhood and agency, which has been ongoing in dementia literature within four decades (Bartlett & O'Connor, 2007; Higgs & Gilleard, 2016). The second part is about the broader structural and institutional context the narratives are embedded in. Thus, the discussion also aims to unfold how the local narratives' negotiations on different perceptions of personhood in dementia and hence, their shaping of different life chances (Loseke, 2007) for people with dementia are influenced by the broader structural and institutional context.

A plurality of organizational narrative identities

Following the narrative polyphonic, people with dementia have to adapt to a plurality of organizational narrative identities, each representing different perceptions of personhood and dementia. As dementia care including rehabilitation is defined as genuinely person-centred (Clare, 2017; Thuesen et al., 2021b), we consider the discussion on personhood relevant. The lack of theoretical discussions on personhood in person-centred rehabilitation has been documented in previous research (Thuesen et al., 2021a). We suggest that the different narratives represent distinct perceptions of personhood and consequently, different possibilities for performing individual agency.

According to the first narrative, to be a legitimate member of the organizational narrative one should be able to partake in setting goals for one's own development and to follow these goals. In rehabilitation literature, this has been associated with Foucault's idea of 'conduct of conduct' (Clotworthy, 2020; Hansen & Tjørnhøj-Thomsen, 2007). According to some informants, this may be difficult when the user is a person with dementia; a perception also found in previous research (e.g. Cations et al., 2020; McFarlanen et al., 2017). This mirrors traditional views on individual personhood, which have developed in western philosophy for centuries, focusing largely on cognitive abilities as a prerequisite for personhood (Bartlett & O'Connor, 2007; Naue, 2008) and the view on personhood as a continuing authorship of change (Higgs & Gilleard, 2016). Such perceptions have been criticized for depriving persons with dementia of their personhood status, and consequently, new perceptions evolved in the 1980'ies, in particular with reference to the British psychologist Tom Kitwood, who made personhood central to dementia care (Kitwood, 1990). According to Kitwood, personhood is 'a standing or status that is bestowed upon one human being by others in the context of particular social relations and institutional arrangements' (Kitwood, 1997, p. 7). Hence, in this understanding, personhood is socially constructed as a result of relationships with others (Bartlett & O'Connor, 2007). Thus, what is important in sustaining personhood is not as much the individual but the social life, the individual takes part in (Higgs & Gilleard, 2016), as illustrated in the second narrative.

According to the third narrative, to be a legitimate member one should be subject to the idea of disengagement as a natural withdrawal from former social activities in later life. This may conflict with the first rehabilitation narrative, which stresses goal setting and maintenance of former life, and the importance on social relationships emphasized in narrative two. Yet, this may also promote a vision of the person with dementia as someone with agency, transcending the notion of agency from the former rehabilitation narratives. When the professionals say that 'Maybe you are being totally real when saying: "please leave me alone, I just want to sit here"' it may reflect a recognition of withdrawal as agency – and it may offer the person with dementia some opportunity for resistance towards an enhancement narrative. The disadvantage of the personhood lens, developed by Kitwood and followers is, that 'it does not explicitly recognize a person with dementia as a social actor, capable of exerting power and influence' (Bartlett & O'Connor, 2007, p.110) – or resistance, one may add. Hence, this narrative may provide a platform for agency for people with dementia, not

being excluded from rehabilitation but having the right to resist taking part in it. This narrative is, however, not only conflicting with the two former narratives but also counter to the fourth narrative. When the professionals in the fourth narrative discuss whether they should consider acts of resistance as aspects of agency or consequences of pathology, it mirrors the ideas of a threatened personhood as dementia progresses and choice, consciousness, rationality and memory is threatened. In this narrative, dementia threatens the capacity to perform as a self or person (Higgs & Gilleard, 2016), which poses a responsibility upon the professionals to act as a surrogate decision-maker (Sulmasy & Snyder, 2010).

Summing up, when rehabilitation is introduced in dementia care it may amplify the organizational polyphonic and provide a plurality of organizational identities expressing different perceptions of personhood and agency for people with dementia taking part in dementia care.

Structural and institutional influences on the legitimacy and position of narratives

Scholars have highlighted how institutionalized norms, structural factors and that some narratives and some narrators hold more weight than others result in some narratives being perceived as more legitimate than others (Gubrium & Holstein, 2009; Loseke, 2007). We will argue that this is also the case in this study, as the structural and institutional contexts for the negotiations of the narratives support some narratives more than others.

Rehabilitation has been introduced in dementia and long-term care in Denmark within the context of the global discourse of societal challenges related to the ageing of societies and the prospect of financing an escalating proportion of care for older people (Rostgaard, 2016; Hjemmehjælpskommissionen, 2013). Globally, rehabilitation has been presented as a major answer, building on the idea that improving people's functional ability and thus making them as self-reliant as possible will have a positive impact on quality of life as well as on health- and care consumption (World Health Organization, 2017). In Denmark as in other Western countries, the rapid spread of reablement service models (Metzelthin et al., 2022) has been the most notably example of this, with the Danish legislation on reablement explicitly stating that the aim of reablement is to increase people's independence in order to lessen the need for long-term care. The individualized rehabilitation perspective exemplified in the first narrative is thus supported by both the legislation and by the discourse in both policy and public care organizations of the necessity of containing costs on care. The first narrative furthermore gains support by drawing on the influential transnational discourse of active ageing that permeates ageing policies in Denmark. Within this framework of ideas, age-related decline is malleable and shaped by the individual's goals, choices and life style (Rowe & Kahn, 1997; Walker, 2002), whereby the narrative also links agency to performing individual choice (Thuesen et al., 2021b). Organizational narratives represent usual practice (Loseke, 2007), but in the first narrative usual practice is challenged when the user has dementia. As the empirical data show, it is not agreed on whether people with dementia can assume this particular organizational identity (Loseke, 2001, 2007). This study thus mirrors the findings from studies in other national contexts showing different perceptions of the relevance of rehabilitation for people with dementia, based on similar assumptions about dementia and goal setting and considerations about cost-effectiveness and use of resources (Cations et al., 2020; Isbel & Jamieson, 2017; McFarlanen et al., 2017; McGilton et al., 2021). In this study, we found that rehabilitation in dementia care as a result of this was less oriented towards an individualistic and goal-oriented rehabilitation perspective than towards the second narrative's social and relational perspective of rehabilitation as stimulating social environments. However, the second narrative risks being perceived as less legitimate than the first as it is not supported by the structural or institutional context

like the first narrative. In addition, the second narrative also goes against widespread and more medicalized perceptions regarding the restorative potential of rehabilitation that to a certain degree relates rehabilitation to physical functioning. The widespread idea that rehabilitation is primarily connected to physical decline is historically grounded (Cations et al., 2018; Timm et al., 2021), and contemporary understandings of rehabilitation to a greater extent emphasize a more holistic and inclusive perspective (Hammell, 2006, 2015). However, by drawing on recognizable and thereby weighty ideas (Loseke, 2012) relating rehabilitation to physical decline combined with the narrative gaining legitimacy from the structural and institutional context of dementia care in Denmark, the first narrative holds a strong position in the negotiations as well as in general. The third and the fourth narratives also challenge the individualistic rehabilitation perspective but in different ways. The disengagement narrative challenge the orientation towards the goal of optimization and restoration but is not only facing dominant health and care perspectives but also the societal aim to strengthen care-needing people's independence and contain public spending. The fourth narrative instead challenges the emphasis on individual agency but is up against contemporary societal values positioning service users as active and empowered participants in society (McLaughlin, 2015). Hence, neither narrative seems to be a threat to the narrative precedence of the first narrative's perspectives.

The narratives' implications for practice and for people with dementia

Due to the structural and institutional context for the negotiations of the local narratives, and especially by being well aligned with dominating discourses, the first organizational narrative of identity seems privileged in dementia and long term care in Denmark. As people with dementia risks exclusion from this narrative due to not being perceived as legitimate members, rehabilitation in the context of dementia is instead positioned within the second narrative's social and relational perspective. However, the second narrative draws on understandings of dementia and personhood that do not explicitly address agency and, due to being apolitical, do not generate room for exerting agentic power (Bartlett & O'Connor, 2007) to resist the narratives or the organizational identities they produce. Because of this, discussions of agency risks being absent in rehabilitation in dementia care. As this is an under-researched area we suggest it becomes a subject for future research but just as importantly that agency is given attention in dementia care in general but especially in practices focusing on enhanced social environments.

Despite being privileged, the first organizational narrative is also challenged. The introduction of rehabilitation in dementia care has entailed a plurality of co-existing organizational narratives, creating tensions and contradictions in daily practice. The pluralism of narratives also holds potential for dementia care though, as they point towards the importance of having multiple and multi-faceted approaches to people with dementia. People with dementia have shifting needs and wishes at different times and over the trajectory of dementia (Hodgson et al., 2014). They may also simultaneously have ambivalent expectations to their future (Thuesen & Graff, 2022) and the co-existence of multiple narratives may increase the opportunities to take care of different needs. However, if rehabilitation is to be an actual option for people with dementia, it is necessary to discuss both the structural frames for and the prevailing understandings of personhood within the organizational narratives in dementia care.

Conclusion

We have identified four organizational narratives that addresses personhood and agency in people with dementia in different ways. The narratives were negotiated within a structural and institutional framework that gave precedence and legitimacy to some narratives more than others. The first narrative is the most influential in the Danish rehabilitation context but poses risks of excluding people with dementia. Instead, rehabilitation in dementia care is positioned in a social and relational perspective, which may silence important discussion of agency and resistance.

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