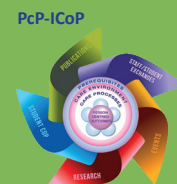


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ORIGINAL PRACTICE DEVELOPMENT AND RESEARCH

'Hybrid' thoughts on care for people with dementia and their families: critical perspectives on care work

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Abstract

Background: Inclusion and participation are rights for all, according to the United Nation's Universal Declaration of Human Rights. Historically, dementia has been defined primarily in terms of loss – loss of cognitive and communicative skills, loss of identity and personhood, and loss of personal relations (Capstick and Baldwin, 2007). Critical perspectives have challenged this view on people living with dementia and enabling people to participate as equal citizens in society is a significant theme in dementia research. This article uses a citizenship approach to dementia and illustrates how care and care work needs values shifts to enable people with dementia to become equal citizens in society.

Aim: This article aims to demonstrate the effect on care work when citizenship is chosen as a value for care.

Methods: This article draws on empirical qualitative interviews with families living with dementia, healthcare and medical personnel, and care managers who are part of everyday life for these families. Analytically, the article draws on citizenship theory and empirical philosophy.

Results: Two necessary values shifts are outlined: from patient to citizen and from personal care to care collectives. These ways of doing care work depend on other practices, especially the way knowledge and experience is constructed and understood. This article discusses the need for other forms of knowledge and expert experience.

Conclusions and implications for practice:

- Caring for people with dementia needs a values shift toward enhancing agency
- Re-orienting care work towards care collectives shapes new possibilities for people living with dementia
- Care work that pays attention to the construction of everyday life can promote participation and inclusion for people living with dementia

Keywords: Dementia, caring, care work, citizenship, practice theory

Introduction

Inclusion and participation are rights for all, according to the UN's Universal Declaration of Human Rights. Historically, dementia has been defined primarily in terms of loss – loss of cognitive and communicative skills, loss of identity and personhood, and loss of personal relationships (Capstick and Baldwin, 2007). Persons with dementia have historically been portrayed as dependent on others in terms of being care receivers (Fine and Glendinning, 2005) but in the past two decades, this view has been challenged by critical perspectives. Enabling people to participate as equal citizens in society is a major theme in dementia studies, which is a relatively new field of research about people living with dementia (Hydén and Antelius, 2017). This article draws on a citizenship approach to dementia and illustrates that there needs to be a values shift in care services to enable people with dementia to become equal citizens. To do so, this article gives attention to relations, which have the potential to shape things. (Callon and Law, 1995). Agency is one such thing; here, it is the ability for those living with dementia to make choices about their own lives, created by interactions between different actors and relations (Callon and Law, 1995, p 485). The term 'hybrid' is used to highlight the importance of thinking about care as an effect of the interplay between relations and people, things and places.

Citizenship and dementia

Citizenship entails participation, belonging and recognition, and means being in control of one's life and having influence on society (Lister, 2003). To promote such qualities Bartlett and O'Connor (2010) suggest broadening conceptualisations of dementia and citizenship. The same authors introduce the concept of social citizenship for people living with dementia (2007), setting out six fundamental rights: growth; social positions; meaningfulness; participation; solidarity; and freedom from discrimination. Through a citizenship lens, people living with dementia are approached as active participating agents in their own lives as well as residents in their local communities. According to Lister (2003) citizenship as active participation represents an expression of human agency. Understanding of agency is an important task for dementia studies, and is under-analysed (Österholm and Hydén, 2014; O'Connor and Nedlund, 2016). The agency-based approach to dementia studies has been actualised in different ways: Baldwin (2008) proposes that a narrative approach can give people with dementia the opportunity to tell their stories and experiences of living with dementia, while Nedlund and Nordh (2015) show how the agency of people with dementia is constructed in policy documents. Bartlett (2015) argues that creative activities such as art can offer a way of expressing oneself, while Boyle (2014) suggests agency is recognised as habituated, embodied or emotional. Kontos and Grigorovich (2016) talk about 'agential status' to express how people living with dementia can express themselves through body language and emotional reactions. Hydén (2013) believes narratives for people with dementia must be developed as a co-creative activity to promote agency. Therefore, agency is not a personal skill, but rather a construction between body, other persons and relations to places and things. This is elaborated by Ursin and Lotherington (2018), who argue for a collectivist and distributed understanding of agency. This offers a new way of understanding everyday life with dementia and will be used in this article.

Care and dementia

As no real treatment for dementia is available, support mainly consists of care delivered by professionals. Research has therefore primarily focused on providing knowledge about how that care can best be provided and which interventions are most beneficial (Hydén and Antelius, 2017). In dementia studies, care and care work are linked to relational work, which centres on interpersonal relationships between caregivers and care recipients, and regards dyadic relations as a focus for analysis (Wærnes, 1982). Furthermore, Daatland (1983) suggests care can be studied as care systems, arguing for it to be understood as a collective action, depending on different actors, including care recipients themselves. In line with this understanding of care, Mol et al. (2010) argue that care is a natural part of our daily lives. Care is a mode or a way of working that emerges from a specific construction of how actors interact. Care is a particular way of acting – it is practice.

Dementia studies aim to understand citizenship for people with dementia, what it is and how it can be enhanced. Care studies concern the philosophy of care and how to do care work. This article brings care

and citizenship together in everyday life, even though the two are often researched separately (Kröger, 2009). There also seems to be a lack of studies exploring how agency is constructed in relational care practices and the impact this approach has on care work.

This article studies agency as a collective and distributed construction emerging from the interplay of care collectives (Ursin and Lotherington, 2018). Care collectives can be briefly defined as heterogeneous, flexible and changeable networks, the construction of which involves different actors, and when one element changes the whole collective changes (Callon, 2001). This approach invites us to extend the types of activities and actors that are generally considered relevant to care, and have the potential to offer new understandings on how everyday life is shaped as a collective act. Furthermore, the definition of care has an impact on priorities and on which values are applied to decide what and how care should be performed (Førland et al., 2018). This article contributes to the debate concerning how to do care work when citizenship is a value for care.

The aim is to demonstrate what happens to care work when citizenship is brought into being through various care relations. Empirical philosophy (Mol, 2002) is employed as a theoretical approach through engagement with families of younger people living with dementia. The method is explored below, followed by presentation of two values shifts needed in care work to enhance participation and inclusion of people living with dementia. The discussion addresses how to understand knowledge and expert experiences in care work.

Method

This study is a secondary analysis of a project about citizenship and dementia, which was conducted in 2013-18 in three regions in Norway. Unlike the other publication from this project, which focuses on the practice of agency and the distribution of agency in care collectives (Ursin, 2017; Ursin and Lotherington, 2018), and gender struggles to maintain citizenship (Lotherington et al., 2018), this article discusses the values shifts required when citizenship is the goal of care.

The research strategy was to follow families of younger persons with dementia and conduct qualitative interviews with them. A 'younger' person with dementia is defined as an individual diagnosed before the age of 65 years – approximately 5% of people with dementia (Prince et al., 2015). Such persons' family members' lives tend to be closely entwined (Dooley and Hinojosa, 2004), meaning the entire family is affected more deeply than those of older persons (Svanberg et al., 2011). Dialogue with family members enabled the authors to grasp fluctuating everyday realities, as they talked about their actions and relationships, and responses to daily events.

The research design was inspired by 'following the actors' (Latour, 2005, p 179), which means paying attention to how actors are connected with each other and how they interact. This design made it possible to describe and understand how agency is constructed by the interplay between actors. Initially, interviews were conducted with 15 families living with dementia. Based on these interviews, other family members and healthcare professionals were included. Thirteen families were interviewed a second time, approximately one year after the first interview; in two cases, life circumstances made a second interview impossible. This article is based on a total of 54 interviews, all transcribed and anonymised. Data were collected between January 2014 and June 2015. The public healthcare system helped to recruit families from five municipalities in Norway – a strategy chosen to ensure anonymity. Two family members contacted us in response to public information about the study. The Norwegian Centre for Research Data gave ethical approval for this study (35039), which draws on 'ethical mindfulness' throughout the research process (Guillemin and Heggen, 2009).

Qualitative interviews

The interviews were conducted with spouses and children, although in two cases the person living with dementia also participated. The professionals interviewed include: nurses; ward leaders; homecare unit and daycare ward staff; medical office personnel; memory clinic personnel; and members of an ambulant dementia care team.

The interviews were inspired by ethnographic interviewing (Westby, 1990; Westby et al., 2003), which concerns how everyday life is constructed and lived (Smith, 1988; Lister, 2003), and the enactment of participation and inclusion was the epistemic object for the inquiry and the analysis (Knorr-Cetina, 2008). The interviews had a strong focus on materiality, with little or no attention paid to motives and intentions, but kept the enactment of everyday practices at the forefront (Mol, 2002).

Analysis

The analysis can be described as a two-step process of zooming in on individuals and their actions, and zooming out on the interplay within care collectives (Nicolini, 2009). First, all socio-material relations were mapped employing a version of social network analysis (Ursin, 2018). These maps of each family gave a static representation of relations but supported the process of keeping track of the emergence and evolution of care collectives and any new additions to them. The analysis was informed by a combination of maps and paying attention to 'who did what', and how participation was talked about. Second, these actions were analysed to understand any achievements, such as agency (Coffey and Atkinson, 1995). Transcribed interviews, imported for coding into data analysis software [Nvivo 10](#), formed the basis for this step of the analysis. By exploring the interviews and connecting codes to each other, care collectives shaping agency gradually emerged. Citizenship emerged as an effect of relational and invisible work of care collectives, such as flexibility and coordination of tasks and services. These analyses are theoretically inspired by researchers who view care as a practice – as a way of doing certain things (Mol, 2008; Mol et al., 2010). In this article, only two care collectives are deliberated in detail, others are elaborated in articles connected to the project.

Results: two required values shifts

First shift – from patient to citizen

The first value shift concerns when dementia goes from being a case of individual suffering to a public health issue. The World Health Organization (2012) has called dementia a public health priority and recommends that all countries develop national dementia-care plans. In a Norwegian context, such a plan has existed since 2012. A traditional understanding of dementia still dominates this plan, with its concern regarding a lack of resources and function in daily life. This approach defines the 'nature' of dementia and its progress, although it is already known that dementia is enacted in various ways (Moser, 2008). Dementia plans need to move away from a medical model dominated by the disease process. Care from this perspective compensates for lack of ability and function, and professionals have to define and provide care according to such needs. The focus on each individual and their lack of ability turns people living with dementia into passive care receivers and patients, and family members become carers. A consequence is that little emphasis is put on the value of contributing and participating in society.

However, citizenship is all about participating in decisions, choosing between services and treatments (Boyle, 2008; Sørly, 2017) and being recognised as an equal person with agency (Lister, 1997, 2003; Ootes et al., 2013). How participation is conceived and what society perceives to be relevant will vary (Mouffe, 2013). A citizenship approach is less concerned with individual ability and more with the relationship between citizens, whether they are living with dementia or family members of those who are. Citizenship, in this context, is about articulating the different subject positions of social agents (Mouffe, 2013). To address people in institutions as citizens is a way to make them more independent; a citizenship approach towards people living with dementia makes them co-creators of their own everyday lives. Attention is given to the relations that shape agency for people living with dementia, and this approach focuses mainly on relations that shape acts. This leads to a values shift from a lack of ability to focus on resources and agency. Linda's story (Box 1) illustrates this shift.

Box 1: Case study – Linda's story

Linda is a woman with dementia, not yet 60 years old. She was a teacher for many years and most recently deputy headteacher. Two years ago, she was diagnosed with dementia. She lives with her husband and they have three children who live nearby.

After several moves onto different projects at work, she had to quit her job because she was no longer able to teach or supervise others. When she got the diagnosis, she applied for disability benefits because she could no longer to do paid work. However, she was still too healthy to apply for assistance and services in her community.

One day she saw an advertisement about volunteer work. Her daughter helped her to contact the volunteer centre, which welcomed her. As a volunteer, Linda assists others in reading newspapers, preparing meals and serving food, and has been a conversation partner. Linda has a lot of resources and her main challenge is how to get to volunteering appointments at the right time. This is her need.

A values shift from patient to citizen concerns what kind of knowledge guides our understanding of needs in care work. Linda has a lot of resources but in order to do the voluntary work she needs assistance to attend meetings on time. The volunteering work makes everyday life with dementia liveable for her and for other people. A citizenship approach has made Linda an active participant.

This values change could be criticised for being ideological and normative in how reality is interpreted, and as an ideology, citizenship can be accused of being a singular way of knowing that often excludes medical illness and deviant behaviour (Bracken and Thomas, 2001). At the same time, a citizenship approach is not a way to draw on theory regarding what is studied but is instead a way to make possible another way of providing care that allows people living with dementia to be active participants in their own lives and in society. The goal is to realise their full potential and the potential of a community (Lister, 2007). Although there is a risk of identifying all people living with dementia as a homogeneous group to be given equal status to others (Higgs, 1997), a citizenship approach contributes to the discussion of power, power relations and, most of all, the lack of power of those living with dementia.

Second values shift – from personal care to care collectives.

The second shift concerns care as a process. Humans, like animals, need food and security, and bodies need to be washed. The word 'care' is something we all use, and it is enacted in our everyday lives. In dementia care, it is all about daily activity and everyday practices (Sudmann, 2015; Gjernes and Måseide, 2019). Care can be understood as looking after someone or something and providing for needs. It is often connected to the home arena and the private domain. In nursing science, care has been theorised and made part of a philosophical discussion, and it is understood as a skill. Hence, care can be criticised for encouraging passivity and creating dependence. A sociological perspective adds a new dimension and argues that care is something we 'do'. Care can be understood as a way of working (Daatland, 1983), but it is most often associated with social aspects or with relationships between social actors. According to Callon and Law (1995), these are shaped by different kinds of networks containing human and non-human actors that produce certain relations. For people living with dementia, it means that agency is not only connected to their abilities, but to how a network of actors and relations makes it possible to act as a citizen (Ursin and Lotherington, 2018). The example in Box 2 illustrates a care collective and shows that care is a collective activity.

Box 2: Case study – Magne's story

Magne is 57 years old and has recently moved to a nursing home after living at home for five years with a dementia diagnosis. When Magne lived at home, personal assistants accompanied him to concerts and other musical events; he is highly educated and loves music. At the institution, they therapeutically use music to calm anxiety, which works well for Magne because he has trouble sleeping at night. Music has become a way to communicate with Magne because his language is inadequate.

Because he is still young and physically fit, the nursing home arranged for daily walks. Sissel, his wife, provided important information regarding his interest in music. After several meetings between Magne, Sissel, the nurses and the head of the ward, it was agreed that Magne would travel once a week to a friend who is a music teacher. These meetings resulted in the production of a CD for sale. Magne sings clearly, and his words are pronounced correctly. When he listens to musical quizzes his answers are always correct.

Making this happen requires a lot of coordination between the nursing home and the transportation authority. In Norway, people who are not able to use mass transit can apply for a 'TT-card' (transport card) and Sissel applied for this. The municipality chooses how to organise this service. In the case of Magne, it was outsourced to a private company. Trips between the nursing home and the music studio worked well when the same driver came. When other drivers came, chaos often resulted because Magne told the driver to stop or to drive to different locations, and the drivers lacked information and understanding of how to act with persons with dementia.

After several meetings, Sissel finally succeeded in making a special arrangement with the service to send the same driver every time. For this arrangement to work, the family, the ward leader, the duty nurse and the music teacher had to cooperate in specific ways because Magne had to be outside the nursing home and music studio when the taxi arrived and the nurses had to be there when the taxi returned.

This second shift, from care to care collectives, suggests that care is not just an activity for managing dementia, but should be carried out in ways that assist people to realise their potential and their agency. In the case of Magne it became clear that different actors had to cooperate in a specific manner to enable Magne to act as a citizen with the opportunity to use his musical skills and knowledge. The interplay between actors turns them into a care collective. These collectives are performative and create care in many different directions at the same time (Mol, 2008). Such a relational approach to care is less preoccupied with who is doing what, as attention is instead paid to the effect the care collectives have for people living with dementia and their families. With this values shift, care goes from a private or professional activity to one where specific interests and capabilities are developed through constructive and helpful relations. Care, then, becomes a local and specific function with actors cooperating in certain ways. Care work no longer has the intention to develop good relationships but is an activity that can be performed in different ways according to how the actors interact. These interactions can shape recognition, belonging and agency (Ursin, 2017) as well as trust (Carpentier, 2012).

Discussion

The two values shifts described have been elaborated on by following families living with dementia and analysing their everyday lives as a practice using the lens of empirical philosophy. It has been demonstrated that there is a need to change the way we understand the capabilities of people living with dementia when doing care work, and also that specific styles of coordinating relations and actors can result in agency for people living with dementia. This analysis has kept action at the forefront to show the interplay among elements of care collectives, such as care relations, agency and knowledge. The way these collectives are constructed is of importance for participation and inclusion. Zooming out from these values shifts demonstrates that approaches to knowledge and expert experiences are central linkages to enhance the participation and inclusion in society of people living with dementia.

Knowledge about practices

The two cases show that living with dementia requires a lot of work. How people do this, and what kind of knowledge is needed for people living with dementia to become equal citizens is debatable. Some people, notably policymakers and care managers, have ideas concerning what is best for those living with dementia. These tend to reduce everyday life to measurable needs, and services are then

assigned based on those needs. This concerns how we think about knowledge. Needs are often related to the diagnosis or lack of function and are based on observations, score sheets, or direct questions. However, people living with dementia often find it difficult to articulate their needs; instead agency can be expressed by body language and emotional reactions (Kontos and Grigorovich, 2016). Research shows that there are many ways of living well with dementia, but knowledge about how to shape these ways of living seems to be disregarded in the political agenda and less valued in science as well (Pols, 2008). Within healthcare, 'evidence-based' knowledge is dominant, which indicates a process of searching for the best available knowledge. This knowledge is typified by its objectivity and thus can be taken for granted. Within dementia care, evidence-based knowledge is about treatment based on the illness and how to assist the person according to their lack of function (Engedal et al., 2009). This way of understanding knowledge, in combination with an increasing need to control economic and professional resources, leads to specialised services (Seikkula and Arnkil, 2014). These are said to provide high-quality care but also to result in fragmented services that reduce continuity of care (Seikkula and Arnkil, 2014). Thus people living with dementia are categorised to fit the available services. This article suggests a need for more knowledge on how to do care work under conditions where everyday life, rather than the disease, is central to the discussion. And care work should not only concentrate on the relationship between humans, but also include many other elements, like the TT-card, the telephone, work procedures, work descriptions, administrative decisions and exclusive agreements. Care work then is related to how multiple actors and relations perform together.

Expert experiences

In dementia studies, the voice of people living with dementia is highly respected (Hydén and Antelius, 2017). Patients with experience of living with dementia are seen as experts who should be listened to. Unlike clinical experience, which is often considered less reliable due to significant subjective variations, lived experiences become individual claims that are considered important. In other words, if the patient has experienced poor care or care that excludes them from places or things, then that is what happened; lived experiences are used as empirical knowledge (Pols, 2014). To develop lived experiences into knowledge requires these experiences to be processed so that they are transferable from one place to another and from one situation to another (Pols, 2014). Another approach to experience is care as a practice. This approach does not solve the problem of whose experiences to listen to or which are most important (Mol, 2002), but instead looks at how different knowledge is put into practice. A crucial issue is to follow objects, such as care, in practice in order to understand how they are enacted. With the first values shift case study described above, there is a glimpse of how care is practised and that it could have been practised differently if care professionals had not been made aware of Linda's wish to do voluntary work. In practice anything can happen – the question is, what values is care based on.

Shaping knowledge of practices relies on different types of 'expert' knowledge. Instead of observing, the practitioners' actions become the focus of theorising (Mol, 2002). The knowledge that is produced is no longer a set of statements about reality but describes practices that often interact with other practices (Mol, 2002). In the case of Magne, many practices had to interact in order for him to live as a competent musician: taxi arrangements; the music teacher's organisation; the institution's routines; and the spouse's ability to coordinate. In general, when the practice becomes our entrance into the world, ontology is not a monist whole but exists in multiple forms. Objects such as care are enacted from the simple to the complex due to the intricacy of their relations. For Magne, there are many versions of how care work might have happened; for him to become a citizen relies on a certain way of practising dementia. Shaping knowledge of practices means including various voices of experts and exploring how they relate to one another, even if they 'belong' to other disciplines, such as medicine, for example. This way, we might shape good knowledge that does not draw its value from living up to reality, but rather to seek ways of living with the real (Mol, 2002).

Concluding remarks

This article discusses what kind of values should guide care and care work for people living with dementia. It demonstrates two values shifts that are necessary if participation and inclusion are rights to be achieved for people living with dementia. The first shift, from patient to citizen, describes that rather than understanding dementia only as a disease, there should be greater focus on relationships that allow people living with dementia to become active citizens. Additionally, dementia care can be done differently, by changing focus from preoccupations about disabilities towards how to practise dementia. With the second values shift described, this article has demonstrated the need to understand care as a collective entity rather than a person-to-person interaction. This collective approach to care illustrates that in some practices, people with dementia become care recipients, while other practices allow people with dementia to emerge as citizens. These two values shifts underline that we are present with our bodies – we eat, we dance, we forget, we argue, we love, we suffer, we are treated, and we are struggling people who are engaged in relationships with each other. Hence, care work is a way of practising dementia that is connected to how knowledge and experiences are understood. The article has discussed how certain forms of knowledge and expert experiences can realise and preserve participation and inclusion.

When developing future care practices, healthcare professionals and researchers should consider thinking in new ways and creating fresh alternatives to living with dementia. Becoming an active citizen is a result of the relations we are part of. Agency and power are distributed in the ‘hybrid collectif’ that we are a part of at all times (Callon and Law, 1995). To promote citizenship as distributed agency might help to develop new ways of living with dementia and new ways of doing care work. As the article’s title indicates, we need to think in a hybrid manner, which means thinking beyond dichotomies, encouraging the vocalisation of multiple experiences, describing everyday complexity, and being aware of agency as different ways of acting, thinking, feeling, expressing needs and living.

Practical implications

This article highlights that caring for people with dementia needs values shifts toward enhancing agency. Enhancing agency means rethinking how to do care work and what to prioritise. Everyday life, rather than the disease, should be a starting point for how to create good care. There is a need for healthcare professionals to discuss what good everyday life looks like and for whom. In developing new ways of doing care work, an important aim should be to help people living with dementia to maintain relationships, assisting in new activities or/and places that make them active and engaged in their own life and in society. This article proposes that the values chosen for care have an impact on the care work we do.

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