

RESEARCH

Citizenship as Distributed Achievement: Shaping New Conditions for an Everyday Life with Dementia

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Citizenship for people with a disability has become a notable subject within disability studies, but dementia has only sparingly been included in these studies. However, an important international debate on citizenship for people with dementia is emerging, highlighting rights, empowerment, agency, and new socio-political understandings. Yet, even though these studies often entail a relational understanding, they tend to perceive citizenship as allocated statically to individuals. This article contributes to the debate by conceptualizing relational citizenship as the distributed achievements of care-collectives consisting of a complex set of socio-material agents, including the person with dementia and the disease. Rather than adding more knowledge about experiences of dementia, the article develops an understanding of the critical mechanisms producing citizenship for all, and of care-collectives as potential facilitators for such distributed achievements. The results indicate that citizenship is a malleable and precarious enactment that needs continuous nourishment to be maintained, and that localized knowledge about the emergence and development of care-collectives is crucial for this maintenance and, hence, for shaping decent conditions for an everyday life with dementia.

Keywords: dementia; citizenship; distributed achievement; care-collective

Introduction

Enabling people with disabilities to participate as equal citizens in society is a major theme within disability studies (Dwyer, 2010; Houten & Bellemakers, 2002; Kjellberg, 2002), and increasing attention is being devoted to studying citizenship for disabled people (Kjellberg, 2002; Lin, Lin, & Hsu, 2016; Redley, 2009). Citizenship entails membership, participation, belonging, and recognition, and means being able to control one's life and influence one's society (Lister, 2003). Despite international reports on the increasing prevalence and future evolution of dementia (Prince et al., 2015), the condition is rarely included in disability studies (DiZazzo-Miller & Pociask, 2015). To enhance such inclusion, Bartlett and O'Connor (2010) suggest broadening the conceptualizations of both dementia and citizenship. Citizenship for people with dementia promotes a view of people as active agents in their own lives and society, with rights and duties extending beyond healthcare. Bartlett and O'Connor emphasize growth, social position, purpose, participation, community, and freedom from discrimination. Others recognize agency as embodied consciousness (Kontos, 2003), or as alternatively habituated, embodied, or emotional (Boyle, 2014). Yet another body of literature shows that the practice of citizenship is situational, depending on other people (Österholm & Hydén, 2014), places, and materialities (Pols, 2016). Such conceptions of citizenship and dementia have been given more attention lately but are still under-researched and under-theorized (O'Connor & Nedlund, 2016; Österholm & Hydén, 2014). We would add that, even though they employ a relational approach, they continue to conceive of citizenship as a capacity pertaining to the individual, thus neglecting issues of the maintenance of citizenship, which is the problem this article addresses.

Our aim is to demonstrate a possible way to eradicate the individual as the holder of citizenship, and to promote a collectivist and distributed understanding. Leaving citizenship with the collective rather than the individual draws attention to networks of relations, or care-collectives, and what they may accomplish *as networks*. Such an approach might carry the potential to shape new conditions for an everyday life with dementia.

The concept of care is criticized for its understanding of care recipients as passive and dependent (Morris, 2005), but we understand care as 'processual, relational and, critically, world-forming' (Latimer 2013, 37). We draw on research treating care as collective action, and the persons in need of care as active agents (Daatland, 1983). From this perspective, care practices become societal and political processes forming everyday life, not only for the person with dementia but

also for formal and informal carers, and the society in which they reside. Mol (2002) describes this as good practice, and a localized way of being in human-material relations. The emphasis on 'localised being' underscores the reality that care is not one universal phenomenon but is done differently in different everyday situations (Mol, Moser, & Pols, 2010). This move brings care and citizenship together in everyday life, even though the two are often kept apart in disability and citizenship studies (Kröger, 2009).

Our contribution to this debate is an enhancement of the understanding of citizenship as brought into being through the actions of multiple care-relations. To do this, we have employed empirical philosophy (Mol, 2002) as our theoretical approach, and engaged with families of younger people with dementia: We explore the links between multiple care-relations, citizenship, and knowledge, demonstrating how different care-collectives act and produce citizenship differently, and consequently how agency emerges as an effect of care in practice. Our substantiated argument is that citizenship should be understood as an on-going and distributed achievement.

Approach and Methods

Theoretical Approach

This article is an exercise in empirical philosophy, a concept and method originating with Mol (2002) and Law (2009), relating to Actor-Network Theory (ANT), which understands objects as something manipulated in practice (Mol, 2002), as on-going generated effects of the webs of relations within which they are located (Law, 2009). In our case, the object is the dynamic practices of citizenship.

The term *agency*, as used by ANT, has been important for our detachment from prior ideas of what citizenship is for people with dementia. Agency is not seen as a property of individuals but as being achieved and distributed through the membership of networks, where possibilities are attained and released (Law, 2009). Following this line of thought, citizenship becomes an effect of the actions of a complex set of socio-material agents, including the disease, on which all agents depend for achieving citizenship, not only the person with dementia. Hence, a care-collective producing citizenship for all is not scaffolding the younger person with dementia but is enabling mutual empowerment of the younger person with dementia and significant others.

Care-collectives are heterogeneous, malleable, and mutable networks that are shaped by, but also shape, the relations between the socio-material agents that constitute them. The concept of the 'care-collective' is an adaptation of the 'collective patient', encompassing 'patient collectives', 'medical collectives', and 'surgical collectives' (Callon & Rabeharisoa, 1998; Moreira, 2004). A care-collective is not one fixed thing but an effect of specific configurations of certain agents brought together in time and space, shifting along with changes in the relations comprising them. Care-collectives, and each agent, are, therefore, also always networks (Law, 2009). The underlying assumption of the approach is that numerous and intricate connections between people, places, and things are what form society, and in our case care-collectives, thereby shaping the conditions for life (Law, 2009). The distribution of agency through care-collectives might be uneven, shaping empowering conditions for some, whilst creating harmful conditions for others (Moser, 2003). Hence, different care-collectives enact citizenship differently, and it is, therefore, important to attend to these differences if an even distribution, empowerment, and citizenship for all is to be achieved. Our research questions follow from these considerations:

- *How, if at all, do care-collectives facilitate the distribution of agency, and produce citizenship for families living with dementia?*
- *What are the critical mechanisms for the enactment of citizenship for all?*

Research design and ethical considerations

Due to the chosen theoretical approach, our study required a design enabling us to make an account of the socio-material agents forming care-collectives, and the effects of the activated interactions. The strategy for obtaining such knowledge was to follow actors, or agents, in practice (Latour, 2005). We followed family members of younger persons with dementia, and conducted ethnographic interviews with them. The interviews had a strong focus on materiality, and little or no concern with motives and intentions, but kept the enactment of everyday practices at the forefront (Mol, 2002). A 'younger' person with dementia is defined as an individual diagnosed before the age of 65 years; that is, approximately five per cent of all people with dementia (Prince et al., 2015). Because of their age, they have different experiences than older individuals (Roach et al., 2008; Werner, Stein-Shvachman, & Korczy, 2009), as they are often in good physical shape (Roach et al., 2008), are employed, may have children living at home, and are engaged in various activities when diagnosed (Alzheimer's Society, 2016). Their spouses are in similar circumstances (Ulstein, 2009). Family members' lives are closely entangled (Dooley & Hinojosa, 2004), which means that the entire family is more severely afflicted than those of older families (Svanberg, Spector, & Scott, 2011). The dialogue with family members enabled us to grasp fluctuating everyday realities, as they talked about their actions and relations, and reactions activated throughout a day.

With help from the public healthcare system, we recruited families from five municipalities in Norway. This was one strategy to ensure anonymity. Two family members contacted us in response to public information about the study.

When we made the interview appointments with family members, we asked permission to include the younger person with dementia in the study. This was a necessary procedure due to restricted ability to consent on their own behalf. Only two family members were willing to consent on behalf of their spouse, which we conceived of as an act of respect and acknowledgement of an equal. Because there were only two, we found it difficult to ensure anonymity, and decided not to include them in the study. In the end, a total of 15 family members comprising 14 spouses – seven men and seven women – and one daughter, were included. Twelve were interviewed twice, nine to twelve months apart.

We interviewed professionals as well. They were recruited from a pool provided by family members during the interviews. We asked permission to contact the professionals they mentioned, and followed up only when given permission. In this way, we extended the tour on which we were following the family members. Twenty-seven healthcare professionals from auxiliary care, respite care, home care, nursing homes, day-care centres, and provider offices were included.

In total, the study consisted of 54 interviews.

A weakness of our design might be the omission of younger persons with dementia from direct participation in the study. However, they were not our epistemic objects (Knorr-Cetina, 2008), as the aim of the study was to analyse the becoming of citizenship, not to produce knowledge about the experiences of younger persons with dementia. The study was not about them per se but about potential enactments of citizenship in everyday life situations defined as care-collectives. Hence, we do not consider this omission critical. Understanding the emergence and evolution of care-collectives means at the same time finding a way to understand them as potential 'facilitators of voice and agency' (Ashby, 2016: 16); that is, as facilitators of citizenship. Rather than seeking to give voice to someone (Alcoff, 2016; Ashby, 2016), our research process has been driven by the desire to understand the mechanisms producing citizenship.

Even so, recent debates on proxy consent have criticized the practice for being limiting and potentially disempowering for people with dementia who participate in research (Dewing, 2002). The involvement of people with dementia in qualitative research should rather be sought through a 'process consent model' that ensures on-going monitoring of consent (McKeown, Clarke, Ingleton & Repper, 2010). However, such inclusionary consent depends on continuous face-to-face encounters between the researcher and the study participants (Dewing, 2002), and on gatekeepers' willingness (Sherratt, Soteriou & Evans, 2007). In our case, over-protective gatekeepers prohibited direct contact, so the process consent model would require a different study design than the one chosen. Therefore, the omission of younger persons with dementia from direct participation in the study remains a potential weakness.

All participants provided informed consent for study participation and the audio recording of interviews. The first author conducted, recorded, and transcribed the interviews. Unique numbers and letters were assigned to interviewees to preserve anonymity. All names used are fictitious. Norwegian Social Science Data Services approved the study.

The interviews

Depending on family members' preferences, we conducted the interviews at convenient times in their homes, workplaces, or a rented space. We interviewed the professionals at their respective workplaces. The interviews with family members centred on everyday life situations. A typical interview lasted one to two hours, and started out with a question about the actions and features of an ordinary day. If necessary, we followed up with open questions, to elicit more information about what happened, who and what were involved, when and where, and how changes in everyday life had come about. We asked the professionals about their work, who they cooperated with and how, their views about everyday life for younger persons with dementia, the organization and delivery of healthcare services, and how services were initiated and changed. We asked both family members and professionals about the material and social aspects involved in their practices. This enabled an interviewee-researcher co-production of knowledge about what formed the care-collectives (Hilden & Middelthon, 2002).

The analysis

The analysis took advantage of a two-step process of zooming in on individuals and their doings, and zooming out on wider collective and societal connections (Nicolini, 2012).

Firstly, we mapped socio-material relations by employing a version of Social Network Analysis (SNA), but because original SNAs take the social to be fairly definite and devote little attention to space and materiality, we added materiality to these networks (Rabeharisoa, 2006). The maps were static representations of these relations but still helpful in the process of keeping track of the emergence, evolution, and change of different care-collectives. A combination of the maps and our stress on 'who did what', and how participants talked about their actions in the interviews enabled us to analyse the unfolding of four different care-collectives. These were not stable entities but dynamic socio-material configurations that shifted according to changes in the materiality, activity, and competencies enacted. The care-collectives were nothing unless the relations were activated through action (Callon & Law, 1995).

The second step of the analysis was to attend to these actions and analyse accomplishments, such as agency (Coffey and Atkinson, 1996). The transcribed interviews formed the basis for this part of the analysis, as we imported them into Nvivo 10 qualitative data analysis software for coding. The interview guide was helpful in the coding process. We

had asked family members and formal carers about what they did, when, and with whom, and turned the answers they gave about established and new connections between people, institutional practices and material resources into our raw material for analysis. By exploring the raw material generated from individual interviews, and connecting the codes to each other, we gradually recognized the emergence of the four different care-collectives and what they accomplished. This process also enabled us to see how different care-collectives in different situations enacted objects differently, and to understand the precariousness and vulnerability of citizenship when a dementia was one of the agents. Our understanding of citizenship as an effect of the relational and invisible work of care-collectives emerged through these analyses. The next section presents the four different care-collectives, named according to certain enactments.

Results

Care-Collective 1: Establishing a New Normal

'Establishing a new normal' highlights the work being done to maintain everyday life in as normal a form as possible and, hence, to retain citizenship for all. All the families in the study were concerned about the consequences of the labour market not allowing people with dementia to stay in work. Because they could not perform their job as before, and there were no alternative tasks, or they were not offered any, the person in the family with dementia had been forced to stop working. Work as a social and professional arena was, therefore, no longer part of their everyday lives. Nevertheless, many were able to fulfil everyday household tasks (e.g. driving, and shopping for groceries), attend activities (e.g. joining fitness classes), and participate in other meaningful activities (e.g. volunteering). Also other family members did a lot of work to maintain a good everyday life for everyone in the new situation. How to do this could be a challenge, as Mike revealed: 'It's a dilemma all the time, it's an adjustment process, should I act as before, or should I start to operate in new ways and by new paradigms?' (Mike, Spouse, Ph 2.4.).

Mike was a full-time worker who travelled a lot as part of his job. He was married to Linda, who had been diagnosed with dementia one year before we met them. Her employer had made attempts to find suitable alternative tasks for her but none of them were successful. She was still physically fit, and went for daily walks with her dog. Every sixth month she attended the memory clinic to measure the progression of the disease, and evaluate the medication. At one point, the staff at the memory clinic understood something she talked about as having trouble remembering appointments and daily activities. The clinic contacted an occupational therapist to find out about, and test, a technological device that could potentially help her. The device, called MemoryPlanner®, is meant to compensate for the declining ability to remember. Healthcare personnel often suggest this technology as a means to maintain an approximately normal life. However, this was not what Linda had in mind. She had seen an advertisement in the newspaper about the need for voluntary workers in a nursing home, and wanted to join in to be useful and connected to others. Rather than receiving constant reminders about her losses and declines, as the MemoryPlanner® would do, volunteering appeared meaningful to her. Linda successfully contacted the nursing home, and the occupational therapist joined in at the first meeting, because:

I saw that there was a need for someone to coordinate and follow up in order for it to work. If she had gone alone to this first meeting, I believe it would be frustrating, not only on her part but also for the other volunteers. (Professional, Ph 2.4. tj.)

Here, Linda's potential for an active and engaged life was realized through the enactments of the care-collective, in which the occupational therapist was one agent. The care-collective did not attempt to eliminate the effects of the disease, like the MemoryPlanner®, but enabled Linda's resources and capabilities, and helped to develop them further.

The refusal of the MemoryPlanner® was not a denial of Linda's declining memory but a denial of the idea that her memory had to be supported for her to be able to cope in life; that is, the idea that the disease is located in the brain. Her coping in life and mastering of the volunteering did not solely depend on her individual abilities but on what was enacted in the care-collective. For example, the interaction between Mike, Linda, a notebook and a telephone enabled Linda to arrive for her shift at the nursing home on time – every time. Mike and Linda wrote down day and time for the appointments in the notebook, and Mike called her to remind her when to go. This made her confident in what she did. Furthermore, with Linda's consent, the occupational therapist wrote a note in Linda's medical journal that reminded her to regularly call Linda and discuss how she experienced volunteering, and also to call the leader of the voluntary services to make sure that the other volunteers welcomed Linda, and that together they managed the work well. This interaction between Mike, the occupational therapist, Linda, the leader of the volunteering services, the other volunteers, Linda's medical journal, and a telephone enabled successful volunteering, not only for Linda but also for all the others involved.

Mike and Linda's case exemplifies how a new normal is enacted for both. The various socio-material configurations of the care-collective enabled Linda's capabilities, which means that it is not Linda as an individual but Linda as an active agent in a complex socio-material practice that enacts citizenship. Citizenship becomes an effect of interactions distributed in time and space, maintained as long as the activities are repeated.

Care-Collective 2: Assisting in Meaningfulness

Another care-collective emerged with the increasing demands to make life meaningful for the person diagnosed with dementia. Major new agents were public day-care centres. The organized activities included visiting art museums, cafés and pubs, cooking seasonal foods, and hiking. As explained by one day-care organizer: 'We try to use their residual capacity' (Professional, Tdp 2.0.), which indicates a need for assistance to evoke and utilize capabilities and resources. We have called this care-collective 'assisting in meaningfulness' because it develops the performance of such assisting activity.

The day-care activities produced meaningful moments for the younger person with dementia in particular situations; however, they might also have further reach. One example is Kristin, who struggled to find words and keep up a conversation. She was a social person but deterioration of speech had become a barrier for her. However, the day-care centre discovered that walking enhanced communication:

We walk a lot, not only for fresh air, but also for her to find the words. We have experienced that when we walk in a certain rhythm the words come more easily. She often says 'let's walk, let's walk'. And when we stop walking the words stop coming. (Professional, Tdp 2.0)

The walks not only increased Kristin's ability to speak, but were also a way of enabling agency. Through the walks, Kristin became an active agent with desires and wishes. The walking process facilitated talking and staying connected, which may be seen as a form of bodywork not often recognized as part of formal care (Twigg, 2002) that promotes social citizenship (Phinney et al. 2016). In this practice, embodied knowledge guided the work at the day-care centre in ways that enabled Kristin to express herself. In a casual telephone call, a worker at the day-care centre told Eivind, Kristin's husband, about the effects of walking on Kristin's speech. Even though Eivind worked full time, and had a busy schedule, he asked Kristin to walk with him, and from that day on they went for walks together every day. These walks soon became one of the most important activities they shared: 'So, I experience that when she has been out, then she feels better' (Eivind, Spouse, Ph 2.1.). The day-care centre used the embodied knowledge of the walks therapeutically to assist Kristin, but when transferred to the home situation the walks had other important effects on the relationship between Kristin and Eivind. The walks generated moments constituting them as equals, and mutually assisting them in meaningfulness.

A number of socio-material agents were enrolled in this care-collective, allowing the maintenance of connections to society, and retaining or regaining citizenship. Collaboration between family and day-care centre as a new socio-material configuration became an important agent for enabling agency and assisting in meaningfulness. For Kristin and Eivind, this collaboration promoted the ability to stay together and to share some moments of mutual joy. Albeit to different degrees, the walks enabled agency not only for the younger person with dementia but also for her spouse; and the emergent effects of the care-collective may well be understood as citizenship for all.

Care-Collective 3: Coordinating Everyday Relations

A third care-collective, also emerging in a home setting, enrolled an increasing number of healthcare services and healthcare professionals at various times and for various purposes. In accordance with Norwegian dementia care policies, healthcare services are distributed to the homes of persons with dementia to make it possible for them and their families to stay at home and enjoy life together for longer. However, home as a place of joy and happiness changes character with the arrival of new public healthcare agents. It becomes a workplace for professionals, often associated with suffering rather than joy, and a place where all activities must be rigorously organized. We have called this care-collective 'coordinating everyday relations', as it highlights the necessary and continuous work being done to re-establish home as a place where the person with dementia can be recognized as a citizen. Two stories illuminate the kind of necessary work that is being done.

Hege is a full-time shift worker and is married to Jonas, who needs extended help and supervision to live at home. In addition to home-care, Jonas attends a day-care centre and, in situations where communication becomes difficult, writing messages in notebooks becomes a means of communication. The professionals write about activities completed during the day but the notes provide information beyond mere activities. Reading between the lines, Hege understands more about how Jonas is doing during the day; for example, the professionals' understanding of him, their level of training, their calmness, rush or stress when they are with Jonas, or the extent to which they use and integrate the information Hege has given them about Jonas' situation. Hege says: 'Some have been hiking, gone for a drive, been to a café, or gone for a walk round the harbour, whilst others have stayed indoors watching TV, in spite of the nice weather' (Hege, Spouse, Pa 3.2.). The remark 'in spite of the nice weather' hints at Hege's dissatisfaction with the service provided in this instance. The healthcare-dominated care-collective may well provide what is considered to be good care from a healthcare perspective, but from a citizenship perspective such care is in danger of not enacting citizenship – either for the younger person with dementia or for the family members. To do that, the care-collective calls for an extension beyond healthcare, which requires someone's effort and coordination. However, apart from family members, there is no coordinating agency, and there is a lot to coordinate, as Kari – a full-time worker – describes:

There's much to do at times, a lot of coordination and much to organize (but) the most important thing is not to be stressed because that makes him anxious. I, therefore, try to adjust to his speed, even though I am used to a faster pace. I have to find the balance. (Kari, Spouse, Ph 1.1.)

Because ensuring reduced or no stress is key to a good everyday home situation, Jonas' anxiety becomes an active agent in this care-collective. That is, his anxiety plays a role in actions and what is enacted and, as a result, in how home is shaped as a temporarily stable place.

Healthcare services, such as home care, provider offices, and day-care centres are prominent agents in the enactments of the third care-collective but so are friends, notebooks, and, not least, spouses and adult children. The coordination of complex socio-material relations shapes home into a stable and safe place, making it possible for the younger person with dementia to stay at home longer, and to enjoy recognition as a citizen. However, home is not fixed and stable but must be kept together under shifting circumstances through the continuous establishment and re-establishment of heterogeneous relations. All the work that is being done in such processes of enacting citizenship for the younger person with dementia has the potential downside of reducing citizenship for the family carer. Therefore, the third care-collective may fail to enact citizenship for all, as Pernille, whose loved one had recently moved to a nursing home, recalled: 'I felt I was about to lose my life' (Pernille, Spouse, Pi 3.2.).

Care-Collective 4: Disrupting Relations and New Possibilities

A fourth care-collective emerges within institutional care. The transition to institutional care is challenging for both the person with dementia and the spouse, but in different ways. An economic and practical consequence for many family carers is moving to more inexpensive housing, due to having only one income. At the same time, relief from responsibilities at home allows them to reconnect with friends, socialize, and return to full-time employment. To paraphrase Pernille, they may be able to take their lives back. The partner who has moved to an institutional home, on the other hand, must adjust to a new place, new professional carers, and fellow residents with their families. Because of the double-edged nature of this situation, we have called this care-collective 'disrupting relations and new possibilities'.

Many family members talk about a desire to stay connected after the younger person with dementia has moved to an institution. They furnish the room with private items to promote recognition, and adjust their visits to times when they have experienced that the connection between them is optimized. Sissel says:

It's very, very important for me to visit him. It's enjoyable and it makes me happy. ... He gives me positive responses, even though his condition varies, but it's good to be near him. (Sissel, Spouse, Pi 1.1)

Desire should be understood here as a positive and productive force. The desire to stay connected makes spouses aware of embodied knowledge as a way to value their connectedness. Many talk about body language as being the voice of the younger person with dementia. Professionals also try to attend to it, but relatives have greater knowledge of the individual's life history, which makes the interpretation of body language easier. Some family members provide the nursing home with written notes about such factors, whilst others orally inform about routines, embodied expressions, and preferences. However, according to Ole, who is married to a nursing-home resident, such information might be overruled. Because of his wife's restlessness, on one occasion he was called in to a meeting with the ward's head nurse. Ole recalls:

I tried to tell them that a social support person, a wheelchair, and taking her out would help. She wants to get out, because she's used to walking for hours every day. For me, this was not an unusual behaviour. Then, the head nurse says that they must give her something with a sedative effect first and then go for a walk. ... It had adverse effects on her. (Ole, Spouse, Pi 3.1. d.)

Consequently, medication becomes a prominent agent in the care-collective. Although the woman becomes calmer and easier for the nursing-home staff to care for, the husband faces difficulties making connections with her. Thus, two knowledge systems – embodied and biomedical – interact in the care-collective, and in the nursing-home setting biomedical knowledge takes priority. In a biomedical understanding, restlessness and repetitive bodily behaviours are interpreted as expressions of the disease, whilst other interpretations are ignored. It is not that biomedical knowledge has no value; the key point is how negotiations between the two knowledge systems materialize (Moser, 2011), as the following story illustrates.

A younger male nursing-home resident used his mobile phone every day to maintain communication with his wife. He carried the phone in his pocket and, on two occasions, the phone ended up in the laundry. Following each occurrence, the wife provided him with a new phone and, because the phone was important for them to stay in touch, she informed the nursing home that she was willing to take the risk of it happening again. However, when she brought the third phone, a staff member informed her that, from this point onward, the phone would be kept in the staff room, and if she wanted to call him: 'please don't call him on his phone, because we can't hear it ringing' (Professional, Pi

2.1.). From an institutional perspective, the problem was identified as biomedical and located in the resident's damaged brain, and locking up the phone made sense as a precaution against damage and a way of minimizing risk. However, the problem could equally be located in nursing-home routines. Why did they not check pockets before clothes were put in the washing machine? And in any case, from the couple's perspective, staying connected was more important than the cost of replacing a mobile phone.

In this fourth care-collective, the production of citizenship is turned upside-down. Whilst institutional care opens up new possibilities for the family carer, it disrupts relations of agency and citizenship for the younger nursing-home resident. In addition, the spouse's desire to stay connected is followed by a conflict with the nursing home, as biomedical knowledge overrules embodied knowledge. Consequently, agency is denied to both.

Discussion

By following the families of younger people with dementia, and analysing their everyday practices through the lens of empirical philosophy, we have demonstrated how various configurations of socio-material agents produced citizenship differently for the younger person with dementia and the spouse in different situations. In some situations, both were provided with agency, in others one obtained agency at the expense of the other, and in some cases no citizenship effects were produced at all. Throughout the analysis of the emergence and development of the care-collectives, we explored the links between care-relations, citizenship and knowledge, paying attention to what the care-collectives accomplished. Whilst most citizenship studies conceive of agency and citizenship as individual capacities (Boyle, 2014; Kontos, 2003), we have demonstrated that agency and citizenship might instead be understood as collective achievements demanding continuous enactment and re-enactment. We found that care-collectives are socio-material networks of relations that might facilitate the achievement of agency and citizenship. However, to enable citizenship for both people with dementia and their significant others, some critical mechanisms must be pursued. In the process of zooming out from the single care-collectives, we found four such mechanisms.

Invisible work

In order for agency to emerge, a lot of work must be done. The first care-collective took shape in the encounter between the diagnosis and the family, as this encounter brought about changes in the rhythm of everyday life. Family members did a lot of work to shape a supportive environment, not only for the person with dementia, but also for themselves through this process. The work done was critical for the promotion and maintenance of flows in everyday life, but it was invisible, and therefore often not appreciated. In contrast to the professionals' work, which entails identifying needs and categorizing people in order to route them into and through the public healthcare system (Allen 2007), the work of family members does not result in any concrete products or processes. Nevertheless, such invisible work holds the care-collective together, helps to reshape it when needed, and serves the enactment of citizenship. Invisible work is, therefore, a critical mechanism in need of attention. It must be made visible.

Coordinating work

Continuous movement between home, society and healthcare services constituted the formation of all four care-collectives. As new services, professionals and practices were added, a lot of coordinating work was done to stabilize the care-collectives. We saw how this work changed character from one care-collective to another: from the shadowing activity of the occupational therapist, to assisting in finding meaningful activities and, finally, to detailed planning of daily work. In situations of less successful coordination between professional care and the home, the informal carers took responsibility and promoted the enactment of citizenship. Necessary and continuous coordinating work entailed coordination not only between human actors, but also between human and material actors. The story of the first care-collective illustrated how the interplay between a notebook, phone calls and Linda enabled Linda to act as a citizen and, hence, to care for others. In contrast, the mobile phone was withdrawn from the last care-collective, resulting in disruptions of agency for both the person with dementia and the spouse. Hence, because citizenship is achieved, or not, *inter alia* as an effect of continuous coordinating work, we have defined coordinating work as yet another critical mechanism.

Flexibility

A characteristic of all care-collectives was that being respected and treated as a person was possible only when services were made flexible. The first care-collective highlighted how the healthcare services were made flexible by extending their collaboration to organizations normally not part of public care: Cooperating with a voluntary organization enabled the person with dementia (Linda) to use her resources in a meaningful way, which contributed to the joy of others. The second and third care-collectives highlighted the need for flexibility in how services were performed and organized. Thanks to flexible day-care activities, professionals were able to realize that bodywork, such as walking, was able to improve speech, and the capacity to express meaning. In contrast, the fourth care-collective demonstrated how institutional routines made the service less flexible, and how this inflexibility impeded the production of citizenship. Hence, a critical mechanism for care-collectives to produce citizenship is that services are flexible and able to adapt to changes in everyday life.

Shifting between knowledge regimes

The last mechanism entails the ability to shift between knowledge regimes, here an embodied and a biomedical regime. The embodied regime became a prominent actor within the second care-collective, where speech and communication were results of embodied acts, and in the third, where anxiety as embodied acts had to be acted upon to keep home a joyful place for all. The biomedical regime tends to dominate dementia care (Moser, 2011); hence, it is also dominant in care-collectives primarily formed by formal healthcare services, in our case the third and fourth examples. We saw how the biomedical regime shadowed other regimes in the fourth care-collective, and how agency consequently declined for both the person with dementia and the spouse. Instead of promoting and supporting existing resources, the care home acted to disconnect the person with dementia from society. Hence, to enact citizenship for all, the ability to shift between knowledge regimes and detect the timeliness and appropriateness of various regimes is a critical mechanism that care-collectives must pursue.

Conclusion

In this article, we have described what care-collectives facilitating the distribution of agency and citizenship for families living with dementia must accomplish: They must provide for a lot of invisible work and coordinating work, incorporate flexible services, and be able to shift between different appropriate regimes. A fundamental premise for this conclusion was that we allowed for an understanding of citizenship as on-going and distributed achievements of care-collectives. That is, we opened up space for a collectivist and fluid approach. However, the realization of empowering effects for families living with dementia demands an increased awareness of care-collectives and what they may accomplish from researchers as well as practitioners.

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Competing Interests

The authors have no competing interests to declare.

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