

ARTICLE

Configuring possibilities: day programmes for people living with dementia as technologies in practice

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Abstract

There is a need for new imaginaries of care and social health for people living with dementia at home. Day programmes are one 'care in the community' solution that requires further theorisation to ensure that its empirical base can usefully guide policy. In this paper we contribute to theorising day programmes through an ethnographic case study of one woman living with dementia at home using a day programme. We collected data through observations, interviews and artefacts. We observed Peg, whose case story is central in this paper, over 9 months for a total of 61 hours at the day programme, as well as during 16 hours of observation at her home and 2 community outings. We use a material semiotic approach to thinking about the day programme as a health 'technology in practice' to challenge the taken-for-granted ideas of day programmes as neutral, stable, bounded spaces. Peg's case story is illustrative of how a day programme and its scripts come into relation with an arrangement of family care and life at home with dementia. At times the configuration of this arrangement works to provide a sort of stabilising distribution of care and space to allow Peg and her family to go on in the day-to-day life with dementia. At other times the arrangement may create limits to the care made possible. We argue that how we conceptualise and study day programmes and their relations to home and the broader care infrastructure affects the possibilities of care they can enact.

Keywords: community care; day programmes; dementia; ethnography; socio-materiality

Introduction

Current community supports for people living with dementia at home in Canada generally comprise services that have been adapted from other purposes, and so carry with them assumptions from these original intended audiences. Day programmes are one example of a programme built on ideals of 'care in the community' which evolved from their original design for other populations, such as those with mental health issues, to

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secure a niche in community care for people living with dementia in the Western world. Like much 'care in the community', day programmes have significant limitations in their design and evaluation (Dabelko and Balaswamy 2000; Dabelko and Zimmerman 2008; Gaugler 2014; Gaugler and Dykes 2019; Weir and Fouche 2017) as they are typically designed and studied drawing on assumptions that tend to ignore the contested nature of care and the complexities of the social worlds in which they are created and implemented (Ceci et al. 2012; Matheson et al. 2018; Symonds-Brown and Ceci 2022; Symonds-Brown et al. 2021; Twigg and Atkin 1994). Typical evaluation approaches to community programme interventions often attribute linear outcomes to an isolated delivered service, leaving the interactions and relations of the programme with family and broader community infrastructures unexplored (Ceci et al. 2018; Matheson et al. 2018; Twigg and Atkin 1994). Several key day programme researchers have identified a persistent gap in knowledge related to theorising how day programmes work, how they achieve their effects and the types of outcomes possible (Dabelko and Zimmerman 2008; Gaugler 2014; Gaugler and Dykes 2019; Zarit 2018). To ensure that day programmes are a helpful part of 'care in the community' for people living with dementia, a clearer understanding of the processes involved with their organisation and implementation (Gaugler 2014), as well as consideration of the effects of their relations to home and other spaces of everyday life, is needed.

Thinking differently about day programmes and care

In this paper we respond to the need to better understand day programmes and their effects for families by taking Mol's (2002) approach to studying services (like day programmes) as a package of relations that make up the realities in which they are lived. The task then is to work to 'unravel' how these services work well, when they do not and when they might work better. To do this we tell the story of one participant in an ethnographic study of the relations between day programmes and people living with dementia at home (see also Symonds-Brown et al. 2022). Case studies of community care interventions can offer important information about how they are lived in the complexity of everyday life (Paparini et al. 2020). From this perspective, the lived realities of a health-care service are, in fact, the 'central plot' and not the side story of how services work (Greenhalgh and Papoutsi 2018, 2), providing key information as to how to make services as useful as possible to people.

Additionally, we bring a material semiotic approach to thinking about care and its socio-material arrangements. From this perspective, day programmes can be understood as a health technology 'in practice' enacted within and by the relations of home and the broader care infrastructure. Through attention to these relational and material arrangements of care, we show how a day programme can configure the versions of life made possible for a person living with dementia and their family over time. In an effort to stimulate new imaginaries of health and care systems for people living with dementia at home, we argue that the ways in which health interventions are conceptualised and studied matters. These conceptualisations shape what we understand as their effects and possibilities and, more importantly, they offer direction as to what can be improved upon. We begin with a short overview of the theoretical framing that informs

our understanding of health services as technologies 'in practice' and then describe the study and its findings.

Situating day programmes as health technology

The conception of a programme as a technology is less common in health-care research and evaluation than analyses that typically focus on technology as medical devices or information systems (Sandelowski 1999). However, in our analysis we draw on a broader definition of health technologies that is inclusive of 'physical objects, procedures, social interventions, and health care systems' (Timmermans and Kaufman 2020, 584). In these terms, health technologies have in common that they all involve strategies 'developed to solve a health problem and improve quality of life' (World Health Organization n.d., para. 1). Health technologies are enacted to produce societal transformations, largely through their ability to question or establish new social relationships and to stabilise certain orderings of everyday life according to their particular and embedded rationales (Schillmeier and Domenech 2010).

Embedded rationales are apparent in ideas of care in the community for people living with dementia, as well as in the strategies intended to support care at home. These rationales involve particular ideas, and ideals, about individuals, community, care, dementia and space. For both individuals and formal providers, strategies to provide care are designed based on representations of what 'could be'. Within these strategies, particular ideas of care are made manifest and work to both organise and produce relations between materially distinct elements, such as the people involved and the tasks and spaces of care (Law and Mol 1995). These ideas are material in that they connect to ways of doing things with particular actions and/or materials, and they are held together through organising activities like strategies (Cooper and Law 1995, 245), which often materialise as interventions in the form of health technologies. In these terms, day programmes can be understood as a health technology offering 'care in the community' for people living with dementia at home. However, health technologies such as day programmes do not simply exist on their own. Rather, they are built into existing care infrastructure, the sort of relations or 'tracks' on which formal care in the community runs, creating paths and movement through a configured system that classifies and channels people into particular care settings (Star 1990; Symonds-Brown et al. 2022). Within these infrastructures, assemblages of overlapping and entangling technologies, people, materials and objects, and their logics connect and interfere with each other as they work out terms of connection and flow (Farias and Blok 2016; Langstrup 2013; van Pijkeren et al. 2021).

Material semiotics of 'technology in practice'

With origins in Science and Technology Studies (STS), material semiotics is a sensitising tool based on a relational worldview that works to draw attention to the heterogenous, relational and uncertain social and material practices that make up our world (Law and Singleton 2013). This is a useful approach from which to consider health technologies and their effects. Instead of assuming that phenomena like technologies and their related infrastructures are stable entities, an analysis informed

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by material semiotics assumes that technologies are social-material accomplishments achieved by a variety of actors, both human and non-human, coming into relation in a particular way within specific practices. The effects of a technology, then, are not only technology-centred (technical determinism), with users positioned as merely passive recipients; nor are technologies passive objects shaped only by human ideas/actions (social essentialism). Instead, from a material semiotic view, technologies and people/users are mutually defined and defining through recursive relations enacted within particular configurations. This understanding of 'technology in practice' situates what health technologies do and how they work in heterogeneous relations with other people, things and spaces as an open empirical question (Timmermans and Berg 2003), which can be investigated by examining 'the way in which they [technologies] build, maintain, and stabilize a structure of links between diverse actants' (Akrich 1992, 206). Understanding any technology, then, requires observations of both the technical and the social or, as Akrich (1992) explains, moving from the established 'inside' to the 'outside' of a technology, looking for the relations it brings together, how it is adapted and used, and paying attention to the negotiations and breakdowns that

To summarise, from this technology-in-practice approach, understanding how day programmes work as care in the community requires paying attention to how day programmes relationally materialise in and with a broader infrastructure of care in the community and specific family arrangements, how they are used and how this use is negotiated, as well as when there are points of potential breakdown. The effects of such technologies may include new subjectivities, forms of agency and relations with space. As Callon (2008) suggests, configurations with technology can act as 'agencements' to make particular kinds of action and ways of being an 'individual subject' possible. The template of who an individual 'is' can be built into technologies in a way that affects the configuration of the arrangement and distributes agency in particular ways (Callon 2008). Because arrangements involve tentative and fluid entanglements over time, so do their configuring effects (Gan and Tsing 2018). Thus, in planning the study described here, we assumed that in a life with dementia at home over time, the day programme would emerge with family care arrangements in family-specific ways, enacting both possibilities and limits for care. It is these configurations of arrangements and their effects that we explore in this paper through an examination of the case of one study participant - Peg - an 87-year-old recently widowed woman who was living with dementia at home and attending a day programme.

The study

Peg was one participant 'case' in a larger ethnographic study examining how day programmes work as care in the community for people living with dementia and their families. The study was centred on two key objectives. The first was to explore the ways in which day programmes affected the everyday life of people living with dementia at home and their families, and the second was to understand how day programme care practices related to other formal and family care practices for people living with dementia at home.

Methods

In an effort to move 'inside and outside' the health-care technology of a day programme to see the relations between the day programme, home and the broader community, we used a multi-sited ethnographic approach to follow four people living with dementia across the time and spaces of the day programme and their everyday life at home. We recruited through flyers sent out by two day programmes to their participants. We also recruited through dementia caregiver support groups located in close proximity to the different programmes. We collected data using traditional ethnographic methods of observation, interview and document analysis (Hammersley and Atkinson 2019). Author 1 completed all the data collection. Participant observation at two day programmes in a mid-sized Canadian city was undertaken for one to six hours/week for nine months. This observation involved being part of group activities, meals, care planning meetings, outings and staff meetings. Informal interviewing of those present during these activities was done to explore multiple accounts of what was going on at the time. Data collection also involved observation during home/community visits. Home visits involved informal interviewing, observing daily routines or visits from other care providers, and taking part in the activities of the home or community outings. Peg, whose case story is central in this paper, was observed over a period of 9 months for a total of 61 hours at the day programme, as well as during 16 hours of observation at her home and 2 community outings. Observation notes were kept in a field notebook then transferred into longer electronic field notes soon after each visit.

Semi-structured interviews with families at the beginning of the study were undertaken to gather an overview of family member roles, care routines and history of using the day programme and other supports. In addition, semi-structured interviews with four key informants were completed towards the end of the study. These informants included a dementia care policy planner, a regional manager and two programme managers. Information gathered in these interviews was related to the formal systems account of the organisation and allocation of day programme services for people with dementia. Interviews were done in person and online, lasted 45-60 minutes and were audio-recorded and transcribed. Document analysis included day programme and community care policies, programming guides, family information letters, behaviour tracking, participant care plans and documented communications with family, homecare and family doctors. Document analysis notes were included in electronic field notes. Photos of materials at the programme, such as signs and public notices, were also included in the field notes. The study was approved by the Health Research Ethics Board at the University of Alberta and all participants and guardians consented to be part of the study. In this paper, pseudonyms are used for all participants and identifying data (i.e. related to programme name and locations) has been anonymised.

Analysis

As is typical with ethnography, analysis was undertaken in an ongoing and iterative way during fieldwork. Attention was focused on reading field notes and then making analysis notes describing the relations between materials and the activities of the participants and staff, and their accounts of what they were doing or trying to accomplish. This would often lead to following particular practices further in the next

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field visit to understand the relations that supported them (i.e. focusing observations on certain routines, paperwork trails, procedures and informal interviews with staff or families). At the end of the fieldwork, all the field notes, transcribed interviews and photos were compiled into a single text document organised by participant and programme and then re-read closely alongside theoretical readings about care practices, infrastructure and organisational theory. During these close readings, open coding was done across each participant case to identify themes in their accounts, and how materials and relations came into being and changed across time and space. This was followed by tracing and comparison of materials and relations across cases. Following STS traditions, thick, descriptive, empirical case studies were created to 'articulate and rework theory' (Law 2008, 628). A central point of analysis in the case studies concerned the ways in which participant family care arrangements were adjusted and configured over time in relation to, and with, the day programmes. In each case study, the day programme emerged in specific relations and yet some common relations between day programme, home and broader community infrastructure were present in each case. Peg's case story is one empirical example of 'working through' theory to show the day programme as a technology in practice and the configuring effects that emerge in specific relations over time.

Introducing Peg and the programme

Peg, who labelled herself an 'old Saskatchewan farm girl', a 'nurse' and a 'mom', had four children, two of whom lived nearby. At the time she was enrolled in the study, Peg had been experiencing symptoms of dementia for about three years and had been attending a day programme twice a week for one year. The programme was located in a hospital outpatient building and included a large programme for 20 older adults with medical rehabilitation needs and a smaller programme (the Oak room) for 8 people diagnosed with cognitive impairment.

Peg begins the programme

Peg begins the programme shortly after her husband dies, as the family looks for a way to keep her living at home and socially engaged. Peg's sons say that their biggest concern was their mother's isolation and seeing her 'just sitting in her chair'. The sons originally thought about moving Peg into a supportive living setting, but realised that if she was going to be sitting in a chair looking out of a window, 'it should be her window and her tree she was looking at'. At first they try homecare, but the family finds the limited task-oriented services do little to meet Peg's social interaction needs. The family hires a live-in caregiver, Gwen, so that someone is home with Peg most of the time and then, a little later, a place at a day programme becomes available.

Ron: So, I think that was what it was, just to get her out, and the social aspect. You know, being with people your age and your experiences and just to get you out doing something ... you know, you ... you are a social person, you like to be chatty, and she is a lot of fun and

Bob: Yes, just the social element is ... you got to get out of the house and not be sitting there every day ... right? (Family Interview, 15 August 2019)

Ron and Bob made efforts to keep Peg at home and found ways to support Peg in maintaining attachments that are both social and material. It is to this arrangement of people, places, materials, values and attachments that the day programme is added. López Gómez (2015) offers arrangements as a useful ecological and symmetrical tool for showing the diversity and precarity of how lives are configured and practiced in relation with health technologies. In his study on telecare services for older adults, López Gómez (2015) found that the effects of reconfiguring arrangements are often overlooked when new forms of care technology are added into already existing routines. These effects included new subjectivities, forms of agency and relations with space. In Peg's case, the day programme begins as part of a new arrangement of 'home' (Ceci et al. 2020). Much of the day programme evaluation research excludes consideration of the home space as a site of day programme effects, but it is clear that in Peg's case the day programme is brought in to help arrange and stabilise a home. The day programme along with the materials of the house, the neighborhood and the family work together to enact a place that grounds who Peg is, and who and what she is connected to, These relations secure the attachments between the people, places and identities of Peg that are familiar to her and her family. Attachments, as Hennion (2017) explains, are 'our ways of both making and being made by the relationships and the objects that hold us together' (118).

Returning to Callon's (2008) conceptualisation of 'agencements', including the ways subjectivities may be actively configured in relations with technology, Peg achieves a certain 'fit' at the day programme. At the day programme, Peg is engaged with cognitive stimulation activities such as word puzzles and socialising activities such as games. She is verbal, intelligent and physically active, essentially the trifecta of abilities required for 'successful' engagement in the programme activities. Each day she attends, Peg is situated at a small table in relation to other patients; their commonalities are encouraged and provoked by staff discussion; and opportunities for engagement are structured through rituals like morning coffee, game activities and meals. She is encouraged to 'go for a walk' several times a day around the halls of the programme site, which are lined with pictures of local scenes and art that stimulate conversation amongst Peg and the other people. The staff frequently draw on Peg's identities and attachments in conversations and activities, referring to her nursing background, her kids and her love of horses. Her relaxed, friendly relations with the staff and other group members are obvious.

The practices of the programme extend to Peg's family as well. Some day programme activities are oriented towards building a local community with the participants that includes common goals like preparing for craft and plant sales and going on outings beyond the programme's walls, as well as activities such as teas and fundraisers that draw families into the programme. Through these family teas, bake sales and visits during pick-up and drop-off, Peg's family's attachment to the place and the people of the programme solidify the programme's relations within the family arrangements. For the family, these relations maintain Peg as a humorous and socially engaged woman. This is the Peg who is familiar to them and is one of the first things they tell [Author 1] about the programme. Peg's son Ron says: 'She gets out with people, there is a couple of old ladies, and my brother says that she is as smart as a whip out there ... they take jabs at each other and ... mom usually wins those arguments, I think ... with what is

her name? [refers to staff member at day programme]' (Family Interview, 15 August 2019).

Peg is asked what she likes about the programme and she responds, after being reminded of what the day programme is: 'Just the fellowship of other people ... I think that is probably what it is. Because I don't really feel that I am one of them ... well, I guess I am. I can't explain it. I belong there, but I don't, I don't belong there. Does that make a lot of sense?' (Field notes, 15 August 2019). Interestingly, from this comment it seems these arrangements may be enacting Peg to others and only vaguely to herself – she both belongs and does not belong, she is not quite sure. Peg notes the fellowship with people she is arranged with in the programme, and yet the details of these relations are vague to her when she is not in the space. Through the arrangements, however, certain realities are made possible. Peg has a place she belongs to outside of the home. She is enacted as an active subject, recognisable to her family as the social person she has always been. While her former attachments have decreased with the loss of her husband and her changes in memory, the day programme works to stabilise her in 'her chair at her window', within a new network of attachments that enable her to act and choose her level of participation.

Peg and the 'scripts' of the programme

But adding a technology like day programme support into the arrangement is not simply a 'plug and play' type phenomenon. Day programmes are not neutral or static entities; there are scripts embedded in the programme that come into relation with the arrangement's people and places with configuring effects. Any technology is designed with ideas of who the user will be and what it will be used for (Rose and Blume 2003). These assumptions are 'scripted' into the design and shape, affecting both how users come into relation with the technology as well as the relations that are generated through its use (Akrich 1992; Oudshoorn et al. 2016; Rose and Blume 2003). Besides positioning Peg as an active person with dementia, the programme care practices also work to circumscribe her in a particular role: Peg is a care receiver, not a caregiver. This is a sort of morality built into the programme, prescribing the roles of staff and clients and their capabilities (Akrich and Latour 1992). The division of roles becomes noticeable during participant observation when a new group member attends the exercise group and sits next to Peg:

The Oak room is set up for exercise group with the chairs arranged in a circle; small hand weights are at the base of each chair. Everyone comes in and takes a seat. The staff turn on the '80s music and exercise begins with arm movement. Around the circle everyone but the new woman participates Peg is smiling at times, looking at others, and she is focused on the movements. The new woman is talking to herself and not moving. About halfway through the session Peg is looking at the new woman and seeming concerned, while another woman (Kay) in the group has now started to also prompt the new woman to move her arms. It looks like this person's non-participation is a concern or a distraction to the group, but staff continue on with no intervention. Peg and Kay look at the group leader pointedly, then shift their gazes back to the new woman (Field notes, 9 August 2019).

Later, staff are asked about the new woman and how they support people's transition to the programme. The staff say that it takes time but with this new woman, the issue is that the other patients are babying her, and that last week they had to tell Peg and Kay to stop trying to help her so much.

Since the programme is designed around a script of older people needing assistance, there is no room for mutual aide between group members. Instead, such efforts to help are framed by staff as a sort of interference in the operations of the programme. Here the configuration has a disciplining effect (Callon 2008), narrowing the subject positions available – programme participants are to be helped, not to help. Interestingly, it is the identity of 'an old nurse' that is often drawn on by staff in their reminiscing conversations with Peg, one that at times challenges the arrangement of roles scripted into the programme. But as Akrich and Latour (1992) also point out, the scripts of technologies are not deterministic; they may be inscribed but can be de-inscripted by the actor's resistance. So when Peg enacts this 'nurse self' of hers, she is redirected. Peg resists, and conflict ensues.

During a reminiscence discussion, the staff calls on a patient (Alice) to answer a question about a favourite birthday, but another patient, Susan, answers instead. Staff Gina says, 'Wait, it's not your turn; it's Alice's turn.' At this point, Peg speaks up and says to Staff Gina sharply, 'Don't yell at my friend!'

Later at lunch, Staff Gina tells First Author that Peg is always trying to 'nurse other patients'. I joke that old nurses never stop working, and she laughs and says, 'Yeah, and when I tell her to stop babying the other patients, she bites my head off!' (Field notes, 16 October 2019)

Through resistance to the one-way caring script, Peg maintains her identity as an 'old nurse' and a person who cares for others. As Peg reflects in her earlier statement, 'I belong there but I don't belong there'; some of her selves are included and others require work from her to maintain.

Looking 'outside' the programme

At home the family uses the day programme as a sort of anchor. They build other supports around it, finding other pieces of care to spread out and support the times away from the programme. The day programme's script of supervised space extends beyond the walls of the programme and acts as a guide to the family as they look for similar activities on the other days of the week. They tinker with the arrangement, adding a yoga class (with great disdain from Peg), then an exercise class is trialled along with weekly trips to the mall with her caregiver. As Akrich (1992) notes, technologies can 'generate and naturalize' (207) how we think about people and the world. The day programme's effect on organising people and space beyond the programme walls is evident in Peg's daughter's (Sue) account of the challenge of trying to structure the week for Peg and the lack of suitable spaces for her:

'The week is kind of unbalanced with Monday and Tuesday having nothing to do ... so I wish the day programme was on Mondays too.' When asked if Peg has

ever gone to anything at the local seniors' centre, she says, 'I don't think so ... but do they have anything for people with dementia there?'

Sue says that she would love to get her mom involved with something else but reiterates again that 'there are few places for people with dementia'. First Author asks if that is necessary for Peg. Sue says that it's just that with programmes geared for dementia, like the day programme, 'they [the day programmes] know what they are getting' (Field notes, 9 January 2019).

Peg's daughter's comment suggests that there is a classifying effect of the day programme that works to define Peg and her world. Peg is enacted as a socially active person and also as a person with dementia who requires a certain kind of space where the inconveniences of her condition can be accommodated. As Moser (2005) notes, this idea of active agency is both a common feature and a bug of normalising orderings that guide interventions for people with disabilities. From the policy level to the practice level, there is a promotion of supports that can enact a person with dementia in these presumed 'normal', active ways - that is, as an independent and engaged senior with dementia. Moser (2006) explains that this 'order of normal' (374) is, in fact, limiting for people with disability in that it promotes a norm of a subject who is centred and independent, and ignores the actual distributed nature of agency as an achievement of many things working together - a view of agency that applies to most, if not all, of us. Through this normalising view, the web of supports seen as needed for Peg to achieve 'normal' activity seems somewhat insurmountable to her daughter, and to be found only in specific and restricted locales that work to limit Peg from accessing other less contained and containing spaces. That is, as independence as an individual achievement is posited as the norm, a division is established and enacted between the perceived safe inside and the risky outside of the programme. This inside and outside of the programme is further enacted in day programme practices that have configuring effects of dividing home and programme in particular ways.

Infrastructural arrangements of the day programme and the spatialisation of care

The day programme, while part of Peg's home arrangements, is also part of a distal infrastructure of care (World Health Organization 2018). Within this infrastructure, the day programme is arranged into relation with and apart from other formal care structures such as home care, primary care acute and long-term care. This arrangement leads to the formalisation of step-wise increments of care and an established sequence of how services can connect or not. People move into and out of the day programme from these sites, shaping the technology of the day programme as a sort of intermediator on the paths created by a formal system that is oriented to what could be called 'continuity of care' (World Health Organization 2018). Gubrium (1990) notes that formal care systems are often designed in discrete service units that divide parts of the care trajectory that each service is responsible for. While this separation may be useful for defining specific mandates, the needs of everyday life with dementia rarely line up in the same linear, discrete way (Ceci et al. 2018; Gubrium 1990). In the case of

Peg, it is these arrangements of inside–outside the programme that had serious effects when she experienced a change in health status.

Changing status and the limits of arrangements

Autumn comes, and First Author continues to follow Peg at the programme weekly and at home monthly. Peg's gait becomes a little unsteady and she frequently tips sideways when she is standing up from a chair. She refuses to use a walker or cane. Staff also report that they see Peg becoming less active in games and more irritable with them at times. They say, 'She is really going downhill with her memory.'

At home, Peg's family have also noted some of the changes in Peg's functioning, and decide that they need to have more help. They hire a regular weekend person to cover Gwen's [Peg's live-in carer] days off. Thanksgiving comes, and Peg's 'out-of-town' son Mike comes for a three-week stay. He says he has noticed during this trip back that Peg's memory has worsened and she seems to be more suspicious and irritable in conversations. He is wondering if there are medications to help stop his mom's decline in functioning. He has not asked the day programme staff. He says he did drop his mom off on Friday at the programme and said 'Hi to the ladies', but didn't mention it to them (Field notes, 14 October 2019).

It seems that somehow, while the family appreciates the programme's social activities and relations, they don't seem to think of the staff there as a source of feedback or information about Peg's health or functioning. Communication home from the programme involves an activity calendar of planned events but no information about staff's concerns about Peg's obvious decline. Staff frequently account for this limiting information to families as a way to protect caregivers from spending time and energy on the person with dementia, revealing the day programme's strategy of respite as creating space between 'carer' and 'cared for'. This divide between programme and home is an effect of the design of the programme, something not only embedded in its practices but also reinforced in how interactions with it are conceived of and evaluated (Akrich 1992).

Two weeks later, Peg has become increasingly confused, and one afternoon at the programme, First Author notices her using the bathroom every 20 minutes. During craft time, Peg is distracted by a few coloured sprinkles on the floor. She is not her usual self. The staff notice this as well and say they could arrange for a urine test to be done there, but the nurse is only part-time, so they will not get to this matter until Monday. The staff work to connect with the family doctor and the family, but the material communication paths are clunky, and the feedback loops are not predictable. Several phone calls are made and voice mails are left, and finally, a week later, a urine sample is collected at the programme and sent to the lab. There it is processed, and results are sent to the ordering physician's office and placed in Peg's chart there. The nurse at the programme can see the results on the electronic health record and assumes that the doctor has prescribed treatment, but because the typical trigger for the test was not an office visit, the results are not communicated by the physician's office to the family. As such, the delirium related to Peg's confirmed but not acted upon, so the urinary tract infection continues, and Peg's functioning continues to decline. Over a month later, during a holiday gathering, the family notes that her declining condition seems to be more

than dementia, and she is brought to the doctor for another urine test and then, finally, a diagnosis of an infection is made, and treatment is started.

As Twigg and Atkin (1994) noted many years ago, evaluation of day programmes is literally bounded by the walls of the programme, making the extensions of its effects hard to consider. In Peg's programme chart, for example, there were copies of letters sent to her family physician and to home care, a sort of extension made from the day programme as an attempt to connect or insert into the web of care services around Peg. But in practice, staff reported, despite these letters, they rarely received information from home care or the family doctor: 'It's really only one-way.' There was no feedback involved in the arrangement. With Peg's delirium, the demands for communication between home and the programme exceeded the usual scripts, and the bounded nature of the programme was challenged.

Despite the common goals of the care infrastructure, connections attempted between actors are not always the most efficient at addressing the issue at hand, pointing to the boundaries between parts of the arrangement, and the organising work going on to maintain these spaces as separate. Responsibilities are distributed among the various health technologies, and since the day programme is a respite solution, not a medical one, medical concerns must be referred elsewhere. So while the technology of the day programme includes practices of monitoring Peg and her body, and material forms of connection such as nurses, fax machines, voicemails and electronic health records, the local practices travel slowly, and only at certain thresholds of perceived risk, to other areas of the care infrastructure.

While separateness from the home is part of the day programme's design for respite, it also creates conflict and work for staff. For example, when the staff hear of the delay in Peg's treatment, they say that they wish they knew more about Peg's changes at home as they recognise their impact on the programme. The recreational therapist says, 'This is the part that is frustrating sometimes as we don't have a good picture of what's going on; like it would be good to know if she's tired 'cause maybe she's been up or not feeling well.' First Author asks the recreational therapist how she thinks the programme sets up families to know when and what to share about their family member's condition. The recreational therapist explains, 'Well, when they come for their first day, we tell the family to let us know about any changes in attendance and we give them this sheet of paper.' However, the information sheet she points to primarily provides information about attendance rules and does not include any information about when to call. When this is pointed out to her, she takes a closer look and says, 'You're right, it doesn't' (Field notes, 15 January 2019).

Good passages, bad passages

Recognising the day programme as a technology in practice within a larger care infrastructure allows for a different account of when 'things go wrong' beyond one centred on staff knowledge or attitudes. Instead, despite the good intentions of all the actors, the design and the relational connections of the technology determine its limits (Poland et al. 2005).

Moser and Law's (1999) ideas of good and bad passages are relevant in this situation. Moser and Law point out that the character of the materials that enable 'passages'

between heterogeneous networks enacts people's dis/ability. Good passages are about the ability to move easily between specificities, and bad passages lead to 'awkward displacements' that impair or stop the movement (Moser and Law 1999, 205). The arrangements of the day programme and its related care infrastructure create both good and bad passages for Peg as she attempts to move with a continuous biography between her home, the community and the programme. At times the arrangements enable Peg to spend a day out sipping coffee, playing crosswords and bingo with people she feels connected to. Other days Peg moves from home to the programme, and her subjectivities and attachments are not supported; she is limited in who she can be and what she can do. It's perhaps not a terrible passage, but it is not as good. For example, classified as a person living with dementia and thus a care receiver, she is not able to continue her lifelong role of being a care giver.

Much of the time, the arrangements that support her in these passages remain invisible and are difficult to account for within the 'bounded' explanation of day programme space. Later, with the changes in Peg's body, with her urinary tract infection and delirium, her specificities change, and the configured arrangements aren't enough to accommodate her physically or cognitively. The practices oriented to maintaining the programme as a separate space result in limited connections to other parts of the care infrastructure, making the adjustments needed to enable a smoother passage for Peg difficult. The day programme's relations within the larger care infrastructure both enable certain parts of its classifying and standardizing technology and limit its ability to accommodate specificity not already inscribed. Peg's cognitive and physical changes shifted her out of the standard specificities inscribed in the programme. A certain helplessness emerges, and gaps appear between the care she needs and the care that is available. Discussion begins at home and the programme about 'placement'.

Conclusion

Thinking about a day programme for people living with dementia and their families as a health 'technology in practice' offers an opportunity to see the variety of social and material actors involved and the extension of their relations beyond the walls of a day programme. It also challenges taken-for-granted ideas of day programmes as neutral, stable, bounded spaces, and offers the potential for new insights into what day programmes are and how they work.

López Gómez (2015) explains that paying attention to existing arrangements of care is critical when adding in new care resources and ensuring that 'help' is actually helpful. These arrangements are not static; they are fluid and shift over time and place, configuring people, relations and places as they go. At times, the arrangement of day programme care and family care can provide a sort of stabilising distribution of care and space to allow people to go on in day-to-day life with dementia; at other times, the arrangement may create limits to the care made possible and add to care work. Rather than simple math, adding services like day programmes to family arrangements is more than a quantitative increase in support: there are configuring effects that require ongoing evaluation and tinkering to ensure that the resources added are helpful.

In health and social care policy, day programmes are positioned as a contained version of the community operating as a satellite of the health-care system. Within

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this positioning, their situatedness within the broader care infrastructure is often not attended to. As a result, the limitations and possibilities of day programmes and their role in working out a good life with dementia in the community are neglected. A more intentional connection to the broader infrastructures that they articulate with is needed. Moving beyond programme walls to evaluate effects as they travel (or not) might help account for the challenges that staff at day programmes consistently deal with in their attempts to provide good care within truncated networks.

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References

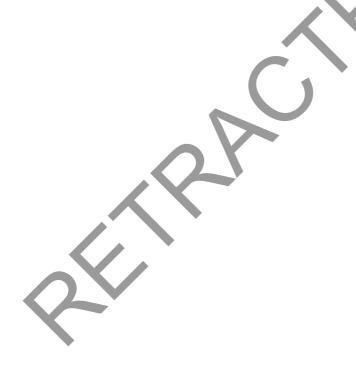
- Akrich M (1992) Description of technical objects. In Bijker WE and Law J (eds), Shaping Technology-Building Society: Studies in Sociotechnical Change. Cambridge, MA: MIT Press, 205–224.
- Akrich M and Latour B (1992) A summary of a convenient vocabulary for the semiotics of human and nonhuman assemblies. In Bijker WE and Law J (eds), Shaping Technology-Building Society: Studies in Sociotechnical Change. Cambridge, MA: MIT Press, 259–264.
- Callon M (2008) Economic markets and the rise of interactive agencements: From prosthetic agencies to habilitated agencies. In Pinch T and Swedberg R (eds), Living in a Material World: Economic Sociology Meets Science and Technology Studies. Cambridge, MA: MIT Press, 29–56.
- Ceci C, Björnsdóttir K and Purkis ME (2012) Introduction: Home, care, practice Changing perspectives on care at home for older people. In Ceci C, Björnsdóttir K and Purkis ME (eds), *Perspectives on Care at Home for Older People*. New York: Routledge, 1–19.
- Ceci C, Moser I and Pols J (2020) The shifting arrangements we call home. In Pasveer B, Synnes O and Moser I (eds), Ways of Home Making in Care for Later Life. Singapore: Palgrave Macmillan, 293–312.
- Ceci C, Symonds Brown H and Purkis ME (2018) Seeing the collective: Family arrangements for care at home for older people with dementia. *Ageing & Society* **39**, 1200–1218. https://doi.org/10.1017/s0144686x17001477.
- Cooper R and Law J (1995) Organization: Distal and proximal views. Research in the Sociology of Organizations 13, 237-274.
- Dabelko H and Balaswamy S (2000) Use of adult day services and home health care services by older adults: A comparative analysis. Home Health Care Services Quarterly 18(3), 65–79. https://doi.org/10.1300/j027v18n03_04.
- Dabelko HI and Zimmerman JA (2008) Outcomes of adult day services for participants: A conceptual model. *Journal of Applied Gerontology* 27(1), 78–92. https://doi.org/10.1177/0733464807307338.
- Farias I and Blok A (2016) Introducing urban cosmopolitics: Multiplicity and the search for the common world. In Blok A and Farias I (eds), *Urban Cosmopolitics: Agencements, Assemblies, Atmospheres.* New York: Routledge, 1–22.
- **Gan E and Tsing A** (2018) How things hold: A diagram of coordination in a satoyama forest. *Social Analysis* **62**(4), 102–145. https://doi.org/10.3167/sa.2018.620406.
- Gaugler JE (2014) The process of adult day service use. Geriatric Nursing 35(1), 47–54. https://doi.org/10.1016/j.gerinurse.2013.10.009.
- Gaugler JE and Dykes K (2019) Assessing mechanisms of benefit in adult day programs: The adult day services process and use measures. *Aging and Mental Health* 23(9), 1180–1191. https://doi.org/10.1080/13607863.2018.1481931.
- Greenhalgh T and Papoutsi C (2018) Studying complexity in health services research: Desperately seeking an overdue paradigm shift. BMC (BioMed Central) Medicine 16, 95. https://doi.org/10.1186/s12916-018-1089-4.

- **Gubrium JF** (1990) *The Mosaic of Care: Frail Elderly and Their Families in the Real World.* New York: Springer. **Hammersley M and Atkinson P** (2019) *Ethnography: Principles in Practice*, 4th edn. New York: Routledge.
- Hennion A (2017) Attachments, you say? ... How a concept collectively emerges in one research group. Journal of Cultural Economy 10(1), 112–121. https://doi.org/10.1080/17530350.2016.1260629.
- Langstrup H (2013) Chronic care infrastructures and the home. Sociology of Health and Illness 35(7), 1008–1022. https://doi.org/10.1111/1467-9566.12013.
- Law J (2008) On sociology and STS. Sociological Review 56(4), 623–649. https://doi.org/10.1111/j.1467-954x.2008.00808.x.
- Law J and Mol A (1995) Notes on materiality and sociality. Sociological Review 43(2), 274–294. https://doi.org/10.1111/j.1467-954x.1995.tb00604.x.
- Law J and Singleton V (2013) ANT and politics: Working in and on the world. *Qualitative Sociology* **36**(4), 485–502. https://doi.org/10.1007/s11133-013-9263-7.
- **López Gómez D** (2015) Little arrangements that matter: Rethinking autonomy-enabling innovations for later life. *Technological Forecasting and Social Change* **93**, 91–101. https://doi.org/10.1016/j.techfore.2014. 02.015.
- Matheson A, Walton M, Gray R, Lindberg K, Shanthakumar M, Fyfe C, Wehipeihana N and Borman B (2018) Evaluating a community-based public health intervention using a complex systems approach. *Journal of Public Health* 40(3), 606–613. https://doi.org/10.1093/pubmed/fdx117.
- Mol A (2002) The Body Multiple: Ontology in Medical Practice. Durham, NC: Duke University Press.
- Moser I (2005) On becoming disabled and articulating alternatives: The multiple modes of ordering disability and their interferences. *Cultural Studies* 19, 667–700. https://doi.org/10.1080/09502380500365648.
- Moser I (2006) Disability and the promises of technology: Technology, subjectivity and embodiment within an order of the normal. *Information, Communication and Society* 9(3), 373–395. https://doi.org/10.1080/13691180600751348.
- Moser I and Law J (1999) Good passages, bad passages. Sociological Review 47(1), 196–219. https://doi.org/10.1111/j.1467-954x.1999.tb03489.x.
- Oudshoorn N, Neven L and Stienstra M (2016) How diversity gets lost: Age and gender in design practices of information and communication technologies. *Journal of Women and Aging* 28(2), 170–185. https://doi.org/10.1080/08952841.2015.1013834.
- Paparini S, Green J, Papoutsi C, Murdoch J, Petticrew M, Greenhalgh T, Hanckel B and Shaw S (2020) Case study research for better evaluations of complex interventions: Rationale and challenges. *BMC* (*BioMed Central*) *Medicine* 18(1), 301. https://doi.org/10.1186/s12916-020-01777-6.
- Poland B, Lehoux P, Holmes D and Andrews G (2005) How place matters: Unpacking technology and power in health and social care. *Health and Social Care in the Community* 13(2), 170–180. https://doi.org/10.1111/j.1365-2524.2005.00545.x.
- Rose D and Blume S (2003) Citizens as users of technology: An exploratory study of vaccines and vaccination. In Oudshoorn N and Pinch T (eds), *How Users Matter: The Co-construction of Users and Technology*. Cambridge, MA: MIT Press, 103–132.
- Sandelowski M (1999) Troubling distinctions: A semiotics of the nursing/technology relationship. Nursing Inquiry 6(3), 198–207. https://doi.org/10.1046/j.1440-1800.1999.00030.x.
- Schillmeter M and Domenech M (2010) New Technologies and Emerging Spaces of Care. Farnham: Ashgate. Star SL (1990) Power, technology, and the phenomenology of conventions: On being allergic to onions. Sociological Review 38(1 Suppl) 26–56. https://doi.org/10.1111/j.1467-954x.1990.tb03347.x.
- Symonds-Brown H and Ceci C (2022) The day program multiple: Noncoherence and ontological politics. *Health* 28(1), 126–143. https://doi.org/10.1177/13634593221116501.
- Symonds-Brown H, Ceci C, Duggleby W and Purkis ME (2021) Re-thinking the nature of day programs for people with dementia: Implications for research. *Dementia* 20(1), 326–347. https://doi.org/10.1177/1471301219884429.
- Symonds-Brown H, Ceci C and Judge H (2022) 'Sand in the works?' Infrastructural affordances and life with dementia in the community. *Sociology of Health and Illness* 44(9), 1517–1532. https://doi.org/10.1111/1467-9566.13532.
- **Timmermans S and Berg M** (2003) The practice of medical technology. *Sociology of Health and Illness* **25**(3), 97–114. https://doi.org/10.1111/1467-9566.00342.
- Timmermans S and Kaufman R (2020) Technologies and health inequities. *Annual Review of Sociology* **46**(1), 583–602. https://doi.org/10.1146/annurev-soc-121919-054802.

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- Twigg J and Atkin K (1994) Carers Perceived: Policy and Practice in Informal Care. Bristol: McGraw-Hill Education.
- Van Pijkeren N, Wallenburg I and Bal R (2021) Triage as an infrastructure of care: The intimate work of redistributing medical care in nursing homes. *Sociology of Health and Illness* **43**(7), 1682–1699. https://doi.org/10.1111/1467-9566.13353.
- Weir A and Fouche C (2017) Community-based dementia day programmes: Common elements and outcome measures. *Dementia* 16(3), 297–314. https://doi.org/10.1177/1471301215590504.
- World Health Organization (2018) Continuity and Coordination of Care: A Practice Brief to Support Implementation of the WHO Framework on Integrated People-Centred Health Services. Geneva: World Health Organization. Available at: https://apps.who.int/iris/handle/10665/274628 (accessed 6 March 2023).
- World Health Organization (n.d.) Health Technology Assessment. Available at: www.who.int/teams/health-product-policy-and-standards/assistive-and-medical-technology/medical-devices/assessment (accessed 20 April 2023).
- Zarit SH (2018) Past is prologue: How to advance caregiver interventions. *Aging and Mental Health* 22, 717–722. https://doi.org/10.1080/13607863.2017.1328482.



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