Neurodegeneration and the Intersubjectivities of Care

Narelle Warren & Dikaios Sakellariou

Published online: 01 Feb 2019.

Submit your article to this journal ⬚

Article views: 75

View Crossmark data ⬚

Routledge
Taylor & Francis Group

Neurodegeneration and the Intersubjectivities of Care

Narelle Warren [a] and Dikaios Sakellariou[b]

aSchool of Social Sciences, Monash University, Melbourne, Australia; bSchool of Healthcare Sciences, Cardiff University, Cardiff, United Kingdom

ABSTRACT

Caring for a family member or friend with a serious health condition is a common feature of social life. Often, such care is framed as a burden, an unwelcome rupture in the fabric of everyday life. We draw on research conducted in Australia and the UK to examine care in the everyday lives of people living with and caring for neurodegenerative diseases and to trouble care as a burden. Participants in our studies mobilized practices of care to collaboratively produce a "good life". We argue that above all, care is a relational, enacted practice requiring examination in its local context.

Caring for a family member or friend with a serious health condition is a common feature of social life, and particularly family life, globally (Seltzer and Heller 1997). Within highly industrialized settings, this is due, at least in part, to strong preferences by policy makers and funders, health providers, advocacy groups, and community members to move care away from institutionalized or residential (care facility) settings (Heaton 1999). Considerable efforts have been made to develop strategies to support people to remain in their homes for as long as possible, through subvention (grants) or pensions, caregiver support programs and advocacy, caregiver counselling services, and government-sponsored respite care. However, there is considerable variance between countries in how this is realized. In this article, we focus on research conducted in two settings—Australia and the UK—to examine the effects of these political shifts on the everyday lives of people living with and caring for age-related neurodegenerative diseases, and to consider how ideas of a good life are collaboratively produced and put into practice through acts of care. Our attention to two different— yet complementary—landscapes of care helps us bring in dialog the different ways people negotiate and assemble practices of care.

Care is a relational, intersubjective activity that emerges in the spaces between people, and through practical activities that are performed by one person with or for another (Sakellariou 2016; Warren and Ayton 2018). It is idiosyncratic and takes diverse forms, from preparing medications—getting tablets out of a bottle and putting them beside a morning coffee cup, to doing activities (such as going to the pharmacy to collect medications, or doing grocery shopping or gardening), to accompanying someone to their weekly support group meeting, to toileting and bathing. Even within any one activity, caregivers and care recipients negotiate, adjust, devise and innovate, employ trial and error, and resist in order to develop strategies and practices, often with the purpose to avoid undesired outcomes and produce a good life, however defined, with a chronic condition. Through in-depth descriptions and analyses of what happens in specific instances, including those interactions when people negotiate care to effect some sort of change that can be evaluated as "good", we seek to problematize the notion of "burden" in the context of care and argue for a focus on the enactment of care within people's local worlds. We draw upon empirical evidence

---

from research carried out with people living with Parkinson's disease (hereafter, "Parkinson's")[1] in Victoria, Australia, and people living with motor neuron disease (MND) in Wales, United Kingdom, to focus on people's micro-worlds.

Informal care in Australia and the United Kingdom

Prioritizing the experiences of informal carers is particularly significant given the nature of care. In Australia, nearly two-thirds (60%) of all care is estimated to be provided by informal carers, the majority family members, and over half (57%) of these do not receive any government financial assistance (ABS 2016). The "replacement value" of informal care—if these hours were provided by formal services—is approximately $60.3 billion annually (ABS 2016) or equivalent to more than half of government expenditure on health ($114.6 billion; AIHW 2017). At the person level, this reflects data indicating more than one in nine Australians aged 15 and over (2.7 million people or 11.6% of the total population) provide care. One-third of these are primary carers, undertaking the bulk of care work, almost half (40%) of whom provide over 40 hours care each week (ABS 2016).

Similar trends are evident in the United Kingdom: one of every 10 adults in the UK—some 5.3 million people—provides informal care (New Policy Institute 2016). The total value of informal value tripled between 1995 and 2010 to £61.7 billion per year (Office for National Statistics 2013). The most recent figures show that the care provided by informal carers is worth an estimated £132 billion per year (Buckner and Yeandle 2011), roughly comparable with the entire health budget. From these figures, it is clear that informal care is an essential—although often under-recognized—part of these health care systems. This is especially true when considering care for the elderly, as the majority of informal carers—who may be older themselves—provide this form of care (Pickard 2004). In both Australia and the UK, women are the main providers of care (New Policy Institute 2016; ABS 2016).

Informal carers have a value beyond the significant reductions in costs and consequent savings in health expenditure, although this added value also delivers economic outcomes. People who have access to an informal carer have lower levels of reliance on state-delivered home health care services (Van Houtven and Norton 2004). Informal care delays admission into permanent or long-term institutional and residential care (Van Houtven and Norton 2004), with consequent affective benefits to care recipients and economic benefits to their guardians and the state. People who remain in their homes are posited to have a better quality of life and outcomes than those who enter residential care (Bilotta et al. 2011). They also report greater happiness, which is understood as related both to their relationship with the informal carer, often their spouse, and also to higher levels of autonomy (ABS 2016; Brouwer et al. 2005). Despite these benefits, the shift to home-based care has implications for care recipients, care providers and other family members, given resultant personal, familial, community, and social changes (Warren and Manderson 2015).

Family plays an important role in personal and political imaginaries of informal care (Mattingly 2014). Often, informal caregivers are relatives of the person to whom they provide care and, thus, for most people, providing informal care is inseparable from their familial relationships of spouse, son, daughter, mother, father, and so forth. Relationality is reinforced at the political level, where the blurring of family relationships with informal caregiving has its roots, at least in part, in government policy. Prior to 1981, the category of "informal care" did not exist as distinct entity in either Australia or the UK (Heaton 1999; Karasaki 2015), an artefact of assumptions that there was no separation between family relationships, with their associated filial responsibilities, and practices of care. Indeed, Heaton (1999) demonstrated the interchangeable use in the United Kingdom of the terms "carers" and "family". Gradually, following shifts to deinstitutionalization and community-based care, an expectation was constructed that care offered in and by the community would largely be the province of family members or, to a lesser extent, friends. This expectation is made explicit in most contemporary carer policy documents (such as the Australian Carer Recognition Act 2010 or

the UK Care Act 2014), which both provide operational definitions of caregivers and outline government obligations to those who provide informal care. Such care, has often been regarded as an indication of increased power for people who receive or who provide care, because they can employ care within their own environments, in ways that are best suited to their needs (Fine 2007).

For Heaton (1999), the emphasis on informal care in the UK health and welfare policies rather than giving more power to people, offers the ground for a different modus operandi of the medical gaze, through the carers who act as its agents. Through their delineation as a specific group, carers are also subjected to surveillance, amplifying the role of the state, and are the subject of policies in their own right. Not only do the Carer Recognition Act (Australian Government 2010) in Australia and the Care Act (Department of Health and Social Care 2014) in the UK give rights to carers, they also outline the obligations of carers (for example, to engage in local authorities' processes of assessment). This represents, in many cases, increased involvement of the state in the relationships between family members, under the guise of ensuring quality informal care and the provision of carer support. Important within this shift, as Cash and colleagues (2013) argue, focusing on the community benefit and (claimed) power afforded by carer policies, is that it obscures both the reliance of neoliberal governments on carers and the moral obligation to care placed on people who become informal carers.

Care and burden

Whether care is a tool for the extension of the medical gaze or a means to greater autonomy makes little difference to people living with chronic conditions and who give or receive care from others in their everyday lives. As we track in this article, on an everyday level, those engaged in relations of care are largely concerned with the practices of care, and the elements that support, subsume, or detract from care. Central to our argument is a critical reflection on the concept of "burden of care" which permeates policy and psychosocial discussions about care.

The extensive changes in the everyday lives of carers that derive from informal care are often framed under the broad category of *burden*, in response to efforts to capture the investment of carers in their caring roles. The idea of caregiver burden sought to recognize the all-encompassing, engulfing nature of informal care provision (Skaff and Pearlin 1992), which can lead to a loss of identity, social participation, and enjoyment of other activities that exist outside of the caring role (Adelman et al. 2014). As a concept, care burden was developed to capture the (mostly negative) impacts of care across primary and secondary domains, with the goal of identifying opportunities for intervention (Pearlin et al. 1990). Importantly, it sought to disrupt the assumption, embedded in the shift to state recognition of informal care, that providing care for a family member is unproblematic and natural. The focus on burden of care is on the resultant psychosocial impacts, particularly the hardships, challenges and difficulties that are directly related to the caring role. Caregiving involves significant time contributions, emotional commitment, and physical labor—and reduced involvement or relinquishing of previously valued roles—on the part of the person providing care, all of which may lead to adverse and compromised health and wellbeing outcomes (Carretero et al. 2009). While this concept of burden has been extremely influential (Burke et al. 2018; Tessitore et al. 2018), highlighting the importance of carer wellbeing, it has simultaneously led people to think about caring in negative terms precisely because it constructs the care relationship as unidirectional, in which the independence and autonomy of the carer is compromised by the care needs of the dependent care-recipient.

The independent/dependent dichotomy at the center of the burden concept is troubling, and relies on policy and biomedical perceptions of the work of carers, which focus on activities and function—what Manderson and Warren (2013) term "caring for." At a phenomenological level, carers find it difficult to distinguish this from their social experiences ("caring about"), which can only be understood within the context of roles which give rise to this care. For the most part, at a practical level, people who provide care of a family member find it difficult to determine whether

they are actually a caregiver—asking "how is what I do as a caregiver distinctly different from what I do as a spouse/child/parent?" Providing care does prompt the transformation of relationships, and the intimacy within, so that new forms of engagement between family members often result. These engagements are broad-ranging, from helping with toileting and bathing, to wiping faces or helping people to eat (Buse and Twigg 2018; Sakellariou 2016; Team, Manderson and Markovic 2013). While caregivers are often family members, sometimes neighbors and acquaintances also engage in such relationships (Brownlie and Spandler 2018). Caregivers adapt their understanding of their familial role—as "wife", "husband", "son", or other—to accommodate these activities of care; this shift is largely seen by carers as unproblematic, and instead is perceived as another part of caring about (Manderson and Warren 2013).

We contend that the language of burden is insufficient to capture the everyday realities and contingencies of informal care. Further, we seek to problematize the relational aspect of the burden concept itself to argue that, in some cases, it is the very absence of the affective dimensions of care that produce a sense of burden.

Methodology

This article draws upon empirical evidence from two studies: one conducted with people living with Parkinson's disease (PD) in Victoria, Australia, and the other with people living with Motor Neuron Disease (MND) in Wales, United Kingdom. Both Parkinson's and MND are adult-onset, incurable and progressive neurodegenerative conditions (Ben-Shlomo, Whitehead and Smith 1996; Braak et al. 2004). Although the two conditions have different disease courses, with MND typically progressing faster than Parkinson's, both result in limited bodily capacity and physical functioning over time (Ben-Shlomo et al. 1996). Consequently, they give rise to different practices and relations of care; despite this, they offer opportunities to unpack the various relational and affective components of care.

Motor Neuron Disease (MND) is characterized by the wasting of voluntary muscles secondary to the destruction of motor neurons, leading to partial or complete paralysis (Kiernan et al. 2011). As the disease progresses, people with MND often require help with activities such as eating, toileting, dressing, and other everyday activities (Locock and Brown 2010). MND often affects people over 50 years of age and has an average duration from diagnosis to death of three to five years, although duration and the rapidity of loss of function vary (Kiernan et al. 2011). Because of this relatively short disease progression, intimate relationships can rapidly transform into those of caregiving and care receipt. *Parkinson's disease*, in contrast, typically affects older people and is characterized by tremor, bradykinesia (difficulty in initiating—akinesia—or maintaining and executing movement), and rigidity (see Jankovic 2008; Warren and Manderson 2015). The average duration of Parkinson's is 10 years, although there is significant variance in terms of life expectancy (Marttila and Rinne 1991). It is slower progressing than MND meaning that, in many cases, there is more opportunity for care to be negotiated or improvised. For both MND and Parkinson's, personal and functional care needs increase as the disease progresses and, most notably in the case of Parkinson's, with associated cognitive decline.

The studies

In both studies, our concern was to understand how people do the best they can with the personal, social, economic, and other resources available to them to develop shared meanings in response to living and caring for someone with a profoundly disruptive health event (Riessman 2001). Using evidence from two countries and two different chronic conditions enables us to focus on people's micro-worlds. Because many participants in both studies had communication difficulties, paired interviews were often conducted, with the carer and the recipient of care together. While this may have impeded the capacity of either person to talk about the difficulties they faced, because of their

concern for the wellbeing and happiness of the other, it allowed them to emphasize the reciprocity and relational aspects of care (see Hydén 2008). Without seeking to essentialize people's experiences as country- or disease-specific, we focus on how people negotiate the complexities of care across different environments to illustrate the deep connections between care and people's local worlds. Importantly for broader discussions around social constructions of disability, which we do not elucidate in the current article for reasons of space, all of our participants were in heterosexual spousal relationships; this provides an important social context for the notions of care examined here. Before we present our analysis, we describe each study.

MND study

Between 2011 and 2013, the second author carried out a study on experiences of living with an incurable, neurodegenerative disease in the United Kingdom. The specific aim was to explore how people make sense of living with MND in their local contexts, through in-depth meaning-sharing between the researcher and participants. Seven people (four households) participated in the study, which resulted in the production of unique narratives for each participant. Participants were from a variety of working class to middle class backgrounds, with only one being educated at university level. All of the participants and their spouses had retired and were supported financially through a combination of work pension and disability benefits. Participants were involved in the study between 14 and 18 months each. Data collection took place through from four to six observations for each household and multiple (at least 4) joint in-depth interviews, lasting between one and two hours on each occasion (see Sakellariou, Boniface and Brown 2013 for a detailed discussion of data collection). Each narrative was viewed as an enacted performance in which people engaged with the intention of creating meaning and making sense out of their life (Mattingly 2014). Narratives were understood—and deployed—as co-constructed events, which emerged from interactions between listener (researcher), narrators (research participants), and other important people in the narrators' lives; they were unique to each participant, even within the care relationship.

Parkinson's study

Drawing upon a similar desire to understand how people make meaning and give sense to their life experiences, the first author explored Australian people's experiences of Parkinson's, both as care recipients and caregivers, using narrative methods between 2012 and 2015. Fifty-eight people with Parkinson's and thirty-seven carers (mostly spouses) took part in the study. Participants represented considerable diversity in terms of income, ranging from people receiving state-sponsored welfare payments in the form of the aged pension and/or carers' allowance to those living off self-funded superannuation schemes. Few participants were in paid employment at the time of study participation, and the few who were still working had were either on light duties or in part-time employment. Each participant was interviewed at least twice over a six to nine month period, with most also participating in a third interview 18 to 24 months after the first interview. The sample was considerably larger than the MND study, which reflects the different study durations, the size of the research team (in this case, two research assistants conducted interviews), and the number of interviews undertaken with each participant. Narrative interviews were informed by Riessman's (2008) thematic and dialogical narrative approaches, used in concert, in which participants discussed their experiences of life with Parkinson's.

Narratives and neurodegeneration

In both studies, the interviews were treated as opportunities for the production of rich stories; participants were left free to narrate any stories they perceived as relevant and important (Kvale 2007). Interviews often included both the caregiver and the care-recipient and enabled extensive narration; through explicit discussion and through the interlocutory role of the caregiver in these couple interviews, participants reconstructed their lives: not only did they tell the story of their

(shared) life, but they negotiated the process of meaning-making through discussions that formed the heart of each interview. This was especially salient when the participant was experiencing difficulties in speech production or expression; in these instances, the caregiver literally filled in the gaps to ensure that the account was complete. Intersubjectivities of care were re-constructed in the narrating of experiences, either directly—as occurred in couple interviews—or indirectly—through reflection during individual interviews. However, these two approaches to data collection provide differing lenses into the intersubjective experience of care, and we caution against treating individual and paired interviews as offering equivalent insights. Rather, they may be seen as different points on a continuum whereby intersubjective dimensions can be more or less clearly articulated; the very performativity of the paired interview reshapes this intersubjective lens (see Riessman 2008).

People make sense of their lives in different ways, finding ways to connect the past with the present and projecting their selves into the future (Ricoeur 1980). Doing so requires the construction of stories that give meaning to a person's life. This meaning-making was especially notable in couple interviews, whereby participants would explicitly engage in discussion about the narrative itself, such as when one Parkinson's caregiver asked her spouse, "Was that how it was for you?" Narratives were unique to each participant, with subtle shifts in the narrative over time which reflected the refining of the story being shared. In our analysis here, we were less concerned with exploring common themes across participants. Rather, we drew upon two excerpts from narratives with the explicit aim to highlight the complexities and relationality of care. Our findings are influenced by our positions as applied anthropologists (both authors) and clinician (second author).

Findings

First scene: Micro-explorations of changes in care

After first meeting them at a regional Parkinson's support group meeting in 2013, Narelle visited Gail and Stan at their home to interview them about their experiences of Parkinson's. Although they were only in their early 60s, they had been in a relationship for nearly five decades—childhood sweethearts—and were living only a few kilometers from where they first met as teenagers. Stan had been living with Parkinson's for five years at the time of our first meeting, although it had recently progressed suddenly. His very soft and slow speech clearly made it difficult for him to articulate his own experiences. Instead, he preferred Gail to do most of the narrating of their shared story, interjecting where he felt necessary.

For the first three years following Stan's Parkinson's diagnosis, their life had been good:

> Going along fine, it wasn't making a big impact on his life at all. He was driving, and picking up grandkids from school… going [to child's business] 3 or 4 days a week and helping out there, doing the books. (Gail)

Important to Gail's sense of "going along fine" was the feeling that the Parkinson's diagnosis hadn't substantially changed their way of life: Stan only experienced tremor (one of the most common symptoms) when he was tired, and mostly just noticed the effects of Parkinson's on his writing and in an arm which easily fatigued. He was, however, taking large doses of anti-Parkinsonian medication daily. This "going along fine" was illustrated by the above excerpt, where Gail's emphasis on his ability to drive highlighted its importance for mobility and independence in regional Australia. Driving was important to Stan's sense of personhood: it was an integral part of how he did his work, prior to retirement, as a tradesperson. Also important to their lives was Stan's—and by extension, Gail's—active participation in family life, work, and sports. Although medical services most likely considered Gail his informal caregiver, she didn't see herself as so at this point, because—as with their lifestyle—there were few shifts in their relationship as a result of the Parkinson's diagnosis.

However, about three years after Stan's diagnosis, a medication event (described as such by Gail) transformed their lives overnight. Gail and Stan explained this:

Gail: The Parkinson's diagnosis didn't really change our life did it?
Stan: No.
Gail: But the head drop did?
Stan: Yeah.
Gail: Because it stopped him from doing so many things. Like when you can't drive, that impacts on so many things. He used to do the shopping for me sometimes or I would be cooking tea and think 'oh damn, I've run out of that, can you nick down to the shop?' They're just little things but they're major things at the time, these changes… [Losing his license] knocked a hole in your independence?
Stan: Yeah.
Gail: Yeah, he's never been one to ask people to do things for him, but now if he wants to go somewhere he has to ask or I try to mind read (laughs).

Stan had been receiving specialist neurological care in a regional center four hours' drive away, but when a new specialist movement disorder outreach service opened in their home community, they decided to shift providers. At the first appointment, Stan was advised to halve his medication dose, over a period of six weeks; he followed this advice closely. The morning after he started taking the (newly) desired dose, "it was like his chin was glued to his chest… Could not lift it at all" (Gail). This prompted significant changes in both Stan's experience of Parkinson's and Gail's experience of providing care; from leading fairly independent lives, they needed to always be together—or at least nearby:

> Until his head dropped, we never spent, we were never [together] 24/7 [24 hours a day, 7 days a week]… All his life, he's played sport and he had mates [friends]. When his head dropped and he's not clear in his speech, we found out who the mates were. So nobody came to visit or any of that once his head dropped because they didn't understand him. (Gail)

Several aspects of their life were significantly changed by this medication event, which prompted a rapid escalation in Stan's Parkinson's disease progression. From being able to converse readily with his friends, his speech was affected and it was difficult for him to talk and socialize. It also affected his confidence in communicating (which Gail acknowledged); during interviews, he made short contributions confirming or expanding Gail's narrative. Together, they explained the changes in their relationship—which offered a stark contrast to the early days of Parkinson's which Gail described earlier:

Gail: Suddenly he can't do anything much. There's not a lot that he can do for himself anymore, is there?
Stan: No.
Narelle: *So does that mean that as result you spend a lot of time together?*
Gail: Yep.
Stan: Yeah.
Gail: 24 hours a day, [though] I have a break on a Wednesday, [when a] young fellow from the [local government] comes from 1 p.m. 'til 2. He takes Stan up to the gym and one of the ladies in the village here takes me out for coffee.

Within the narratives themselves, too, this transformation was borne out—Gail, who narrated the majority of their story, shifted from talking about "he" and "him" to referring to "we": from this point onwards, "we" made shared decisions around medical appointments, use of allied and complementary health services, taking medications, and everyday care practices. They were clearly a partnership prior to the medication event, but at the same time, Stan and Gail each had their own aspirations and priorities—these were shared and overlapped in many ways, although their everyday

activities were often different: in contrast to Stan's (described above as part of "going along fine"), Gail spent her time doing sewing and craft, working part-time and being involved in the local community. Following the medication event, however, this was dramatically altered. Stan became depressed after his changed friendships and speech challenges left him lacking confidence for socializing, contributing to a sense of social isolation. Gail became his main source of support, except for the brief moments when community-based workers—such as the "young fellow" above—took Stan out. As many of their friendships faded into the background as Stan became increasingly disabled, Gail took on board the task of developing new social relationships while simultaneously maintaining her family responsibilities to their children and grandchildren. Gail's support was simultaneously affective as well as instrumental and practical, and reflected the relational aspects of caregiving. She explained:

Gail: It has definitely impacted on my quality of life. I do sewing and I used to go to craft classes 4 times a week, I was teaching. I gave all of that up willingly because Stan needed me. [Before] we sort of did our own separate things and then came together. We don't do any separate things anymore, because Stan needs help and I wouldn't not help him… I just take that at as what marriage vows meant. If it was reversed, he would do it for me. Maybe not quite as good as I do (laughs). Is that right?
Stan: Yeah.

The affective and relational dimensions of caregiving were borne out in Gail's actions and choices. Out of concern for Stan's mental health, Gail made the decision to move into a lifestyle community for older people. Not only did many other community members also live with disabling and chronic conditions, but there were local facilities in close proximity to their home and there was "somebody around all the time". This environment helped Gail organize activities for Stan to encourage a sense of social engagement. By our second interview, she had recently organized for him to start attending social nights at the community center: "last Friday night, seeing as he's got the wheelie walker [rollator], he went up there on his own for the first time, so I sat here on tenterhooks." For Gail, providing an environment that allowed Stan to socialize in ways that he had previously valued—including actively setting up new friendship ties—was also important.

Caregiving, as Gail and Stan understood it, was part of aging within a relationship; it was something they had committed to in their marriage vows—and as such, was a contingency implicit in the commitment they had made to one another. Importantly, given the effort that Gail put into to supporting Stan to achieve some type of good life, she did not minimize the challenges, but neither did she consider them as a burden: "I don't begrudge any time I spend with him". She passionately believed that Stan had experienced a great injustice from the decisions of his health professional, and sought to alleviate these as best she could. Importantly, they also had good support from their children—which they in turn reciprocated through caring for (and thus, simply enjoying) their grandchildren; however, they also felt "ripped off " [cheated] because of the subsequent changes in the extent of their involvement in their grandchildren's lives.

Gail and Stan's account highlights that caregiving cannot be characterized by singular concepts such as burden, but involves challenging and rewarding aspects—just like the broader relationships which the caregiving is based in. The concept of caregiver burden is too narrow to adequately reflect this; instead, people's experience of care is characterized by highs and lows, great expectations and failed hopes, and futures which are full of contradictions. Below, we draw upon a story of MND care to examine these further.

Second scene: The storytelling group

Maggie and Robert had been married for several decades when they were recruited in the MND study, and Robert had already been living with MND for nine years. Initially, they were told that he

only had two to three years to live, but when five years passed Maggie started researching about the disease and began suspecting that Robert had a more slow-moving variant of MND. This was subsequently confirmed in the MND clinic.

Robert used a wheelchair for mobilizing outdoors and a walking stick or a wheelchair when moving indoors. He also needed help with moving into and out of the wheelchair. Over the course of our meetings, he reported that his arms and hands were becoming increasingly weaker and less dexterous and that he was finding a variety of everyday activities challenging. From combing his hair, cleaning his ears and brushing his teeth to eating and drinking, and from gardening to driving, his repertoire of activities was either becoming narrower or changes were required in the ways he was carrying out these activities.

Partly, these everyday activities were facilitated through Maggie who helped Robert with toileting, bathing, dressing, getting up from the bed and getting into bed, eating, and transferring. She was there to offer help when Robert could not do something, or when he found an activity challenging. She also carried out all those necessary daily life activities, such as paying the bills, driving, attending to the garden, arranging medical appointments, and food shopping. In brief, she carried out what Kleinman and van der Geest (2009) called the "technical/practical" constituents of care. In the following sections, we describe how Maggie made sense of living with MND as Robert's caregiver.

Maggie and Robert had anticipated a long retirement during which they could enjoy time travelling and being together. They would play golf, spend more time with their grandchildren and friends, and maybe renovate their house. The diagnosis of MND changed that anticipated future by introducing many uncertainties and one certainty into their life. The one certainty was that Robert had a progressive disease that would affect his ability to carry out everyday activities. This belied the many uncertainties Maggie and Robert were experiencing; although they knew how MND *could* affect somebody, they did not know, and had no way of knowing, exactly how Robert would be affected, or how fast this would occur. This made it hard to make plans, as Maggie explained:

> Robert just thinks these are the cards that we have been dealt and we've got to deal with it [Robert nods] … All the plans that you've made all through your marriage, the children are grown up, are off your hands, retirement, you know… but of course that all came to, you go from having a wide horizon to having one that is very close to you. You don't think much further ahead than, uhm, a month or two really, if that.

As the condition progressed and Robert's muscles became weaker, Maggie had to step in and help. Fluctuations in care needs resulted in fluctuations in the relationship between Maggie and Robert, with Maggie's role as a carer developing over the years. When Robert first started needing help with some activities, Maggie and Robert did not sit down to discuss it, nor make special arrangements, nor consider other options. Maggie had not planned to become a caregiver. She did it because it was there to be done, as Kleinman (2009) reflected on his own experiences of caregiving.

For the first few years after diagnosis, Robert could still carry out most activities and there was no major change in their daily life. Having lived together for many years, they had learnt to help each other and it felt natural for Maggie to start offering help as a way of adapting to a changing context. Changes were introduced little by little, and it was not until several years later that Maggie realized that she had become a full-time caregiver. For Maggie and Robert, caring entailed all these activities that Robert found difficult to perform by himself. Maggie needed to "sort him out", which could mean helping him to dress, wash, dry out, clean his ears, but also undress, go to the toilet, eat and drink, and get up when he falls on the floor, and other personal activities of daily living. Our meetings and discussions often took place around the kitchen table, and I could see how Maggie would place a glass of water in just the right position between Robert's hands, or help him put on his glasses, or stand behind his chair and hold it steady as he was getting up. These activities were introduced in their lives gradually, but not without any impact:

> Yes, it's just been a very gradual [process]. Don't really notice these things happening until all of a sudden, 'oh, I hadn't noticed that before'. So we now got to a stage where I got to help you to dress, wash. He can manage

the shaving himself. Cut his nails. You know, things that we take for granted. Going to the toilet, [asking Robert] 'you can't manage that on your own any more, can you?' (Maggie)

Maggie was worried about the future and how they would be able to cope, in the face of advancing age and progressing impairment. They had a supporting network of close friends who offered help, but several of them were dealing with ill health themselves. They also received support from occupational therapists and paid carers (paid for by the social services) who had come up with solutions for several of the problems they faced, or that they anticipated they might face in the future. Despite these sources of support, the changes that MND and the associated caring responsibilities brought to Maggie's and Robert's life were major. The following excerpt reflected the anxiety Maggie had about the future.

M: But the storytelling group, I think you are coming to a stage where it is harder and harder for you to go to the storytelling group, haven't you?
R: No. I enjoy going to it, I just have to be careful. Can't go to any venues where there are steps.
M: Yes, it's getting more difficult. There will come a stage when you won't be able to go to the storytelling group.
R: As far as there are no steps.
M: Yes, I know that, but there will come a stage when you can't walk at all.
R: Yes, but I can sit in a chair, so I don't have to.
M: Yes, but I will still have to get you in and out of the car, Robert. It isn't going to be that straightforward, is it?
R: I don't know, I can't tell.
M: So, we don't know. But he does enjoy it.
R: Yes.

Above, Maggie and Robert discussed Robert's involvement in a storytelling group that Robert had been involved in for many years. He enjoyed the group, and he regularly went out for meals with others from the group. Maggie also enjoyed attending the group and thought it was important for Robert to continue to attend. However, Maggie anticipated future difficulties and was reluctant to make any plans regarding Robert's continuing involvement and participation in storytelling events out of town, while Robert focused more on his present experiences.

Discussion

Our two case studies highlight how considerations of care—when viewed in context and discussed, negotiated and lived between people with shared histories and lives—necessarily extend beyond ideas which characterize caregiving singularly in terms of burden. As we illustrate, care interactions are complex, drawing on mutual affection, humor, comfort, frustration and concern, many of these occurring at the same time. These findings reinforce Manderson and Warren's (2013) work on the embedded interdependence of care, in which acts of caring for cannot be readily disentangled from the social experience of caring about another. Caring about, as reflected through the two scenes presented above, captures the give and take of everyday relationships, embedded in affective contexts. In this way, it captures the fondness and love that family members (and friends) extend to one another. In essence, caring about reflects the kinship ties that bind people together in mutually supportive ways. This was explicitly borne out in our two scenes, particularly when Gail associated caregiving with her feelings about Stan as well as to the commitment they have to their relationship. This difference is subtle but important: policy-makers and health providers regularly assume that the latter type of care means that people will unproblematically accept the former type of care, and so provide very limited (if any) effective support for caregivers (Karasaki, Warren and Manderson 2017; Sakellariou and Warren 2018)—despite what is captured in parliamentary acts.

Family caregivers often experience significant changes to their lifestyle when their spouse or family member develops a long-term neurodegenerative condition, as we have shown here. Care prompts widespread adaptations, which may be both straightforward and challenging. It is assumed that the bulk of care work is performed by women, and this is reflected in the broader literature (for example, Broom and Lenagh-Maguire 2010). In many instances, even when they are seen (by health providers, by policy makers, by the wider community) to be the care recipient, women are often simultaneously the caregiver (as documented in Sakellariou and Warren 2018).

Critiquing caregiver burden

The construction of care as burden hides the subtle interactions and co-constructions of a good life that take place in the intersubjective interactions that emerge in the spaces between people. Focusing on burden positions caregivers as individual entities whose right to autonomy is limited because of added responsibilities for someone other than their own self. Such an understanding also obscures the agency of the care recipient, who is rendered passive: our participants' experiences highlight that caregiving is complex and bidirectional.

Care is neither easy nor unproblematic. Our caregiver participants discussed their primary concerns: the hardships, challenges and difficulties that were directly related to the caring role. For some, this included financial strain, depression and emotional stress, social isolation difficulties in lifting a much larger spouse after a fall, or facing challenges in helping their spouse in and out of the car. Being overloaded was also important; our participants rarely took a break from care and, when questioned, they reported rarely or never using respite services. The reasons for this ranged from lack of appropriate services in people's local area, to an ethical imperative to provide all necessary care themselves, and even to a perception of respite care, by the carers, as a small act of abandonment. Instead, they used their social support networks to provide support for their spouse while they did other tasks.

Secondary impacts of care were also felt, where caring affected other aspects of the caregiver's life: social domains (agency, participation, activities, and role performance) and psychological domains (self-esteem, sense of control over their lives, depression, and identity). For Gail, the compromises she had made in order to care for Stan following the medication-related event were worth it so long as they could be together. Indeed, Stan passed away immediately after our third interview, which left Gail bereft of purpose and deeply lonely. Her desire to remain with Stan meant that she willingly accepted the fluctuations of caregiving, moving into a new community as the alternative—to admit him into nursing home care—was unthinkable. This resonates with Kearns and Andrews' (2005) argument that such an option may be undesirable to family members because of its discursive association with decline; for Gail too, Stan was not so unwell that he could not be looked after at home.

A relational approach to care

Human experience, Jackson (1998) reminds us, is intersubjective. Intersubjectivity refers to how people depend on each other to construct and to make sense of experiences (Jackson 1998). Rather than being independent, autonomous subjects with total control over their lives, people are linked to other people with emotional, biological, social, financial, and a multitude of other ties. This network of human interconnections provides the foundations for human experience. Illness can be seen as a rift in intersubjective life (Jackson 1998), changing the ways intersubjective processes are played out in a person's life, often through practices of care.

The experiences described above highlight that caring is often much more complex than we can understand if we focus only on burden. Instead, caring can only be understood fully in the context of the relationship itself. People living with Parkinson's and MND actively sought *not* to be a burden to their friends and family members. The participants in our studies described how they had

deliberately given up things that they really loved—international travel, going to the football or theatre, taking part in large social gatherings, sleeping in a big bed—in order to alleviate the pressure this might place on their loved ones. In other words, they made choices about their life, sometimes compromising their own wellbeing, so they could enhance the wellbeing of their carer. At the same time, caregivers typically highlighted the importance of the relationship—and the positive things that they got from the relationship—as being central to their experience of caring. Gail's unwillingness to be away from Stan was evidence of this. Although she, like others, described significant changes to their social participation as their partner's condition progressed, most did not desire being apart for long periods of time.

In this article, we sought to do bring together two studies of different neurodegenerative diseases, located in different contexts, to elucidate the commonalities of the project of care and offer an extension of current dialogs on the nature of caregiving in the context of aging and neurodegeneration.

Concluding remarks

Care is, we have demonstrated, a relational, enacted practice. While we have considered the multiplicity of care within spousal relationships, experiences of caring for and caring about often co-exist and are balanced in many types of care relations—even those who are paid to provide care, feel connection with and show care *for* those to whom they care (Hochschild 2012). If the cases we include above have something to teach us, it is that care is not something abstract, but instead is a relational and affective—but equally a physical, material and enacted—practice that requires examination in its local context. It is only through recognizing the complexities of care in such a way that health providers and policy makers can effectively work to address the burdens placed upon people engaged in relationships of care. As we emphasize through this article, distilling experiences of caregiving and care receipt to notions of burden—as is evident in policy and clinical practice—ignores the effortful work of both carers and carees. Carers are often left out of clinical decision-making; recognizing their work is essential to good clinical practice, and efforts must be made at the formal care level to better integrate their expertise.

Note

1. This choice of language is deliberate: people living with Parkinson's disease and the key support organizations prefer to refer to "Parkinson's" not the more biomedical "PD". In fact, in the study reported here, only health providers and researchers used PD.

Notes on contributors

Narelle Warren is a senior lecturer in Anthropology and Sociology at Monash University, Melbourne, Australia. Her research concerns neurological disabilities, formal and informal care (including caregiver experiences), temporality, aging, and the role of structural vulnerabilities in shaping people's experiences.

Dikaios Sakellariou is a senior lecturer in the School of Healthcare Sciences at Cardiff University, UK. He is interested in health inequalities, experiences of disability and disablement, and the intersubjective nature of care practices. His most recent book is *Disability, Normalcy, and the Everyday* (2018), co-edited with Gareth Thomas.

ORCID

Narelle Warren http://orcid.org/0000-0003-2623-4078

References

Adelman, R. D., L. L. Tmanova, D. Delgado, S. Dion, and M. S. Lachs
  2014   Caregiver burden: A clinical review. JAMA 311(10):1052–1060. doi:10.1001/jama.2014.304.
Australian Bureau of Statistics (ABS)
  2016   Disability, Ageing and Carers, Australia. Canberra, Australia: Australian Bureau of Statistics. http://www.abs.gov.au/ausstats/abs@.nsf/0/C258C88A7AA5A87ECA2568A9001393E8?Opendocument
Australian Government
  2010   Carer Recognition Act. Canberra, Australia: Australian Government.
Australian Institute of Health and Welfare (AIHW)
  2017   Australia's Welfare 2017. Canberra, Australia: Australian Government. https://www.aihw.gov.au/reports/australias-welfare/australias-welfare-2017/contents/table-of-contents
Ben-Shlomo, Y., A. S. Whitehead, and G. D. Smith
  1996   Parkinson's, Alzheimer's, and Motor Neurone Disease. British Medical Journal 312(7033):724. doi:10.1136/bmj.312.7033.724.
Bilotta, C., A. Bowling, P. Nicolini, A. Casè, G. Pina, S. V. Rossi, and C. Vergani
  2011   Older People's Quality of Life (OPQOL) scores and adverse health outcomes at a one-year follow-up. A prospective cohort study on older outpatients living in the community in Italy. Health and Quality of Life Outcomes 9(1):72. doi:10.1186/1477-7525-9-72.
Braak, H., E. Ghebremedhin, U. Rüb, H. Bratzke, and K. Del Tredici
  2004   Stages in the development of Parkinson's disease-related pathology. Cell and Tissue Research 318 (1):121–134. doi:10.1007/s00441-004-0956-9.
Broom, D. H. and A. Lenagh-Maguire
  2010   Gendered configurations of diabetes: From rules to exceptions. Journal of Gender Studies 19(2):195–209. doi:10.1080/09589231003695997.
Brouwer, W. B., N. J. A. van Exel, B. van Den Berg, G. A. van Den Bos, and M. A. Koopmanschap
  2005   Process utility from providing informal care: The benefit of caring. Health Policy 74(1):85–99. doi:10.1016/j.healthpol.2004.12.008.
Brownlie, J. and H. Spandler
  2018   Materialities of mundane care and the art of holding one's own. Sociology of Health & Illness 40(2):256–269. doi:10.1111/1467-9566.12574.
Buckner, L. and S. Yeandle
  2011   Valuing Carers 2011. London: Carers UK.
Burke, T., O. Hardiman, M. Pinto-Grau, K. Lonergan, M. Heverin, K. Tobin, A. Staines, M. Galvin, and N. Pender
  2018   Longitudinal predictors of caregiver burden in amyotrophic lateral sclerosis: A population-based cohort of patient–caregiver dyads. Journal of Neurology 265(4):793–808. doi:10.1007/s00415-018-8770-6.
Buse, C. and J. Twigg
  2018   Dressing disrupted: Negotiating care through the materiality of dress in the context of dementia. Sociology of Health & Illness 40(2):340–352. doi:10.1111/1467-9566.12575.
Carretero, S., J. Garcés, F. Ródenas, and V. Sanjosé
  2009   The informal caregiver's burden of dependent people: Theory and empirical review. Archives of Gerontology and Geriatrics 49(1):74–79. doi:10.1016/j.archger.2008.05.004.
Cash, B., S. Hodgkin, and J. Warburton
  2013   Till death us do part? A critical analysis of obligation and choice for spousal caregivers. Journal of Gerontological Social Work 56(8):657–674. doi:10.1080/01634372.2013.823472.

Department of Health and Social Care
  2014   Care Act. London, United Kingdom: Department of Health and Social Care.
Fine, M. D.
  2007   A Caring Society? Care and the Dilemmas of Human Service in the Twenty- First Century. Basingstoke: Palgrave Macmillan.
Heaton, J.
  1999   The gaze and visibility of the carer: A Foucauldian analysis of the discourse of informal care. Sociology of Health & Illness 21(6):759–777.
Hochschild, A. R.
  2012   The Managed Heart. 3rd ed. Berkeley, CA: University of California Press.
Hydén, L. C.
  2008   Broken and vicarious voices in narratives. In Health, Illness and Culture. L. C. Hydén and J. Brockmeier, eds. Pp. 36–53. New York: Routledge.
Jackson, M.
  1998   Minima Ethnographica; Intersubjectivity and the Anthropological Project. Chicago, IL: University of Chicago Press.
Jankovic, J.
  2008   Parkinson's disease: Clinical features and diagnosis. Journal of Neurology, Neurosurgery & Psychiatry 79 (4):368–376. doi:10.1136/jnnp.2007.131045.
Karasaki, M.
  2015   Fractured lives: Partnering younger people with stroke. Doctoral dissertation, Monash University.
Karasaki, M., N. Warren, and L. Manderson
  2017   Orchestrating home: Experiences of spousal stroke care. Medicine Anthropology Theory 4(1):79–104.
Kearns, R. A. and G. J. Andrews
  2005   Positionings in the study of older people. In Ageing and Place: Perspectives, Policy, Practice. G. J. Andrews and D. R. Phillips, eds. Pp. 13–14. London: Routledge.
Kiernan, M. C., S. Vucic, B. C. Cheah, M. R. Turner, A. Eisen, O. Hardiman, J. R. Burrell, and M. C. Zoing
  2011   Amyotrophic lateral sclerosis. The Lancet 377(9769):942–955. doi:10.1016/S0140-6736(10)61156-7.
Kleinman, A.
  2009   Caregiving: The odyssey of becoming more human. The Lancet 373(9660):292–293. doi:10.1016/S0140-6736(09)60087-8.
Kleinman, A. and S. van der Geest
  2009   'Care' in health care. Medische Anthropologie 21(1):159–168.
Kvale, S.
  2007   Doing Interviews. Thousand Oaks, CA: Sage Publications, Inc.
Locock, L. and J. B. Brown
  2010   'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). Social Science & Medicine 71(8):1498–1505. doi:10.1016/j.socscimed.2010.06.043.
Manderson, L. and N. Warren
  2013   "Caring for" and "caring about": Embedded interdependence and quality of life. In Reframing Disability and Quality of Life. N. Warren and L. Manderson, eds. Pp. 179–193. Dordrecht, DE: Springer.
Marttila, R. J. and U. K. Rinne
  1991   Progression and survival in Parkinson's disease. Acta Neurologica Scandinavica 84(S136):24–28. doi:10.1111/j.1600-0404.1991.tb05016.x.
Mattingly, C.
  2014   Moral Laboratories: Family Peril and the Struggle for a Good Life. Berkeley, CA: University of California Press.
New Policy Institute (NPI)
  2016   Informal Care and Poverty in the UK. London: New Policy Institute. https://www.npi.org.uk/publications/income-and-poverty/informal-care-and-poverty-uk/
Office for National Statistics
  2013   Household Satellite Accounts—Valuing Informal Adult Care in the UK. Newport, UK: United Kingdom Office for National Statistics. http://webarchive.nationalarchives.gov.uk/20160107021134/http://www.ons.gov.uk/ons/rel/wellbeing/household-satellite-accounts/valuing-informal-adultcare-in-the-uk/art-adult-care.html
Pearlin, L. I., J. T. Mullan, S. J. Semple, and M. M. Skaff
  1990   Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist 30 (5):583–594.

Pickard, L.
    2004   The Effectiveness and Cost-Effectiveness of Support and Services to Informal Carers of Older People. London: The Audit Commission.
Ricoeur, P.
    1980   Narrative time. Critical Inquiry 7(1):169–190. doi:10.1086/448093.
Riessman, C.
    2001   Analysis of personal narratives. *In* Handbook of Interview Research. J. Gubrium and J. Holstein, eds. Pp. 695–710. Thousand Oaks, CA: Sage Publications.
——.
    2008   Narrative Methods for the Human Sciences. Thousand Oaks, CA: Sage Publications, Inc.
Sakellariou, D.
    2016   Enacting varieties of subjectivity through practices of care: A story of living with Motor Neuron Disease. Qualitative Health Research 26(14):1902–1910. doi:10.1177/1049732315584744.
Sakellariou, D., G. Boniface, and P. Brown
    2013   Using joint interviews in a narrative-based study on illness experiences. Qualitative Health Research 23 (11):1563–1570. doi:10.1177/1049732313508014.
Sakellariou, D. and N. Warren
    2018   Caring with others: Constructing a good life with incurable illness. *In* Ethnographies and Health: Reflections on Empirical and Methodological Engagements. E. Garnett, J. Reynolds, and S. Milton, eds. Pp. 159–176. London: Palgrave.
Seltzer, M. M. and T. Heller
    1997   Introduction: Families and caregiving across the life course: Research advances on the influence of context. Family Relations 46(4):321–323.
Skaff, M. M. and L. I. Pearlin
    1992   Caregiving: Role engulfment and the loss of self. The Gerontologist 32(5):656–664.
Team, V., L. Manderson, and M. Markovic
    2013   From state care to self-care: Cancer screening behaviours among Russian-speaking Australian women. Australian Journal of Primary Health 19(2):130–137. doi:10.1071/PY11158.
Tessitore, A., P. Marano, N. Modugno, F. E. Pontieri, N. Tambasco, M. Canesi, A. Latorre, et al.
    2018   Caregiver burden and its related factors in advanced Parkinson's disease: Data from the PREDICT study. Journal of Neurology 265(5):1124–1137. doi:10.1007/s00415-018-8816-9.
Van Houtven, C. H. and E. C. Norton
    2004   Informal care and health care use of older adults. Journal of Health Economics 23(6):1159–1180. doi:10.1016/j.jhealeco.2004.04.008.
Warren, N. and D. Ayton
    2018   (Re)Negotiating normal every day: Phenomenological uncertainty in Parkinson's disease. *In* Disability, Normalcy, and the Everyday. G. Thomas and D. Sakellariou, eds. Pp. 142–157. London: Routledge.
Warren, N. and L. Manderson
    2015   Credibility and the inexplicable: Parkinson's disease and assumed diagnosis in contemporary Australia. *In* Diagnostic Controversy: Cultural Perspectives on Competing Knowledge in Healthcare. C. Smith-Morris, ed. Pp. 127–146. New York: Routledge.