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ABSTRACT

In this paper we use Alvesson and Sandberg's strategy of problematisation to analyse the assumptions embedded in the development and use of the concept of 'care-giver burden'. We do this in order to develop an explanation as to why decades of research into the experience of providing home-based care to a family member with dementia has had little effect in relieving or reducing the 'burden' of that care. Though some part of this is undoubtedly political, our analysis suggests that key assumptions of the research limit both knowledge development and intervention effectiveness. Especially problematic are first, an overriding focus on the isolated care-giver–recipient dyad as the appropriate object of inquiry and target of intervention, and second, an absence of an analysis of the materiality of care and care-giving practices. The heterogeneity of care situations, including interrelations among people, technologies, objects, spaces and other organisational worlds, appear in much of the research primarily as methodological problems, variables to be subdued through a more rigorous application of method. The high volume of research and acknowledged low impact of interventions, however, suggests that rethinking the nature of care practices, and how we come to know about them, is necessary if we are to develop and implement strategies that will contribute to better outcomes for people.

KEY WORDS – care-giver burden, dementia, problematisation.

Problematising care burden research

The purpose of this paper is to analyse the development and use of the concept of care-giver burden in the special case of dementia care in order to contribute to an explanation of why progress towards the goal of 'relieving or reducing' the impact of home-based care on informal care-givers has been slow.

Home-based caring for persons with dementia is a problem that has been widely acknowledged as in need of long-term sustainable solutions in order

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to address family carers' needs for support and assistance. In the North American health-care literature, the idea of families providing care to ailing family members, primarily older family members, has been discussed since immediately after the Second World War. Hoenig and Hamilton (1966) were among the first to conceptualise this care in terms of burden in their analysis of the effects for families and communities of the deinstitutionalisation of persons with mental illnesses. At the same time, they suggested caution in the use of the term 'burden', observing discrepancies in meanings ascribed to situations by the various actors involved. Attempts to assess, to identify causes and to intervene to relieve burden produced contradictory results, not least because outsiders (researchers) and family members did not seem to share the same frame of reference in interpreting their situations. Discrepancies were noted between researchers' assessments of 'objective' burden, what could be measured and observed, and 'subjective' burden, the extent to which families felt themselves burdened, leading Hoenig and Hamilton to hypothesise that for families, aspects of the situation described as burdensome might in fact be preferable to what outsiders, 'anxious to help, had visualized as "relief"' (1966: 167).

Despite this cautious beginning, the recognition of home-based caring work has been almost wholly transformed into the psychological concept of 'care-giver burden' and, from the 1970s to the present, it has been assessed and measured using increasingly complex techniques and calculations. This research literature, however, continues to be characterised by more or less the same inconsistencies described by Hoenig and Hamilton, including the frequent observation of only small to moderate effects of interventions that are intended to relieve burden. Thus, although early research on this topic was motivated by an interest to 'relieve or reduce' the burden of care (Mohide *et al.* 1988; Zarit, Reeves and Bach-Peterson 1980), and to improve family carers' quality of life, 20-plus years later, such ambitious aims are acknowledged to remain unmet (Zarit and Femia 2008). Recently, Lilly *et al.* (2012) noted that after a decade of government effort to convince people to age at home, with promises of adequate support, family care-givers of persons with dementia find themselves 'forgotten, abandoned to care, alone' (*see also* Ward-Griffin *et al.* 2012). So it appears that at the same time as the causes of the experience of burden in the case of dementia care continue to be carefully documented (*e.g.* Askham *et al.* 2007), and techniques to measure or predict it are increasingly refined (Canadian Institute for Health Information 2010), there is little apparent curiosity about why the knowledge developed through extant research has had little appreciable impact on strategies to support the provision of care at home itself. Some part of this is undoubtedly political as citizens and their governments make choices based on priorities, values and practicalities. However, we argue that an unacknowledged contributing factor is simply that much of the research that has grown up around this concept has been 'under-problematised' as to its assumptions (Alvesson and Sandberg 2013). That is, the research has, for the most part and not surprisingly, been based on and bounded by researchers' assumptions about the subject matter in question, assumptions that have remained relatively unchanged over the many decades of care burden research. But clearly, if the goal of relieving the burden of care-givers is acknowledge to have failed, then identifying and opening up these assumptions to question has become necessary. And, at the same time as we consider the assumptions underlying much of this research, we also raise another question: if the research is not contributing to a project of reducing or relieving care 'burden', what is it accomplishing?

Methodological approach: problematisation

Alvesson and Sandberg (2013), drawing on the work of Michel Foucault, propose problematisation as a methodology for identifying and challenging the assumptions embedded in a field of study. The need to rethink or reconsider established ideas arises when the literature of a field becomes conceptually narrow, ineffectual and in their terms, uninteresting. Interestingness is not so much a judgement as a recognition that theories should challenge our assumptions rather than merely reinforce them, thus making un-interestingness an effect of 'a tendency for researchers to reproduce taken-for-granted assumptions and established vocabularies in their fields' (Alvesson and Sandberg 2013: vii), a situation that they suggest is a not surprising outcome of institutional, disciplinary and professional identity demands and practices. As Alvesson and Sandberg note, mass education and mass research 'make many people unwilling to work with deviant ideas' (2013: vii), and so we fall into the practices of 'gap-spotting' research, stolidly building up a picture grounded in accepted ideas rather than working to develop new and interesting questions. Problematising an established body of research as we intend to do with the care burden research does not undermine or minimise its significance but rather simply questions it as to its assumptions. That is, from a position of understanding what is known or believed to be the case about family or informal carers, we ask what else might be possible, how else might we think about this situation. The point, however, is not to 'over-problematise' or completely dismantle the field, but rather to 'unpack' it sufficiently to allow a serious consideration of the theoretical potential of challenging key assumptions – always then, with an eye to providing helpful directions for further study and action (Alvesson and Sandberg 2013: 61–4).

Still drawing on Foucault's genealogical method, Alvesson and Sandberg (2013) propose a series of questions that help to draw out the presuppositions held about a subject and, importantly, the assumptions made about how we should know it. The proposed questions arise from a stance of curiosity, for example, 'how has a certain subject matter become an object of scientific investigation? How have our research questions been produced, and what makes us ask the questions we ask' (2013: 52)? As is apparent, the central ethos of the inquiry is simply a desire to determine what shapes our present understandings of the subject matter in question because it is through these understandings that our research questions are produced. On this point, they cite Bernauer, an astute interpreter of Foucault's *oeuvre*, noting that central to a practice of problematisation are questions that consider 'how the path to our current understanding of the subject matter has been determined, and how exclusions have operated in delineating the subject matter in question' (2013: 52). These kinds of questions work to open the circle of self-confirming questions and answers somewhat characteristic of research practice, wherein both questions and answers arise 'logically from what others have done' (2013: 52). Instead, the questions of problematisation 'stimulate a rethink of one's established ideas and facilitate imagination and a creative reframing of how one conceptualizes and reasons around the subject matter' (2013: 50).

Problematising the research literature involves two steps: an overview of the field to enable description of its broad characteristics and assumptions, and a close reading of key texts (Alvesson and Sandberg 2013). The materials for our analysis were identified through an initial search of key disciplinary and interdisciplinary databases (*i.e.* Medline and Scopus) using the keywords 'caregiver burden' or 'care burden' and 'dementia' and no date limitations. As expected, this broad search produced thousands of results, so the article type 'review' was used to limit the results to those papers describing the 'state of science' of the field of research. This produced a more manageable set of results that included both narrative literature reviews and systematic reviews. Although our review strategy led us to both narrative and systematic reviews of the literature, it is likely that some forms of research, particularly qualitative studies, would be overlooked in this process. However, it is also the case that reviews of the literature, particularly systematic reviews, are typically understood to represent the 'state of science' of a field of study, tending to include studies that are considered by those reviewers to be best practices in research, and thus constitute a body of research that may, in some sense, be considered 'influential'. At the same time, it should be clear that the research examined does not exhaust the research conducted.

Bibliographies of these papers were reviewed and further key review articles were identified. In total, 48 review articles published between 1980 and 2012 were included in the broad overview (*see* supplementary information). From this overview, key articles that represented exemplars of the research, or papers that sought to define terms, identify important elements of the research problem or critically examined existing work were selected for close reading (Alvesson and Sandberg 2013). These selections represented both early contributions to the field and later efforts, including researchers' own re-evaluation of their early work (*e.g.* Zarit and Femia 2008). Questions for both levels of review and analysis were: What is the object of analysis? What are the tools for making this visible? And what is made possible through these research conceptualisations and practices? Analysis was iterative and oriented to developing understanding of both the assumptions underlying the research and, perhaps more importantly, a sense of what is being accomplished through the research.

Outlining the broad view

What seems particularly notable across three decades of the reviewed research is its sameness: sameness in descriptions of context and justifications for studies, in the questions asked, in the 'objects' of the research, in the range of possible interpretations of study data and in proposals for how this 'problem' might be resolved – which underlines Alvesson and Sandberg's (2013) observation that researchers tend to reproduce taken-for-granted assumptions, and that they (we) do this in established vocabularies that re-inscribe social norms, including those that frame research practices. It is partly this characteristic of sameness that makes it relatively straightforward to identify the assumptions shaping this field, even when these are not explicitly formulated, particularly as researchers seem to hold tightly to them even as they note the ineffectiveness of their efforts – both in terms of achieving 'good' research results, but also more practically, in terms of actually relieving 'burden'. For example, much of the literature demonstrates an awareness, and simultaneous dismissal, of the heterogeneity of care situations, carers and recipients. Though diversity, complexity and particularity might be acknowledged, these characteristics of everyday, relational existence are often treated as (simply) barriers to good research results that might be surmounted through, for example, even greater standardisation in research and intervention practices (*e.g.* Malonebeach and Zarit 1991; Ornstein and Gaugler 2012).

To set the stage for a closer reading of some of these key texts, we briefly overview our main observations regarding the broad assumptions of the field, and then in the remainder of the paper we use a technique of close reading to elaborate those assumptions that seem worthy of further problematisation (Alvesson and Sandberg 2013: 59). It is important to note here that we are not claiming that each singular study is informed by identical assumptions; there will undoubtedly be diversity at that level. But at the same time, there is a clear character to the body of research that is amenable to description at this general level.

As Alvesson and Sandberg (2013) note, the assumptions of a field of research will be both multi-level and overlapping. Here we describe four levels of assumptions beginning with the lowest level, what they call *in-house assumptions* (2013: 54). These are mainly discipline-based assumptions that tend to be widely shared and accepted as relatively unproblematic. For example, in this literature we note that 'care-giver burden' is broadly understood as a psychological concept, most often explained with reference to stress and coping theory. This has meant that care-giving is often treated as a disorder, the very 'model of chronic human stress' (Vitaliano *et al.* 1997: 117). This framing of care-giving is also evident in a reliance on measures of psychological disorder (*i.e.* depression) to evaluate care-giver status, and a tendency to medicalise care-givers, for example by figuring them as 'hidden patients' (Houlihan 1987). The assumption of care-giving as disorder has only recently been challenged (Zarit and Femia 2008). Care-giving is also treated as a 'role' that can be examined separately from other roles.

The *root metaphor assumption*, or the broad image of the subject matter in question (Alvesson and Sandberg 2013: 54), is clearly the image of the provision of care as a burden, something that can be (and should be) assessed as to its weightiness, one implication of which is that researchers are encouraged to design and use tools that will enable them to measure and quantify the dimensions of burden, to assign it a weight, as well as to try to figure how much of this weight care-givers can bear and for how long. In this context, researchers must demonstrate that this stress of care-giving is more than ordinary stress, that care-givers are measurably less well off, *i.e.* bear greater burden, than non-care-givers and that selected interventions have a potential to be significant, *i.e.* have measurable effects in reducing the weight of burden or enabling care-givers to bear it longer. Measuring and comparing in these ways justifies practices of triage in the health and social care systems (Van Mierlo *et al.* 2012).

On a more general level, Alvesson and Sandberg (2013) describe *paradigmatic assumptions* as those concerned with what exists and how it can be known. In much of the care burden literature we can observe an ontology and epistemology that assumes human beings and their relations to be divisible, made up of elements that can be studied or measured in isolation. Thus, we see variables such as gender, race and culture, as well as individual 'traits' such as coping style or specific 'problem' behaviours, extracted and made the focus of inquiry. Or the experience of care-giving itself is seen to be divisible into its emotional and physical elements, which again, are treated as isolatable and amenable to study in that state. In all cases, specific aspects of persons or situations are seen as plausibly knowable when separated from everyday relational existence. Currently, these divisions are becoming more and more attenuated, seen, for example, in the desire to develop more detailed knowledge of 'sub-groups' of care-givers so that care-givers with specific characteristics can be treated or targeted with specific interventions (*e.g.* Van Mierlo *et al.* 2012). This might be more convincing if it were not the case that, across the decades, researchers have been working with the same set of fairly mundane interventions: brief respite, emotional or social support, and education.

Finally, *ideological assumptions* express broad, taken-for-granted views held about a subject matter, often rendered in political or moral terms. These are rarely made explicit, however, they will be easily recognisable, reflecting researcher-reader situatedness in a particular societal ordering. For example, in the North American context, a strong ideology of individualism, including the assumption of norms of independence, autonomy and, importantly, responsibility for self and kin, is deeply embedded in this literature, particularly in the almost exclusive focus on the care-giver–care recipient dyad as the appropriate object of inquiry.

A closer reading

These sets of assumptions constitute the boundary assumptions of the field in the sense that they both inscribe and circumscribe much of the research literature we examined. Though this brief overview does offer an interesting glimpse into how this field of research has been constituted, it is not enough to (simply) identify and describe these as we have done thus far. It is not enough because, in themselves, there is little to comment upon, particularly not whether these are the right or wrong assumptions to guide research practices. Rather, the assumptions shaping the research need be considered in terms of their effects. Thus, in a context where the goal of relieving the burden of care-givers is acknowledge to have failed, we consider these identified assumptions in light of our second question: if the research is not contributing to a project of reducing or relieving care 'burden', what is it accomplishing? We will argue in this next section, through a close reading of selected texts, that alongside building a normative and socially situated picture of 'care burden', what much of this research is accomplishing is a very particular understanding of the relationship between the person requiring care and those caring for that person. Even more, the relationships that are being accomplished through this research are, we argue, isolated from social and organisational supports that have, historically, been accessible to individuals and families who have always provided care for their elders.

This reading is informed by the work of Harold Garfinkel (1967) and his writings on ethnomethodology. Ethnomethodology is at once a more philosophical form of sociological thought and, at the same time, highly empirical (Collins 1994). Perhaps one of the most radical aspects of Garfinkel's thought is that

> he holds that one cannot make inferences about the world based on any kind of report. One must go and look for oneself, and one must include oneself in the observation. In fact, one's own methods of making sense out of experiences are the prime object of investigation. The term 'ethnomethodology' itself refers to this focus: 'ethno' or 'ethnography,' the observational study of; 'methodology,' the methods that people use to make sense out of experience. (Collins 1994: 272–3)

As is likely clear, this paper does, in fact, rely heavily on reports – just the thing that Garfinkel rejected as lacking in any utility for making inferences about how the world works. But we are not reading these reports as indicators of how the world works – even though those writing them surely are. Instead, these reports are read as textual remnants of research practices. The idea of 'practice' is important in ethnomethodology. It is through our engagement in practices, including practices of creating (research) accounts, that we accomplish the activities of everyday life. And as Collins writes,

> as soon as we start paying attention to things, we have made them into signed objects and lost them as *Lebenswelt* [life world] objects . . . the objects of the world are constituted by what makes them accountable; they are what they are to us socially because of the symbolic structure we use to account for them to other people. (1994: 274)

As we explored the research on the topic of care-giver burden, we became interested in the things that those researchers were paying attention to and using as 'signed objects' to create an account of this thing they were calling care-giver burden. That is, as researchers engage in the practice of researching, they use particular concepts – like gender, culture, stress and experience – to constitute the idea of care-giver burden in an accountable way to other researchers. So here we examine the practices of researchers who have developed this notion of care-giver burden in order to further excavate the rules they follow, the assumptions they make, and the recommendations they produce – an analysis that helps us come to some assessment as to what this research is accomplishing.

Burden: a peculiarly psychological concept

As noted above, a close reading of this literature underscores the extent to which the concept of 'care-giver burden' is steeped in the disciplines of psychology and social psychology. An example may help here:

> Informal caregiving **simply refers** to activities and experiences involved in providing help and assistance to relatives or friends who are unable to provide for themselves. Whereas caring is the *affective* components of one's commitment to the welfare of another, caregiving is the *behavioural* expression of this commitment. Giving care to someone is an extension of caring about that person. Looked at this way, caring and caregiving are intrinsic to any close relationship; that is, they are present in all relationships where people attempt to protect or enhance each other's well-being…
>
> Considering how quotidian caregiving is, it hardly seems the stuff out of which severe stress springs. **Under some circumstances**, however, caregiving is transformed from the ordinary exchange of assistance among people standing in close relationship to one another to an **extraordinary and unequally distributed burden**. The emergence of a serious and prolonged impairment, such as Alzheimer's disease, is such a circumstance. Where impairment leads to increasing dependency on others for the satisfaction of basic needs, **a profound restructuring of the established relationship** can occur. Caregiving, which previously might have been but one fleeting component of an encompassing relationship, can now come to be the dominant, overriding component. Under conditions of chronic and progressive impairment, therefore, caregiving may imperialistically expand to the point where it occupies virtually the entirety of the relationship. (Pearlin *et al.* 1990: 583, italics and underlining added)

The words and phrases underlined here are, in one sense, just words. These are words that we all use everyday to describe our worlds. However, within the context of an academic journal, they convey very particular meanings, built up through the use of methodological processes approved by a specific disciplinary context – that is, social psychology.

The other words and phrases that are in bold type are then conditioned by their proximity to the words that have disciplinary meanings. Care-giving can be said to be 'simply' something if you hold a conception of the world such that it is made up of discrete pieces that can be detached from the whole and studied at least somewhat independently of that whole. And the opportunity for such study is signalled with the phrase 'under some circumstances'. If the behaviours of care-giving can be excised from the 'affective component' of caring and bounded for study, then the circumstances that alter its 'behavioural expressions' become available for study. Now, years of stress research conducted on graduate students, standing in as 'normal' human beings, becomes relevant. From those studies, researchers believe they know what stress is – what causes stress, what alleviates stress, what happens in a body that is experiencing stress, and so on. Researchers use their disciplinary understandings of 'normal' stress to develop new understandings of what 'severe stress' might look like, what might cause it and what might be the implications of it for the person experiencing it.

Pearlin *et al.* (1990) advance an argument that caring for a friend or relative diagnosed with a chronic and deteriorating disease such as Alzheimer's disease is such a circumstance where a relationship previously characterised by behavioural expressions where care between members was equally distributed, now is unequal. In this circumstance, the burden leads to a 'profound restructuring' of the pre-existing relationship. This stress and coping framework organises much of the subsequent research.

What sort of approach towards people living in situations of home-based care-giving does such a conceptualisation of the world make possible?

The answer to this question may be more complicated than may be imagined. First, people must be conceived of as divisible into beings who both feel (*e.g.* affective component) and act. Further, their feelings and actions can be attributed to intrinsic factors that can be distinguished from extrinsic factors. The work of dividing people up is limited only by the imaginations of those engaged in the divisions. Ian Hacking (2006) has described this sort of scientific activity as 'making up people'. Hacking's interest is in classifications of people and specifically how those classifications affect people and, then, how those affects on those people in turn change the classifications. In the case of care-giver burden, Hacking's approach would encourage us to ask if researchers revise and adapt their classifications of stress when they are studying individuals already determined as being burdened, in contrast to those who have not previously been identified as exhibiting stress in relation to their care-giving duties. Indeed, a wider review of the burden research illustrates a proliferation of elements contributing to the evolution of the classification of care-giver burden.

Dividing up the care-giving relationship

Measuring burden has produced some of the following results: that people who provide care to relatives suffering from a range of chronic illnesses report feeling burdened by that care and, when tested, they demonstrate symptoms of depression; that people caring for relatives with dementia suffer 'higher levels of burden and depression as compared to care-givers of other chronically ill relatives' (Schoenmakers, Buntinx and DeLepeleire 2010: 44); that depression is the main reason for care-givers to abandon home care (Schoenmakers, Buntinx and DelepeLeire 2010); and that there is 'growing concern in many countries about the social cost of caring for people over the age of 65' (Wijeratne 1997: 69). Together, these 'facts' offer a strong narrative underpinning support for research into the concept of care-giver burden.

It would be impossible to describe the entire range of ways that researchers have divided people up in order to study the burdens that care-givers experience. Here we will draw on a 2008 review of this literature to provide some examples of how this has been done.

Etters, Goodall and Harrison (2008) found that gender was one of the first characteristics to be identified that influences care-giver burden. Here, research by Zarit, Reeves and Bach-Peterson (1980) is cited as demonstrating that wives experienced higher levels of care-giver burden compared with other family members. While noting that more recent studies published within the last ten years found no significant differences in burden between adult children and spouses of either gender, Etters, Goodall and Harrison (2008) go on to cite research published between 1998 and 2001 as indicating that female care-givers tend to report more health problems and depressive symptoms than male care-givers.

Another major characteristic used to study the impact of care-giver burden reported by Etters, Goodall and Harrison (2008) was that of 'coping strategies'. Their review of this literature focused on papers published between 2000 and 2006, although they added three others from 1980, 1986 (both by Zarit) and 1998. The literature on coping strategies referenced by Etters, Goodall and Harrison was published in the latter part of that time period – and interestingly begins to illustrate a stronger tendency towards a narrative of care-givers 'taking time for themselves' rather than the sense of giving all of themselves over to their care-giving duties as conveyed in earlier research by Zarit, as well as that already discussed by Pearlin. For instance, Etters, Goodall and Harrison report that 'caregivers reporting stronger self-efficacy and taking time for themselves had decreased burden and a greater quality of life' (2008: 424). Here again, we see a shifting of the classifications – and in this case one that may have negative outcomes for care-givers: as research shifts from supportive interventions to developing 'resilience factors' such as personal mastery, self-efficacy and 'positive' coping styles (*e.g.* Harmell *et al.* 2011), we see the focus moving ever further away from the earlier goal of 'reducing and relieving' burden.

Perhaps one of the most troublesome characteristics that researchers have addressed in relation to its impact on the experience of burden while providing care to relatives or friends with chronic illnesses has been that of culture. Here, for Etters, Goodall and Harrison, we begin to see a multiplying effect of gender and culture where they report that 'studies from various cultures generally find that female caregivers are at greatest risk of caregiver burden' (2008: 424). A cautious reader will note a range of ethnic stereotypes beginning to emerge: while some US studies claim that Caucasian care-givers report higher levels of care-giver stress, including greater depression, than African American care-givers, other (qualitative) studies suggest that both groups of care-givers *experience* similar levels of care-giver burden but *express* it differently.

Beyond measuring expressions of burden on the part of care-givers, researchers of care-giver burden have also explored characteristics of people living with a variety of chronic illnesses to determine which of those characteristics is found to be most burdensome. Here we see studies of the impact on care-givers of aggression, agitation and night-time wandering of their demented relatives. People diagnosed with dementia who continue to be mobile show up in research reports as causing greater levels of burden on their care-givers than those who are immobile.

Divisions with a purpose

Of course, we could go on and on in this vein. Like the researchers who have divided the care-giver burden relationship up into characteristics that are then studied in terms of their relationship to one another, there is a purpose in showing these divisions. Etters, Goodall and Harrison offer a commonly proposed purpose for this research:

> Screening, assessment and monitoring of the degree of burden associated with caregiving are essential. Tools (developed for these purposes of screening, assessment and monitoring of the degree of burden) along with clinical data can help to *predict those caregivers at risk* for significant burden. (2008: 425, italics added)

An immediate concern with the purpose stated here – and one observed in innumerable other similar research studies – is that the purpose of predicting which care-givers are most at risk seems, from the perspective of the Canadian context, to be one that may be purposeful for researchers but such concerns have no corresponding 'hook' into the organisation context within which systems of support for care-givers are put into place. That is, despite generating an 'evidence-based' tool to identify those at risk, the range of remedies on offer by professional social and health-care support personnel who may, on occasion, communicate with informal care-givers, is virtually non-existent. We will return to this issue towards the end of the paper.

At this juncture, we contrast the research arising out of a strong social psychology perspective, with that of an article characterising what might be described as a 'clinical' perspective on care-giving. This is a paper written by Mohide *et al.* (1988). Mohide and Pringle are both nurses (the latter, at the time the paper was written, was research director with the Victorian Order of Nurses or VON, an iconic Canadian home care nursing organisation).

Streiner is a psychiatrist, Gilbert is a physician and Torrance holds an appointment in a Business School.

Mohide *et al.* conducted a research study that was clearly in line with the influences of the day as well as their location within epidemiology and biostatistics (all but one member of the research team held cross-appointments in a Department of Clinical Epidemiology and Biostatistics). They too were measuring – in this case, the wellbeing of family care-givers – but quite different from the measurements described in the previous discussion, these researchers were keen on developing a tool to measure the impact of interventions designed to alleviate burden. These researchers built on the pre-existing recognition that care-giver burden is a feature of daily life for individuals providing care to friends or relatives in homes and community settings. Recognition of burden, they state, 'has led to the development of interventions designed to relieve or reduce it' (Mohide *et al.* 1988: 475). The purpose of including the team member from Business quickly becomes apparent: 'determination of the relative merit of different interventions can be undertaken by an economic evaluation in which both costs and outcomes are measured' (1988: 475).

The approach taken by Mohide *et al.* (1988) to the concept of care-giver burden can be distinguished from research arising from the more dominant framing offered by social psychology in at least two ways. First, they begin from a premise that the burden of caring can be at least reduced and may even be relieved. Second, and following from the first, their work supports action. Using their tool, interventions such as respite care, day care and home supports can be studied for their impact on alleviating the weight of caring for a friend or relative.

Despite these differences, however, the focus of the work and therefore the issues arising from the work of caring for chronically ill friends or relatives, *rest squarely with the care-giver*, thus constructing that relationship as one of being burdened by care.

Academic writing of the sort reviewed thus far – and indeed all academic writing – organises ideas about how things happen in the world and then how we should expect those things to happen. Academic writing is intentional in its efforts to draw ideas together in order to create particular meanings. We do not exclude our own writing from this claim. And this is the real problem with the literature on care-giver burden: it seeks endlessly to develop ever more precise measures of the characteristics of carers and those cared-for to make a determination of the weight of caring or, as in the case of Mohide's research, the possibility that, through the introduction of an intervention, the weight of caring might be (temporarily) relieved. But when we read of interventions such as the Tailored Activity Program (Gitlin *et al.* 2008) that requires six home visits of 90 minutes each over a four-month period in order to train care-givers how to engage in activities designed to reduce behavioural disturbances of their family member, we wonder about the long-term benefit of such interventions. The Tailored Activity Program is designed for care-givers to use *independently*. That is, after the training programme is complete, the day-to-day experience of life returns to 'normal': in most instances, two elderly people struggling to make a life together under conditions where one is being asked to take on the role of physical care-giver to the other who, on a daily basis, becomes less and less able to care for themselves.

The epistemological effect of care-giver burden research thus forces attention to the level of the individual carer and the person he or she cares for – this independent, isolated dyad is advanced in the care-giver burden literature, quite unproblematically, as the correct unit of study. The precision of measurement advocated by researchers such as Pearlin and others suggests that interventions might be designed to shape the carer into a more ideal form. Indeed, such interventions are part of the Tailored Activity Program designed by Gitlin *et al.* who describe one aspect of the intervention being to instruct care-givers in 'stress reducing techniques (deep breathing) to help establish a calm emotional tone' (2008: 231) when working with their family member/friend in the absence of the home visitor.

Whether assessing the characteristics of the carer or the person cared-for, those assessments are focused on maximising the private home as the most efficient and cost-effective location for health-care delivery for those suffering from dementia and other chronic and deteriorating illnesses of older age. For instance, Marvardi *et al.* have tested the Caregiver Burden Inventory (CBI) in a multi-centre trial to determine the extent to which burden can be determined to be a 'fundamental prognostic aspect in the history of the disease (e.g. dementia)' (2005: 46). In their discussion, these researchers provide a strong illustration of the ways in which such research conceptualises the care-giving context:

> Since family caregivers represent the main resource of society and health service for patients with dementia, family caregivers sustain the heaviest burden. Family caregivers of demented patients suffer more frequently from disorders such as depression, and have more physical problems and little time left for social life and work than the rest of the population. A stressed caregiver may also overestimate the actual burden. This may have a negative influence on the outcome of pharmacological treatment and also facilitates institutionalization of the patient. (2005: 50)

This last sentence highlights two of the major costs of older adult care: the cost of pharmacological treatment and institutionalised care. For governments wishing to keep the cost of public expenditures low, healthy family care-givers represent a key strategy in their achievement of that goal. Tools such as the CBI represent a resource easily transformed from research instrument to clinical information system to be used by clinicians to assess and monitor the relative 'health' of the care-giver – perhaps signalling where an occasional low-cost intervention, such as referral to a voluntary care-giving network offering social supports to isolated care-givers, may be understood as an 'immunisation' against failure to maintain the role of care-giver.

Conclusions and new directions

The close reading, together with our initial overview of the broad assumptions of the field, provides empirical evidence that assumptions defining the field of 'care-giver burden' research are somewhat problematic, hindering both knowledge development and effectiveness. This becomes even clearer when we review the agenda being set out for future research: failure to achieve significant research results, in part attributed to the heterogeneity and fluidity of people and situations, has led not to calls to find methods that can deal with this, but rather an instruction to divide people up ever more finely. Thus, we see calls to more carefully define care-givers (Malonebeach and Zarit 1991), to identify and define subgroups of carers and at the same time, to more rigorously stratify care-givers so that the 'most' vulnerable care-givers may become more visible and thus more easily the targets of interventions (Zarit and Femia 2008; Zarit and Reamy 2013). Interventions are to be tailored for care-giver type, targeted to high-risk carers, made dose-specific (Sorenson *et al.* 2006; Smits *et al.* 2007; Parker, Mills and Abbey 2008) – an injunction which cannot help but seem slightly overblown given the still limited repertoire of interventions to be 'applied'. Yet much of the research continuously produces and reproduces this tightly bound triad of care-giver type, problem behaviours and tailored intervention as both the ground and pinnacle of knowledge. Nothing here encourages us to lift our gaze from the isolated care-giver–care recipient dyad as both the object of inquiry and target of intervention, to conceptualise the care-giving situation as anything other than a potentially pathological, yet highly normative, model of human relations.

What else is possible? Bruno Latour (2004) writes of our (sometimes misguided) disposition to treat matters of concern, such as care-giving situations, as matters of fact. We think, for example, that developing and deploying measures of care burden add to the reality of the concept, make it objective and actionable – but objects such as this are 'useless', as many researchers have discovered, when we try to employ them – complex, fluid experiences resist being treated as matters of fact. Matters of fact, suggests Latour, are 'partial, polemical, political renderings of matters of concern', and poor renderings at that, muddling the question of 'what is there?' with the question of how we can know it (2004: 244).

Latour sees new critical possibilities in thinking through the word 'gathering' – a point of reference that directs us to consider 'how many participants are gathered in a thing to make it exist and to maintain its existence' (2004: 245). In terms of the experience of care-giving, 'participants' are not only the individual humans actually present, but also the multiplicity of the material and organisational worlds that work to constitute the experience. The truly remarkable thing about the half-century of care-giver burden research is that almost nothing of these material and organisational worlds is evident. Dominant research methodologies have, through their (successful) efforts of dividing people up, cleansed sites of care-giving of any evidence that there is anything beyond the individuals themselves involved in the actual work of giving care. The whole gamut of practicalities, the multiplicity of material and organisational worlds that shape daily life – almost none of this is evident in the research literature. Where physical, organisational or familial arrangements are supportive of these care-giving relationships, readers are unable to learn about how such supports are experienced because they are carefully – and deliberately – left out of the research account. Conversely, where physical spaces, families, and health and social care agencies (through policies and procedures) isolate seniors experiencing dementia, that too is rendered invisible. The mundane organisational practices that enable organisations to isolate and limit support for older people cannot be addressed if these are systematically removed from our view.

Our analysis of some approaches of knowing about 'care burden' suggests helpful alternative directions for research. Rather than the tightly bound triad of care-giver type, problem behaviour and tailored intervention noted above, and the tendency to treat both care-giving and living with dementia as isolatable from other parts of life, the complexity of care situations may be better apprehended through an analysis informed by a practice such as that of material semiotics (Pols 2012). From this perspective, the elements of everyday life – people, objects, physical spaces, technologies and institutions – are understood to have significance and achieve their form and effects only in relation to one another. So rather than 'cleanse' care-giving situations of this multiplicity of elements, we try to see how they are arranged and with what effects. An example may help here. Struhkamp (2005) articulates an alternative vision of patient autonomy in rehabilitation medicine. She uses insights from material semiotics and actor network theory to demonstrate that autonomy is not so much located 'in' people as in the arrangements of a social and material world through which they are enabled to 'do' things. These arrangements include technologies, institutional routines and practices, as well as the direct and indirect actions of other people that work to make life easier or more difficult. The central point is that an approach that describes and accounts for the multiplicity of actors and arrangements – human but also technological, physical and institutional – offers wider possibilities for action in terms of care (Moser 2011). Care, good care and good experiences with care-giving will also, then, arise from these multifarious activities, routines, arrangements and practices (*see also* Egdell 2013). Considering these, that is shifting our gaze from the care-giver–care recipient dyad to the socio-political–material relations that constitute the isolated and isolating context of care-giving, may lead to a qualitatively different understanding of the matter of concern.

The theoretical potential of challenging key assumptions thus lies in shifting our attention from interventions to arrangements, specifically to knowing the relations and arrangements that might make care-giving good.

Supplementary material

For supplementary material accompanying this paper visit http://dx.doi.org/10.1017/S0144686X14000269.

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