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Putting responsive behaviours in place: Examining how formal and informal carers understand the actions of people with dementia

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ABSTRACT

Living alongside and working with people with dementia who yell or strike out can be very demanding and sometimes harmful. It is generally understood that such actions may be a response to the social and physical environment, yet very little attention has been paid to understanding what role the environment plays in eliciting and responding to these actions across different settings. Drawing on 27 semi-structured interviews with formal and informal carers, this article examines how carers understand the actions of people with dementia in relation to their environment. We identify individual, interpersonal, local environmental, macro-scale and temporal dynamics that influence the actions of people with dementia and carers' capacities to work with them. Drawing on relational thinking and the concept of structural violence, we argue that many of the problems and solutions associated with aggressive actions are located outside the person with dementia in broader relations and systems of care. We conclude with a discussion of how these understandings can inform developments in the systems of home and community care.

1. Introduction

A growing number of people live alongside and work with people with dementia who sometimes communicate and act aggressively (e.g., yelling, hitting, and kicking). For instance, Morgan et al. (2013) reported that 40 per cent of people with dementia in their study exhibited "aggressive behaviour" (pp. 738). Aggression in care relationships can lead to physical and psychological harm, emotional exhaustion, and burnout for carers (Banerjee et al., 2012; Wharton and Ford, 2014). For a person with dementia, being regarded as violent, aggressive, or difficult can have a direct impact on their sense of self, care relationships, and quality of care (Arnetz and Arnetz, 2001; Dupuis et al., 2012). Indeed, both people with dementia and carers may experience harm as a consequence of these actions.

Drawing on person-centred approaches to dementia care, some dementia researchers, carers, and people with dementia have advocated for the need to understand the actions and expressions of people with dementia as responsive behaviours (Dupuis and Luh, 2005; Dupuis et al., 2012). For instance, a person with dementia who strikes out at someone may be expressing an unmet need or "a response to circumstances within the social or physical environment that may be frustrating, frightening, or confusing to a person" (Ontario Ministry of Health and Long-Term Care, 2007, pp. 2). Although person-centred approaches have become the dominant paradigm in dementia care over the last two decades, very little research has focused on understanding the network of social and physical environments in which these actions take place; the handful of studies that exist focus exclusively on institutional settings (Caspi, 2015; McDonald et al., 2015; Pillemer et al., 2012).

The purpose of this paper is to examine the contextual dimensions of actions that are often perceived as responsive and/or aggressive by people who care for someone with dementia. We ask two questions: how do formal (i.e., paid) and informal (i.e., family) carers understand a range of different actions (e.g., yelling, swearing, screaming, hitting, and kicking); and what role does the social and physical environment play in eliciting and understanding them? In the sections that follow, we outline our relational approach to exploring the actions of people with dementia, our study design, and subsequent findings. In our analysis, we locate numerous problems and solutions outside the person with dementia in relationships, environments, and structures of care. In doing so, we critique and contribute to discussions about the extent to which the actions of people with dementia are a response to the social and physical environment as well as broader policies that shape these environments.

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2. Conceptualizing actions relationally

Many terms have been used to describe actions that might be responsive in nature, including challenging behaviours (Todd and Watts, 2005), behavioural disturbances (Graneheim et al., 2005), violence (Arnetz & Arnetz; Banerjee et al., 2012), and most frequently aggression (Enmarker et al., 2011; Pulsford and Duxbury, 2006). This list of value-laden terms refers to a range of actions (i.e., verbal, physical, and sexual) and reflects the strong influence of traditional approaches to dementia care, which sought to manage people with dementia through control, containment, and medication (Dupuis et al., 2012; Kontos et al., 2017). In contrast, person-centred approaches to dementia care have emphasized that the actions of people with dementia should be understood in terms of the individual's unique history and needs (Kitwood, 1997). Although person-centred approaches have played an essential role in recognizing the meaningfulness of individual expressions and addressing victim-blame, they have provided a very limited understanding of how the actions of people with dementia may be experienced as violent or aggressive in relations of care (Herron and Rosenberg, 2017a,b).

The actions of people with dementia, however they are interpreted, are experienced within the context of relationships. Relationship-centred care was developed to address the exclusion of formal and informal carers in person-centred approaches to dementia care (Adams and Gardiner, 2005; Nolan et al., 2002). Using person-centred and relational approaches, research has illustrated the importance of interpersonal communication, compassion, and gentle approaches in working with people with dementia (Dupuis et al., 2012; Duxbury et al., 2013). Much of the empirical work on responsive behaviours and aggression focuses on the perspectives of formal carers who are working within a broader system of care that is focused on care needs and tasks. As a consequence, research in this area tends to adopt a management discourse in which the actions of people with dementia are interpreted in terms of care needs (e.g., a manifestation of pain or a response to care activities such as toileting, bathing, and dressing) that must be managed. Moreover, Kontos et al. (2017) argue that relational approaches to dementia care have typically focused exclusively on small scale interpersonal relationships excluding the role of the state and its institutions in their analyses.

To address the limits of interpersonal analyses, several scholars have used the concept of structural violence (Banerjee et al., 2012; DeVerteuil, 2015; Herron and Rosenberg, 2017a,b). Structural violence refers to “the role that institutions and social practices play in preventing people from meeting their basic needs or realizing their potential” (Banerjee et al., 2012, p. 390). Banerjee and colleagues argue that the violence that formal carers experience in long-term care is influenced by larger structural factors such as increasing workload, lack of training, and the task-oriented nature of the system of care. Herron and Rosenberg (2017a,b) suggest that home-based carers also experience structural violence as a result of social practices and institutional structures that constrain carers’ ability to talk about aggression. Rather than view violence as a single event occurring between two people, researchers are increasingly interested in understanding how violence is embedded in institutions of care (Clifford Simplican, 2015; Kelly, 2017).

In this paper, we expand relational approaches to dementia care in line with relational thinking in health geography (Andrews et al., 2013; Cummins et al., 2007; Skinner et al., 2015). Relational thinking in geography conceptualizes individuals, places, and macro-scale political processes, such as structural violence, as a complex co-constructed network. For example, the physical and social space of the home is connected and constructed in relation to social norms and material resources in the community in which it is situated, as well as regional centres in which many specialized health and social services are often centralized. Following this thinking and consistent with the critiques above, research on the actions of people with dementia in care relationships must move beyond individualizing approaches and small scale interpersonal analyses to consider a more comprehensive range of interconnected influences on these actions. It must focus, at once, on the situations in which people with dementia act, the social and physical dynamics of the environment (e.g., social proximity, power relations, congestation, temperature, and noise), and the broader political and cultural context of care. Looking at the perspectives of formal and informal carers, we seek to understand actions in care relationships and across a range of settings and scales. In doing so, we contribute to the relatively small body of research on dementia in health geography (see Egdell, 2013; Herron and Rosenberg, 2017a,b; Thomas and Milligan, 2017) and the much more extensive interdisciplinary field of research on dementia care.

3. Methods

To collect detailed information about how carers experienced and responded to the actions of people with dementia in particular contexts, we conducted 27 semi-structured interviews. The interview method was ideal for the project because of its emphasis on understanding the meanings associated with a diverse range of actions in depth and detail (Dunn, 2016). The method also provided an opportunity for the researchers to build rapport with participants, discuss sensitive information at a time and place that was comfortable for them, and carefully follow up with prompts to clarify their interpretations and feelings.

With ethics approval from the University Ethics Committee and the Regional Health Authority (RHA), a purposive sample of carers was recruited for interviews between June 2016 and June 2017 in a largely rural region in southwestern Manitoba, Canada. The region is comprised of a series of small towns and agricultural areas oriented around a single regional service centre, the city of Brandon, with a population of 48, 859 residents (Statistics Canada, 2016). The surrounding health region includes 14 First Nation Band councils/communities, 15 Northern Affairs community councils, 30 Hutterite colonies/communities and a growing number of immigrants (Bollman and Ashton, 2014; Prairie Mountain Health, 2013). To recruit participants in the region, the authors attended monthly Alzheimer support groups for informal carers and staff meetings for formal carers. Recruitment notices were featured in local newspapers and sent to health professionals through the RHA listserv. The authors also phoned all 43 Personal Care Homes (PCH) in the region (ranging in size from 16 to 100 beds); that is, residential facilities that provide personal care services to older people and people with chronic conditions or disabilities who can no longer manage independently at home with family support. In total, 9 informal and 18 formal carers were recruited for the study (see Tables 1 and 2). All formal carers worked in mid-sized (30–60 bed) PCHs in the region. All informal carers cared for someone with dementia who exhibited responsive or aggressive actions and had moved into a PCH. The latter criteria were used because people who are in the midst of caring for someone with dementia whose actions are experienced as aggressive or violent may be too overwhelmed, threatened, or hurt to participate in research during that time. The inclusion criteria was also chosen to

Table 1
Characteristics of informal carers.

Pseudonym	Age	Gender	Relation	Years of care
Patricia	71	Female	Spouse	1
Barry	68	Male	Spouse	3
Evelyn	86	Female	Sister	4
Margaret	63	Female	Spouse	9
Jennifer	32	Female	Daughter	9
Richard	63	Male	Son	9
Ingrid	76	Female	Spouse	5
Rose	66	Female	Spouse	10
William	68	Male	Son	5