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Evaluating dementia home care practices: The reification of care norms

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ABSTRACT

This critical ethnographic study examined how power relations shape the nature and enactment of caregivers' evaluation of home-based dementia care practices. As the home care sector continues to evolve and prepare itself as a key element in caring for people living with dementia and their families, this study grounds our understanding of how dementia home care practices are enacted and evaluated, particularly at the interface of formal and familial caregiving. The critical finding from our data is that not all evaluations of care practices were considered equally meaningful or relevant, and, moreover, their significance depended on whether the evaluation was made by someone in a position of power. Renewed awareness of and attention to power relations, such as class and gender, are implicated in the evaluation of care practices. Consequently, challenging how power is enacted in ways that (re)produces and reifies care norms is vital in order to foster equitable and supportive partnerships in home-based dementia care.

Introduction

The [Canadian Home Care Association \(CHCA, 2008\)](#) describes home care as a strategic area that must be developed in order for our health care system to address the current and future needs of Canadians. Indeed, in the past decade, the home care sector has undergone enormous growth: home care programs across Canada have experienced a 51% increase in the number of home care recipients to approximately 900,000 ([CHCA, 2015](#)). As the proportion of people with dementia living at home continues to increase, so does the need for home care over extended periods ([Cranswick & Thomas, 2005](#); [Manuel et al., 2016](#); [Smetanin, Kobak, & Briante, 2009](#)). In response to this growth, scholars in health, nursing, and gerontology agree that Canada needs an integrated model of dementia care that includes community and home-based care ([de Witt & Ploeg, 2016](#); [Forbes & Neufeld, 2008](#); [Grant et al., 2004](#); [Lilly, Robinson, Holtzman, & Bottorff, 2012](#)). Economists and policy-makers echo the call for a strengthened home care system ([Chappell & Hollander, 2011](#); [Hollander, 2001](#); [Keefe, Légaré, & Carrière, 2007](#)).

Many families turn to the health care system for support when a

caregiving situation becomes untenable, often due to insidiously progressive dementia and high family caregiving demands. This support often entails caregivers entering into relationships with formal care providers who provide care within the home and to people living with dementia. As the demands of dementia care outstrip familial resources, formal (i.e., paid rather than unpaid) carers become involved, often including nurses, therapists, and social workers, as well as para-professional caregivers such as nurses' aides and personal support workers ([Canadian Institute for Health Information \[CIHI\], 2007](#)). In addition to providing family caregivers with respite, formal care providers often perform the same 'dementia care practices' as their unpaid counterparts. For instance, in Ontario, 67% of formal home care has been provided by personal support workers and 27% by nurses ([Ontario Home Care Association \[OHCA\], 2008](#)); however, up to 90% of the time, this in-home care is provided by families and friends, and it is anticipated that these unpaid hours of care will more than triple, increasing from 231 million hours in 2008 to 756 million hours by 2038 ([Manuel et al., 2016](#); [Smetanin et al., 2009](#)).

Since care is most accurately understood as a relationship, the experiences of both its recipients and its providers require further

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attention in the efforts to support and ensure quality of care (Aronson, 2004; Clare & Shakespeare, 2004; Dupuis, Epp, & Smale, 2004; Ward-Griffin, 2012). Furthermore, if the health promoting and supportive elements of the CHCA's definition of home care are to be realized, further attention to the inter-personal relationships inherent in negotiating and evaluating home-based dementia care seems warranted. Our critical ethnographic study focused on home-based dementia care, on examining perspectives from all those involved in the in-home provision of care, and situating these experiences within a socio-cultural context that influence the formation and negotiation of those relationships. In particular, we critically examined the relational experiences of clients, family caregivers, and providers involved in dementia home care to broaden our understanding of how specific socio-cultural factors, specifically power relations such as gender or class, shape these negotiations and evaluations of the care received/provided.

Literature review

Although individuals with moderate cognitive impairment are able to determine their daily care needs and preferences (Butcher, Holkup, Park, & Maas, 2001; Menne, Tucke, Whitlatch, & Feinberg, 2008) and are able to communicate meaningfully with others (Acton, Mayhew, Hopkins, & Yauk, 1999), it has been suggested that person living with dementia often face significant challenges when communicating their preferences to their families as their dementia progresses (St-Amant et al., 2012). As such, people with dementia are often excluded from evaluating aspects of their care (Menne & Whitlatch, 2007). However, it is important to take into consideration their evaluations of the care received to better understand their experiences of living with dementia, and to develop improved treatment and care practices (Phinney, 1998).

Although there is evidence of a need for awareness – that home care supports may be shaped by socio-cultural factors, such as gender, class and age (Ward-Griffin, 2012) – more research is needed to address this insight in order to evaluate and develop appropriate dementia home care practices and policy. In evaluating formal dementia care supports, family caregivers have reported lacking information about services and the ability to access services (Dello Buono et al., 1999; Forbes, Morgan, & Jansen, 2006; Ward-Griffin, 2012), resulting in poor lines of communication between informal and formal care networks.

There have been mixed results in evaluating the effectiveness of community services and/or formal care providers' practices with respect to reducing stress among family caregivers (Stone & Jones, 2009; Ward-Griffin et al., 2012). Although these studies allow for nurses and other health professionals to focus on interventions that may meet caregivers' needs, additional studies are needed to examine home care services and care management for family members who are affected by dementia, and how these services are evaluated and by whom.

Few studies have investigated formal health care providers' perceptions of evaluating dementia care practices (Guberman, Lavoie, Pepin, Lauzon, & Montejó, 2006). However, investigations have been conducted of formal care providers' experiences with home care system issues, such as access to services in rural areas, professional sensitivity to cultural and gender expectations of the client and family (Whittier, Scharlach, & Dal Santo, 2005), workload and workplace satisfaction, and the lack of standardized home care services across Canada (Manning, 2004). One study in particular explored formal health care providers' views regarding their experiences in the dementia care system (Jansen et al., 2009). Participants included nurses, social workers, therapists, home care aids, and Alzheimer Society staff, and the authors conclude that despite client-oriented respite and caregiver empowerment, several challenges to the system of dementia care were identified, namely time constraints, system fragmentation and a lack of coordination. More research that uses a critical lens is needed to identify and address these systemic challenges, particularly those challenges experienced by marginalized or vulnerable groups in society.

Those few studies that have critically examined the relationships

between family caregivers and providers of in-home care (McWilliam & Ward-Griffin, 2006; Ward-Griffin & McKeever, 2000; Wuest, Ericson, Stern, & Irwin, 2001), and specifically relationships between family caregivers and providers caring for individuals with dementia (Ward-Griffin, Bol, Hay, & Dashnay, 2003) have found that those involved in familial dementia home care are not a homogenous group. Family caregivers represent various socio-political locations, such as gender and class, which shape the type of care expected and provided (Butcher et al., 2001; St-Amant et al., 2012). For instance, gendered norms of familial care often influence and affirm gendered care expectations for women to assume traditional caregiving roles (Anjos, Ward-Griffin, & Leipert, 2012; Pavalko, Henderson, & Cott, 2007; Ussher & Sandoval, 2008). In such a case, carers are afforded access (or not) to power in ways that reify their gendered position(s), wherein their ability to speak and be heard, to direct and/or provide care can go uninterrupted, becoming cemented as normal practice, policy and expectation related to evaluation.

Other scholars have examined the caregiving experiences of husbands caring for a wife with dementia (Brown, Chen, Mitchell, & Province, 2007; Kramer, 2000; Sanders & Power, 2009). Similarities to women's experiences exist insofar that husbands also adapt their marital roles to the new roles they assume as caregivers and that they often have to learn how to form new types of relationships with their ailing wives (Sanders & Power, 2009). In a grounded theory of help-seeking among older caregiver husbands, Brown et al. (2007) described how 'changing patterns' leads to the core category 'doing the best I can' and the three sub-categories of behaviors and relating: 'Letting others', 'Getting others' and 'Doing my part'. 'Letting others' was a passive activity where the husbands let others, usually a daughter or other woman, assume responsibility for care. 'Getting others' was an active process involving the husband seeking help either from informal sources, such as neighbours, friends, church members, other family members (usually women) or from formal services such as home health, companion services, and housekeeping. 'Doing my part' occurred when husbands cared for the wife, performed household chores and assisted with activities of daily living, or when there was no one else to do it.

In addition to gender, class has also been found to influence the caregiving experiences of husbands caring for wives with dementia. Kramer (2000) found that more highly educated husbands expressed less gain compared to their counterparts with less education, suggesting the former may perceive tasks of caring as lower status, intellectually unimportant, or less pressing than financial burdens. While a few studies have shown how gendered exemptions (i.e., arguably 'legitimate excuses' for not being involved as a carer, such as living far away; see Finch, 1989) are equally as influential on men's caregiving experiences (Anjos et al., 2012), more research needs to be done to increase our understanding of how gendered and classed values and assumptions of familial care in dementia may enter into the evaluation of care received/provided.

In addition to care provided by husbands and wives, adult children of people living with dementia provide care (Pinquart & Sörensen, 2011), but the care provided by adult children can also differ with their parents. Adult children tend to be characterized as care managers rather than care providers, especially if the other parent is available to provide care (Brodsky & Donkin, 2009). Such discernment places the hands-on care of activities of daily living (dressing, feeding, bathing, etc.) with spouses while informal managerial roles tend to be comprised of arranging for others to provide care (Brodsky & Donkin, 2009). Even when multiple family care managers become involved, the hands-on care is often left to just one individual (Schulz & Martire, 2004; St-Amant et al., 2012). Not unexpectedly, the burden of caregiving is often greater for spouses than adult children, and among all caregivers, it is greater for women than for men (Pinquart & Sörensen, 2011). For example, daughters are three times more likely than sons to provide familial dementia care to their parent (Pinquart & Sörensen, 2006). Additionally, it has been shown that sons' involvement in care is often

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