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From home to ‘home’: Mapping the caregiver journey in the transition from home care into residential care

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ABSTRACT

Family caregivers play a pivotal role in supporting the functional independence and quality of life of older relatives, often taking on a wide variety of care-related activities over the course of their caregiving journey. These activities help family members to remain in the community and age-in-place for as long as possible. However, when needs exceed family capacities to provide care, the older family member may need to transition from one care environment to another (e.g., home care to nursing home care), or one level of care to another (from less intense to more intensive services).

Drawing upon qualitative interview data collected in a populous health region in British Columbia, Canada, this study explores the roles and responsibilities of family caregivers for family members making the care transition from home care to residential care. A thematic analysis of the interview transcripts resulted in the development of a conceptual framework to characterize the “Caregiver Journey” as a process that could be divided into at least three phases: 1) Precursors to transition - recognizing frailty in family members and caregivers prior to transition; 2) Preparing to transition into residential nursing home care (RC) and 3) Post-transition: Finding a new balance - where caregivers adjust and adapt to new caregiving responsibilities.

Our analyses revealed that the second phase is the most complex involving a consideration of the various activities, and roles that family caregivers take on to prepare for the care transition including: information gathering, advocacy and system navigation. We conclude that there is a need for family caregivers to be better supported during care transitions; notably through ongoing and enhanced investments in strategies to support caregiver communication and education.

Introduction

Family caregivers play an instrumental role in supporting the functional independence and quality of life of family members as their health status declines, and their need for care and assistance increases (Gitlin & Wolff, 2011; Levine, Halper, Peist, & Gould, 2010). Some of the care specific activities that family members provide assistance with include help with eating, bathing, laundry, emotional support and companionship, as well as assistance with obtaining formal health and long-term care (LTC) services (Cranswick & Dosman, 2008; Gitlin & Wolff, 2011; Levine et al., 2010; Rosenthal, Martin-Matthews, & Keefe, 2007; Taylor & Quesnel-Vallée, 2016). Other activities family caregivers take on in the caregiver journey include help with tasks that extend beyond the provision of direct, “hands on” care, and into the realm of what might be labelled “care management.” Care management includes such tasks as information seeking, handling finances, doing relevant paperwork, and coordinating family support efforts (Rosenthal et al., 2007).

Current research suggests that around 5.4 million Canadians provide care to an older family member or friend (Turcotte & Sawaya, 2015). The real scope of caregiving however, is likely greater than what is reported, as caregivers’ often underreport their caregiving activities. Moreover, the intensity of caregiving support is greatest for those living with a care recipient. Family caregiving for those living in facilities is also notably high in intensity, with 22% of those in this group indicating that they provide 10 or more hours of care a week (Turcotte & Sawaya, 2015).

Generally speaking, family caregivers are seldom considered to be integral members of the ‘team’ within the long-term care (LTC) sector (Dilworth-Anderson & Palmer, 2011). As a consequence, limited attention has been paid to how these caregivers’ manage a family member’s transition from home care (HC) into a residential, nursing home (RC) care setting, despite this being one of the most common care trajectories experienced by clients (Cloutier & Penning, 2017). Care transitions can be defined as movements from one system of care to another, (e.g., home care to residential care, or one level of care to another) and arise in

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response to changes in health status, and when the need for additional care exceeds family caregiving resources and capacities (Callahan et al., 2012; Coleman & Boulton, 2003).

The formal LTC sector comprises a wide-range of publicly and privately funded services designed to address the health, social, and personal care needs of individuals who have lost some capacity for self-care (Federal/Provincial/Territorial Subcommittee on Continuing Care, 1992). Although LTC occupies a pivotal place in the care continuum, as in other sectors, the supports and services that it provides have been heavily criticized as being fragmented, poorly coordinated, and difficult to access due to variability in provincial policies, funding levels, availability, and eligibility criteria (Chappell & Hollander, 2013; Havens, 1995). Research has shown that older adults are more vulnerable to negative outcomes during care transitions based on their increased frailty, and a lack of continuity in care between health sectors and systems (Dilworth-Anderson & Palmer, 2011). Some of these specific outcomes include: medication errors, poor compliance, inappropriate care and increased hospitalizations (Coleman, 2003; Dilworth-Anderson & Palmer, 2011; Sato, Shaffer, Arbaje, & Zuckerman, 2011).

Care transitions mark significant changes in the lives of older adults, but can also have a significant impact on the lives of family caregivers, including family, friends, and neighbours who bear the lion's share of responsibility for facilitating these relocations (Coleman, Parry, Chalmers, & Min, 2006; Giosa, Stolee, Dupuis, Mock, & Santi, 2014; Moon, 2016). Forced to work largely on their own, within the boundaries of an unfamiliar health care system where eligibility criteria, financing standards, and policies determine the level of care their family member receives, caregivers routinely experience the stress that the transition into RC generates. (Afram, Verbeek, Bleijlevens, & Hamers, 2014; Ashbourne, 2015).

This study explores the primary research question: How do family caregivers navigate and experience the transition from HC into RC for a family member?

The study context

Aging trends and increased longevity are altering the demographic profile of many countries around the world. While the majority of older adults live independently in their own homes in the community, in Canada, as in other jurisdictions, age is associated with the increased likelihood of the need for formal LTC services (CIHI, 2011; Luppá et al., 2010; Sivanthan, Lavergne, & McGrail, 2015). Between 2011 and 2016, the number of people aged 85 and over grew by 19.4%, nearly four times the rate for the overall Canadian population (Statistics Canada, 2017).

In the province of BC, where this research is set, LTC includes a broad continuum of home and community-based services, often called home care (HC), that includes home nursing and personal support work; assisted living (AL) that is, housing for semi-independent older adults; and residential care (RC) for those who need more intensive and supportive care on a continuous, 24-h basis. When an individual can no longer live safely or independently at home, due to substantial changes in medical and functional health, RC may be the only option. In BC, admission to RC requires contacting the local health authority and requesting a formal assessment by a case manager to determine eligibility. From there, individuals and families are asked to identify their top three RC facility choices based on needs, and are then placed on a waitlist until a suitable bed becomes available. According to a recent report by the Office of the Seniors Advocate for BC (2016), the demand for HC and RC services has been increasing, while the range and mix of these services has been shrinking.

Alongside increased demand for LTC resources, there has been a corresponding increase in pressure on family caregivers due to the dynamics of increased divorce rates, decreased fertility rates, and greater geographic distances for family members to overcome in caring for their loved ones (Chappell, 2011). These challenges contribute to caregiver stress and burnout; place greater demands on specific kinds of

health services such as respite, convalescent, and end of life care; and ultimately, may result in decreased quality of life for both the caregiver and care recipient (Health Council of Canada, 2012).

Methods

This study was conducted in a populous and diverse health region located in Western Canada. We stratified the region into three contiguous geographic sub-regions: urban, suburban, and rural based on a range of attributes, including population density and growth rates; number of health care providers per capita; number of hospitals, number of hospital and residential care beds; and nature of economic diversity and development. With lower population densities and fewer economic and health resources in rural communities, our expectations were that aspects of the family caregiver experience and journey would differ depending on where family members were located and receiving care.

Sampling and data collection

In this study, all caregivers were related by blood or marriage to the older adult who was making the transition from HC to RC. Health region representatives on the research team (Hainstock) facilitated initial contact with local RC facilities to support recruitment. These methods included flyer distribution and in-person efforts by the lead author through attendance at facility-hosted family information sessions. Family caregivers who self-identified as the primary person involved in the management of their family member's move from HC into RC in the past five years were recruited to participate. Ethical approval was obtained prior to conducting the interviews through the BC Ethics Harmonization Initiative, a joint process involving the University of Victoria and the health region in which the study took place.

While the original goal was to generate a total sample of 30 caregivers, 10 in each type of geographical setting (urban, suburban and rural), recruitment proved more challenging given time and other pressures facing the existing workforce. In the end, a total of 15 one-on-one, semi-structured interviews were undertaken between July 1st and November 30th, 2015. Fourteen interviews were held in the caregiver's home, and one was held in a private meeting room at the RC facility in which their family member received care. All family caregivers were still caring for family members at the time they were interviewed, although the move from HC into RC occurred anywhere from 13 months, to five or more years earlier. Interviews ranged from 45 to 150 min in length. Each interview was taped and transcribed.

After each interview, field notes and journal entries were recorded. Seven of the 15 interviews were completed with urban, three with suburban, and five with rural caregivers. Nine interviews were conducted with daughters caring for an older parent (eight were caring for their mother, and one for their father), while five were conducted with a caregiving spouse or common-law partner. One interview took place with a husband and wife who provided care jointly to the wife's sister. In this case, both caregivers had equal opportunity to respond to the questions. This resulted in a final sample of 16 caregivers. All caregivers were assigned pseudonyms, and all interviews were matched with numeric identifier codes to protect anonymity and confidentiality for participants.

Caregivers ranged in age from 46 to 87. Most were married ($n = 9$); four were single, two were divorced, and one was in a common-law relationship. The majority of those interviewed had some level of post-secondary education, with only two caregivers indicating high school as their highest level of education. Only two women were employed at the time of the interview, while 13 were retired, and one was unemployed. Caregivers lived between 1.4 km and 34.8 km from their family member's care facility.

Family caregivers were asked questions in two key areas: about the kinds of care activities they had engaged in before, during and after the

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