



## Adult children caregivers' experiences with online and in-person peer support



Marina Bastawrous Wasilewski<sup>a,\*,1</sup>, Fiona Webster<sup>b</sup>, Jennifer N. Stinson<sup>c</sup>,  
Jill I. Cameron<sup>a,d</sup>

<sup>a</sup> Rehabilitation Sciences Institute (RSI), Faculty of Medicine, University of Toronto, 160-500 University Ave., Toronto, ON M5G 1V7, Canada

<sup>b</sup> Department of Family and Community Medicine, University of Toronto, 500 University Avenue, 5th Floor, Toronto, ON M5G 1V7, Canada

<sup>c</sup> The Hospital for Sick Children, Peter Gilgan Centre for Research and Learning, 686 Bay Street, Room 069715, Toronto, ON M5G 0A4, Canada

<sup>d</sup> Department of Occupational Science and Occupational Therapy Rehabilitation, Faculty of Medicine, University of Toronto, 160-500 University Ave., Canada

### ARTICLE INFO

#### Article history:

Received 14 July 2016

Accepted 1 August 2016

#### Keywords:

Peer support

Caregiving

Online support

In-person support

Communication modality

### ABSTRACT

**Background:** Adult children caregivers (ACCs) are increasingly caring for elderly parents, which can cause health declines. Peer support—offered online and in person—can enhance caregiver well-being. To date, studies have largely focused on evaluating online interventions and therefore caregivers' personal experiences with web-based support are under-represented in the literature. Further, online and in-person support have been investigated independent of one another, limiting our understanding of how caregivers engage in and experience peer support across modalities.

**Research questions:** 1) How do ACCs use online and in-person modalities to obtain support? 2) What type of support is exchanged within each modality?

**Methods:** Qualitative descriptive design. We conducted in-depth interviews with 15 ACCs. Data was thematically analyzed.

**Findings:** ACCs mobilized existing network members for support. ACCs pragmatically used a blend of modalities for peer support based on their complex needs. The nature of peer support that ACCs receive transcended the interaction modality.

**Conclusion:** Dichotomizing support as either 'online' or 'in-person' may detract from our ability to understand how ACCs use multiple modalities to achieve their support goals. ACCs' approach to peer support was complex. This highlights the need for future interventions to emulate their naturally pragmatic and flexible support-seeking style.

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### 1. Introduction

As North America and Europe's elderly population continues to grow (Giannakouris, 2008; Raina, Dukeshire, Lindsay, & Chambers, 1998), caring for an aging parent will increasingly become part of adult children's lives (Brody, 1985). In the U.S. and Europe, 49% and 30% of all caregivers are adult children, respectively (National Alliance, 2015; Riedel & Kraus, 2011). In Canada, 62% of caregivers over 45 years old are adult children (Cranswick & Dosman, 2008). The literature suggests that caregiving experiences differ according

\* Corresponding author.

E-mail addresses: [marina.bastawrous@utoronto.ca](mailto:marina.bastawrous@utoronto.ca) (M.B. Wasilewski), [fiona.webster@utoronto.ca](mailto:fiona.webster@utoronto.ca) (F. Webster), [jennifer.stinson@sickkids.ca](mailto:jennifer.stinson@sickkids.ca) (J.N. Stinson), [jill.cameron@utoronto.ca](mailto:jill.cameron@utoronto.ca) (J.I. Cameron).

<sup>1</sup> Twitter: @mbastaw.

to the caregiver and care-recipient relationship (Colvin, Chenoweth, Bold, & Harding, 2004). This underscores the importance of focusing on the specific and unique experiences of adult children caregivers (ACCs). With the aging of the population, parental care has become a normal part of the life course (Cruz-Saco, 2010). However, complex and prolonged care provision to parents is often at odds with ACCs' other age-normative responsibilities such as employment, social activities and commitments to their own spouse and children (Bastawrous, Gignac, Kapral, & Cameron, 2015). In turn, the parent care role can act as an added stress that exacerbates health decline and the restrictions in social functioning and quality of life experienced by ACCs (Anderson, Linto, & Stewart-Wynne, 1995; Bastawrous et al., 2015; McCullagh, Brigstocke, Donaldson, & Kalra, 2005; Wade, Legh-Smith, & Hewer, 1986).

The different dimensions of the caregiving situation (e.g.

situational, personal, behavioral) can overlap and impact caregivers' health and well-being (Pearlin, Mullan, Semple, & Skaff, 1990). Due to the stressful nature of the caregiving situation, this impact is often negative (Pearlin et al., 1990). These caregiving-related declines can be mediated by the presence of social support (i.e. informational, emotional, and instrumental (tangible) assistance) (House, 1981). Conversely, when social support isn't available, caregivers may experience financial, physical and psychosocial costs (Zarit & Whitlatch, 1992). Caregivers' perception of social support (i.e. their appraisal that support from others is valuable and available when needed) is especially important as it has a stronger association with physical and mental health than actual support received (Barrera & Baca, 1990; Bolger & Amarel, 2007; Uchino, 2009). Qualitative investigation within this realm can therefore play an important role in expanding our understanding of caregivers' perspectives on and experiences with social support.

Peers are a key source of social support for caregivers (Toseland, Rossiter, & Labrecque, 1989). Homophily theory suggests that when peers are experientially similar (e.g. share caregiving commonalities such as care recipient relationship or illness), a supportive relationship ensues out of mutual understanding and empathy (Pillemer & Suito, 2002; Sabir, Pillemer, Suito, & Patterson, 2003). When caregivers are similar to their peers, there is a greater chance that the support they receive from peers will match their actual needs (Colvin et al., 2004). Support from peers can decrease isolation, buffer stress, and increase caregivers' self-efficacy (Cohen & Wills, 1985; Hibbard et al., 2002; Pinquart & Srensen, 2007). Several studies have explored the delivery of supportive interventions using various modalities. Peer support interventions have typically been delivered as in-person group sessions that are offered by community or healthcare organizations (Stewart et al., 2006) or through telephone support programs (Shah et al., 2015; Stewart et al., 2001). Due to geographic and time constraints, however, many caregivers are turning to the Internet for this type of support (Lewis, Hobday, & Hepburn, 2010).

Healthcare interventions are increasingly being delivered online due to the Internet's unique ability to reach a large number of people in a cost-effective and convenient manner (Griffiths, Lindenmeyer, Powell, Lowe, & Thorogood, 2006). These features have simultaneously promoted the development and widespread use of online social support groups (Burrows, Nettleton, Pleace, Loader, & Muncer, 2000). For tech-savvy ACCs (i.e. those who regularly use cell phones and have high-speed Internet in their homes (Coughlin, Lau, D'Ambrosio, & Reimer, 2009, p. 12)), the flexibility of accessing peer support from anywhere and at any time can be especially beneficial given their busy schedules. Early comparisons between online and in-person communication, however, argued that online interaction lacked the relational and identity cues (e.g. tone of voice, physical appearance, body language) associated with in-person communication. Therefore it was thought that online communication only permitted impersonal and inferior support relationship (Brown, Broderick, & Lee, 2007; Wright, 2000). In light of this position, a great deal of recent literature has focused on investigating web-based support interventions for caregivers and showing that it is a feasible and valuable modality for intervention delivery and support exchange (Wasilewski, Stinson, & Cameron, 2016). Analyses of online caregiver discussion forums indicate that asynchronous Internet interaction can address caregivers' inability to attend in-person support groups (Smyth & Harris, 1993; White & Dorman, 1999). Online interventions have also been shown to positively improve caregivers' health and well-being (Beauchamp, Irvine, Seeley, & Johnson, 2005; Pierce & Steiner, 2013).

As has been pointed out by Colvin et al. (2004), the literature's

focus on evaluating online interventions and analyzing the content of online communication has led to an underrepresentation of caregivers' personal reflections on using this modality for peer support exchange. While Colvin et al.'s (2004) study on caregivers' perspectives of the unique advantages/disadvantages of online social support provides important qualitative insight to address this issue, its focus on the online experience alone underscores an additional limitation in the existing literature. To date, studies have largely investigated online and in-person caregiver peer support in isolation of one another. This approach affords a detailed focus on each modality and provides valuable insights into their unique aspects—e.g. the benefits of peer-led vs. Professional-led in-person support groups (Toseland et al., 1989) or the effectiveness of Internet interventions tailored to caregivers' worksite or home setting (Beauchamp et al., 2005; Pierce, Steiner, & Govoni, 2002). However, we only gain a partial understanding of how caregivers engage in and experience peer support across modalities.

Non-caregiving communication literature cautions against the view that online interaction exists separately from (rather than being integrated with) other day-to-day forms of communication (Haythornthwaite & Wellman, 2002; Miller & Slater, 2001). In light of this, the Internet should be considered one of many modalities that are used to achieve social and cultural goals as well as maintain relationships (Baym, Zhang, & Lin, 2004; Matei & Ball-Rokeach, 2002). Our study adopted this perspective and aimed to explore ACCs' experiences with online and in-person peer support exchange while caring for an elderly parent. Specifically, we aimed to answer two questions: 1) How do ACCs use online and in-person modalities to obtain support? 2) What type of support is exchanged within each modality?

## 2. Methods

### 2.1. Research design

The data for this paper was derived from a larger mixed method study. For the qualitative portion of the study, we employed a descriptive approach. Qualitative description entails a concise and descriptively rich analysis that remains true to the data. In this way, it is less interpretative than other qualitative traditions and produces a “data-near” report (Sandelowski, 2010). This method of qualitative inquiry produces an account of the data that is easily interpreted by practitioners, thereby making the findings meaningful to these key stakeholders and potentially applicable to care situations (Sandelowski, 2000).

Qualitative description borrows from phenomenology and grounded theory in so far as it uses an iterative data collection and analysis process and allows for a theoretical frame to guide the design of a study and the analysis of findings (Sandelowski, 2010). However, unlike research using grounded theory, we did not aim to use the experiences of individuals to build a theory or conceptual model (Creswell, 1998). Additionally, we did not conduct a study applying phenomenology because we did not aim to construct a prototype of “lived experiences” across ACCs (Creswell, 1998). Rather, we aimed to describe the range and type of experiences that ACCs had with interacting with peers either online or in person.

### 2.2. Participants

Participants were eligible for this study if they were (a) centrally involved in providing and/or coordinating care for their parent (i.e., aiding with one or more activities of daily living (ADLs) at least once a week), (b) English-speaking, (c) 18 years of age or older, (d) assisting their parent in Canada, and (e) in contact (either online or in person) with someone who is also caring for a family member.

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