Reconciling Tensions: Needing Formal and Family/Friend Care but Feeling like a Burden*

Rachel Barken
Department of Sociology, York University

RÉSUMÉ

Dans le cadre d'une politique néolibérale qui transfère la responsabilité pour la santé et le bien-être de l'État aux familles et aux individus, les stratégies canadiennes pour soins à domicile ont tendance à présenter les membres de la famille comme « partners in care ». En s'appuyant sur une étude interprétative fondée sur une théorie qui comprenait 34 entrevues qualitatives, cet article examine les expériences des personnes âgées aux intersections des soins à domicile formels et arrangements pour les soins dispensés par la famille et les amis, dans le contexte de politiques mettant l'accent sur les partenariats avec les familles. Le concept fondamental tiré des entrevues était de concilier les tensions entre le besoin de soins et le souci de surcharger les autres, dans le contexte des soins à domicile et communautaires disponibles. Quatre processus sont identifiés, qui illustrent la façon dont l'accès aux ressources financières et sociales peut conduire à des opportunités et des contraintes dans l'expérience de soins. Les résultats mettent en évidence les défis émotionnels et pratiques que les personnes âgées peuvent rencontrer vis-à-vis le discours encourageant les familles à assumer la responsabilité des soins. Les implications pour la politique et la pratique sont discutées.

ABSTRACT

Within a neoliberal policy context that shifts responsibility for health and well-being from the state to families and individuals, Canadian home care strategies tend to present family members as "partners in care". Drawing on an interpretive grounded theory study that involved 34 qualitative interviews, this article examines older people's experiences at the intersections of formal home care and family/friend care arrangements, against the backdrop of policies that emphasize partnerships with family. The core concept derived from the interviews was reconciling tensions between care needs and concerns about burdening others, in the context of available home and community care. Four processes are identified, which illustrate how access to financial and social resources may lead to opportunities and constraints in experiences of care. Findings underscore the emotional and practical challenges that older people may encounter vis-à-vis policy discourses that encourage family responsibility for care. Implications for policy and practice are discussed.

La correspondance et les demandes de tire-à-part doivent être adressées à : / Correspondence and requests for offprints should be sent to:

Rachel Barken, Ph.D.
SSHRC Postdoctoral Fellow
Department of Sociology, York University
359A York Lanes, 4700 Keele St.
Toronto, ON M3J 1P3
(rbarken@yorku.ca)

As a result of neoliberal policies, which have effectively shifted responsibilities for care away from the state and onto families and individuals, home care strategies in Canada now regard family members as "partners in care" or as the primary care providers to older people living with chronic health conditions and disabilities (Funk, 2013; Martin-Matthews, Sims-Gould, & Tong, 2013; Ward-Griffin & Marshall, 2003). Across Canada, publicly funded home care services provide personal and clinically related care as well as some homemaking, but these services are rarely designed to meet all of individuals' needs for health and social care. Rather, family members and friends, often referred to and relied upon as "informal" carers, give the majority of support to older people in Canada (Keefe, 2011).[1] Estimates suggest that nearly 90 per cent of Canadians who receive care at home are supported by family and friends, and that about half of these individuals also receive some formal home care (Sinha & Bleakney, 2014).

Given the heavy reliance on unpaid care within home care policies and practices, researchers have developed several models that address how the receipt of formal home care impacts on family/friend care and vice versa (Cantor, 1979; 1991; Chappell & Blandford, 1991; Greene, 1983; Kemp, Ball, & Perkins, 2013; Litwak, 1985; Ward-Griffin & Marshall, 2003). Extant research on the relationship between formal and family/friend care, however, tends to overlook older people's everyday experiences at the intersections of systems of care (but see Allen & Ciambrone, 2003; Porter, Ganong, Drew, & Lanes, 2004). On the basis of a grounded theory study that involved 34 qualitative interviews, I explore older people's experiences at the intersections of formal and family/friend care. Their experiences are considered against the policy backdrop of restricted access to publicly funded home care services and a reliance on family members as "partners in care".

Context

Neoliberalism and Home Care

A neoliberal ethos guides the structure and delivery of home and community care services throughout Canada (Armstrong, 2010; Neysmith, 2000). Reflecting a decline in the welfare policies that were predominant in the mid-twentieth century, neoliberal governance is premised on a shift in responsibility for health and social services from the state to individuals (Breheny & Stephens, 2012; Rose, 2000). Rather than providing services directly, states often "govern at a distance" to reduce spending on a variety of services. States encourage personal and familial responsibility for health and well-being as well as the development of private and market-oriented organizations that are controlled through "techniques of accountability such as centrally

set but locally managed budgets, and the practices of evaluation and auditing" (Rose, 2000, p. 324). Fears about looming fiscal crises in a global economy, as well as the so-called economic drain of a population living longer with chronic conditions and disabilities, may be considered rationales for limiting older people's entitlements to health and long-term care (Gee, 2000; Weicht, 2013).

In alignment with this neoliberal ethos, home care services throughout much of Canada are provided through a mixed-market model of service organization and delivery (Aronson, Denton, & Zeytinoglu, 2004; Martin-Matthews et al., 2013). In Ontario, publicly funded home care services are contracted out from the government to a variety of for-profit and non-profit agencies that provide services directly; to access these services, individuals with needs for care must meet certain assessment criteria (Ontario Association of Community Care Access Centres, 2014). Reflecting the emphasis on family and individual responsibility, the stated goal of formal home care is to complement – but not to replace – the care that family and friends provide (Canadian Home Care Association, 2013). Family members are often depicted as "partners in care", and home care organizations may provide support and education for family carers (e.g., Brookman, Holyoke, Toscan, Bender, & Tapping, 2011). Individuals and families with the financial means or with private insurance may also elect to purchase care from a burgeoning private home care industry. Individuals need not undergo assessments to determine eligibility for private home care services, but, rather, may choose the amount and type of services they receive from the available options.[2]

Recent research has demonstrated how family members are increasingly relied upon as primary care providers in policy documents as well as in practice, giving insight into the demands that current policies place on the families of people who are receiving home care. In a context of reduced supports, case managers must increasingly communicate to clients and families that they are expected to take responsibility for providing care themselves and that they cannot expect formal care services to play an intensive role in care provision (Peckham, Williams, & Neysmith, 2014). Paradoxically, policy documents and service providers tend to convey the message that it is at the same time a moral imperative *and* a personal choice to keep an older relative at home (Funk, 2013). Critics argue that such messages obscure the broader goals of cost containment that underlie home care policies. In reality, the lower costs of home care are often borne out by unpaid carers, most often women, who take on significant responsibilities for caring for older people and for navigating a complex home care system (Keefe, 2011; Ward-Griffin & Marshall, 2003).

The Relationship between Formal and Family/Friend Care

Researchers have developed several models that address the relationship between formal home care and family/friend care (see Table 1). As Ward-Griffin and Marshall (2003) explained, some conventional models reflect the interests of service providers and aim to show how family members might effectively complement formal care to reduce health care costs (e.g., Chappell & Blandford, 1991; Greene, 1983). Other models are more critical and shed light on inequalities in care provision and on the invisibility of the care provided by (mostly female) family members (Kemp et al., 2013; Ward-Griffin & Marshall, 2003).

The four predominant "conventional" models date back several decades and examine the partnerships and division of labour between formal and family/friend care providers (Ward-Griffin & Marshall, 2003). The hierarchical compensatory model (Cantor, 1979; 1991) suggests a preference for spousal care followed by care from children or other relatives, with formal care serving as a replacement when family or friends are unavailable. The substitution model (Greene, 1983) posits that formal care results in a decline in family/friend care. The task specificity model (Litwak, 1985) suggests that formal and family/friend care providers perform different tasks, and that the nature of the task determines the source of care. Finally, the complementary model (Chappell & Blandford, 1991) finds that formal care supplements – but does not replace – family/friend care, and that it is typically used when care recipients' needs exceed the caring capacities of family or friends. Although there is limited empirical support for the first three models (Ward-Griffin & Marshall, 2003), several studies support the complementary model (Chappell & Blandford, 1991; Davey & Patsios, 1999; Denton, 1997; Penning, 2002).

Critics argue that these "conventional" models are outdated and are limited because they (1) consider formal and family/friend care as distinct rather than intersecting systems; (2) assume the effectiveness of partnerships between formal and family/friend care providers;

(3) neglect the gender dynamics of care work (Ward-Griffin & Marshall, 2003); and (4) do not account for the full array of systems and individuals involved in care arrangements (Kemp et al., 2013). The emphasis on family care as preferable to formal care may also reflect the priorities of professionals and policymakers – who work in a context that tends to focus on cost reduction – rather than the interests of care providers (Ward-Griffin & Marshall, 2003) or of persons receiving care (Kemp et al., 2013).

In alignment with the criticisms just raised, two critical approaches have emerged more recently and consider the intersections between formal and family/friend care in socio-structural contexts. First, Ward-Griffin and Marshall's (2003) socialist-feminist model views "female caregiving as highly skilled emotional, mental, and physical work that crosses "public and private" boundaries" (p. 204). Ward-Griffin and Marshall's (2003) framework recognizes the interlinkages between public and private spheres, the gender dynamics and power relations involved in care work, and the ways political, social, and economic circumstances, such as cutbacks to services in a market-modelled system, shape the distribution of care work. Empirical research using the socialist-feminist model finds that complex intersections exist between formal and family care work. Nurses and family carers may develop dynamic relationships that change over time, and nurses' tasks are often transferred to family carers (Ward-Griffin & Marshall, 2003). Although Sims-Gould and Martin-Matthews (2010) did not use the socialist-feminist model explicitly, they similarly considered how family carers "share the care" with formal care providers. Examples are when family carers prepare meals in advance of formal care providers' visits, or when formal care providers leave notes for family carers (Sims-Gould & Martin-Matthews, 2010, p. 417).

The second critical model suggests that formal and family/friend care providers and persons receiving care are all involved in "convoys of care" (Kemp et al., 2013). This model builds on Kahn and Antonucci's (1980) convoy model of social relations, which suggests that convoys, or dynamic networks of personal relationships,

Table 1: Models of the relationship between formal and family/friend care

Conventional Models	Critical Models
Hierarchical compensatory: Preference for family care, ordered by primacy of relationship (Cantor, 1979; 1991).	*Socialist-feminist:* Gender dynamics shape transfer of care tasks from formal to family care providers (Ward-Griffin & Marshall, 2003).
Substitution: Formal care leads to decline in family care (Greene, 1983).	*Convoys of care:* Various individuals (*including care recipients*) negotiate care relationships in socially structured contexts (Kemp et al., 2013).
Task specificity: Formal and family/friend care providers perform distinct tasks (Litwak, 1985).	
Complementary: Formal care supplements (but does not replace) family care (Chappell & Blandford, 1991).	

are mechanisms for distributing and exchanging social support. A convoy of care includes all of the people, including formal and family/friend carers, who provide an individual with health care, socio-emotional support, monitoring, advocacy, and help with activities of daily living and instrumental activities of daily living. Convoy members can change over time and "may or may not have close personal connections to the recipient or to one another" (Kemp et al., 2013, p.18). Structural and environmental characteristics of the care setting; power dynamics associated with gender, class, race/ethnicity, health, and age; and the personal characteristics of convoy members all influence the relationships among people who are involved in care activities. In the convoy of care model, individuals directly involved in care relationships are conceptualized as active participants who engage in negotiations in socio-structural contexts.

The aforementioned models represent important advances in critical understandings of the relationship between formal and family/friend care. Yet, extant models tend to overlook the experiences and perspectives of older people in need of care – despite the fact that these individuals are positioned at the intersections of formal and family/friend care arrangements. There are a few notable exceptions suggesting that the constructs of "formal" and "informal" care are artificial and may not reflect the experiences of persons receiving care (Allen & Ciambrone, 2003; Porter et al., 2004). Rejecting the "formal/informal" dichotomy, Porter et al. (2004) suggested a new typology based on qualitative interviews with older widows who receive care in their homes: the regular helper, the can-will doer, the on-call helper, and the mainstay. Based on research with persons receiving care, Allen and Ciambrone (2003) similarly found that formal care providers sometimes take responsibility for needs such as emotional support that are typically met by family members or friends, whereas family members sometimes take on traditionally formal roles, such as that of case manager.

With the exception of these few studies, gaps in extant research leave us with a limited understanding of the relationship between systems of care and of the everyday realities of the older people around whom systems of care are organized. More research is needed to (a) extend knowledge on the relationship between formal and family/friend care, and (b) better understand how policy contexts impact on the experiences of older people in need of care.

Methods and Data

Interpretive Grounded Theory

This study formed a part of the author's doctoral thesis research undertaken in 2014–2015, which used interpretive grounded theory to explore older people's experiences at the intersections of formal home care, family/friend care, and self-care (Barken, 2015). Grounded theory was originally developed as a methodology for generating theoretical concepts that "fit" (are applicable to) and "work" (are relevant to) the empirical settings under investigation (Glaser & Strauss, 1967). Since its inception, multiple versions, understandings, and uses of grounded theory have emerged (Oleson, 2007). On the one hand, objectivist variants seek to develop deterministic predictions and explanations of a universal reality (e.g., Glaser, 1978). On the other hand, the more recent interpretive and constructivist variants – which formed the bases for this study – emphasize understanding rather than explanation; view data as situated, social constructions that emerge throughout the research process; and acknowledge the existence of multiple realities (Charmaz, 2006; Corbin & Strauss, 2008). Drawing on interactionist sociology, interpretive grounded theorists "study *how* – and sometimes why – participants construct meanings and actions in specific situations" (Charmaz, 2006, p. 130, emphasis in original). In this study, I used interpretive grounded theory to conduct and analyse interviews with older people using home care.

Theoretical Sampling

Following ethics approval from the McMaster Research Ethics Board, I used a theoretical sampling framework to recruit participants. Theoretical sampling, a key aspect of grounded theory, involves "sampling on the basis of concepts derived from the data" (Corbin & Strauss, 2008, p. 65). I identified emerging concepts throughout data collection, and then recruited participants whose experiences might present variations to further develop concepts and ultimately lead to theoretical saturation – that is, the point at which additional data cease to provide new insights (Charmaz, 2006; Corbin & Strauss, 2008). For example, I noted that participants who were financially comfortable had different experiences of care than those who had meagre financial resources. To obtain a theoretical sample, I distributed flyers and brochures at subsidized seniors' housing, places where people on low incomes might live.

In the end, I arranged for various means of recruitment, including (a) presenting at seniors' groups and day programs; (b) a research associate at a home care organization contacting clients directly; (c) seniors' ministries at religious institutions contacting members; (d) home care case managers and supervisors distributing brochures; (e) posting flyers in seniors' housing and community centres; (f) distributing information to potential participants at a caregiver exhibition; (g) Meals on Wheels drivers distributing brochures; (h) sending an e-mail through an LGBT seniors' mailing list; and

(i) word of mouth. All participants were age 65 or older, lived in the Greater Toronto and Hamilton Area, and received formal home care services for ongoing support with daily activities such as bathing, dressing, housework, or clinically related care. I excluded people who were receiving formal care on a short-term basis (less than two months) for acute conditions, as well as people with dementia or cognitive limitations due to ethical concerns regarding their ability to understand the interview process and provide informed consent.

Data Collection

I collected data through intensive interviewing, an interviewing technique that "permits an in-depth exploration of a particular topic or experience" from the perspectives of research participants (Charmaz, 2006, p. 25). Intensive interviews are understood as contextual and negotiated processes in which researchers and participants reconstruct their subjective worlds (Charmaz, 2006). Although I used a semi-structured guide to elicit participants' experiences of care, the interview structure was loose and conversational, enabling participants to share any information they felt was relevant. I used probes to inquire further about specific viewpoints and experiences; for example, I often asked participants to describe in more detail their perceptions of receiving support from family and friends. Participants often discussed their experiences of care within a broader life context; relating it to what else it enabled them to accomplish, their relationships with family and friends more generally, and their experiences of growing older.

The interviews lasted between 21 minutes and two hours, with the average length being 56 minutes. With participants' consent, each interview was audio-recorded and professionally transcribed. Interviews took place in participants' homes, with the exception of two that were conducted by telephone at participants' requests. I conducted most interviews with individual care recipients. One married couple participated in an interview together. In three cases, family members participated in the interview and assisted with providing answers at participants' request. I assigned pseudonyms for all participants, which are used in the findings section.

Data Analysis

Following Corbin and Strauss' (2008) principles of interpretive analysis, I conducted open, axial, and selective coding. Open coding involved breaking the data apart to identify concepts; axial coding involved relating concepts to one another; and selective coding involved identifying the concepts that were most central to the final interpretation of the data (Corbin & Strauss, 2008). To conduct open coding, I read each interview transcript very closely and assigned words or short phrases (i.e., codes) to the concepts presented in the interviews. I then conducted axial coding to build process into the analysis. This involved asking theorizing questions of the data in order to consider the contexts and contingencies of incidents within each code as well as the relationships between codes. Here, I undertook a constant comparative analysis to identify similarities and differences among incidents coded in the same way (Corbin & Strauss, 2008). For example, one code that I identified during open coding was "feeling in control of home care". Axial coding involved considering whether feelings of control differed between participants who were paying privately for home care and participants who were receiving publicly funded home care. Finally, during selective coding, I identified the core concept that represented participants' experiences of formal and family/friend care, as well as processes that illustrated dimensions and variations of the core concept. I used QSR International's NVivo 10 (http://www.qsrinternational.com/product), a qualitative analysis software package, to facilitate data storage and retrieval throughout the coding process.

Trustworthiness

Although interpretive research is subject to multiple interpretations, I used three strategies to ensure that the analysis was trustworthy – that is, that it is a fair and credible representation of participants' experiences of care (see Corbin & Strauss, 2008). First, I conducted negative case analysis throughout the iterative processes of gathering and analysing data, and refined emerging concepts accordingly (Creswell, 2013). I carefully considered negative cases, which represented variations in emerging concepts, to provide a holistic interpretation of participants' experiences. Second, I conducted member checking to assess the credibility of findings from the perspectives of both participants and practitioners in the home care field (Corbin & Strauss, 2008; Creswell, 2013). I distributed a lay summary of the study's findings to participants and professionals who assisted with recruitment. Although I did not request feedback directly, some participants and professionals commented that the findings accurately reflected their experiences of receiving care or their observations from working in home care. Finally, I present rich, thick descriptions of research findings, including details on participants' backgrounds and living circumstances. With an in-depth understanding of participants' experiences, readers may come to their own conclusions about the credibility of the data and its transferability to other settings (Erlandson, Harris, Skipper, & Allen, 1993).

Profile of Participants

Of the 34 participants included in this study, 26 (76.4%) were women and eight (23.5%) were men. Participants ranged in age from 65 to 100, with the average age

being 81. All participants were White. Although 21 (61.8%) were born in Canada, 11 (33.3%) had migrated from various parts of Europe, and two (5.8%) had moved to Canada from the United States. All participants lived in the Greater Toronto and Hamilton area. Participants were from diverse class backgrounds. Twenty (58.8%) had some university or college education, six (17.6%) had graduated from high school, and eight (23.5%) had never completed high school (see Table 2).[3]

Participants' health problems or impairments were complex and diverse. Three quarters of participants (*n* = 26) had developed increased needs for care or health problems in later life. Heart conditions, chronic pain, arthritis, and diabetes were some of the more common health problems among participants. One quarter of participants (*n* = 8)* had long-term disabilities and chronic health conditions that began earlier in life (roughly before the age of 60), ranging from cerebral palsy to Parkinson's disease to HIV. Participants received formal care from various sources: the majority of participants (*n* = 30; 88.2%) had undergone assessments by Community Care Access Centre case coordinators and were deemed eligible for publicly funded home care services. Of these 30 participants, five paid for some home care privately, in addition to receiving publicly funded home care. Three participants (8.8%) used only formal home care for which they paid privately.

Participants also had varying levels of support from family and friends. The majority of participants, (*n* = 21; 61.8%) were widowed, divorced, or never married and lived alone, while seven (20.6%) lived with spouses or partners, and four (11.8%) lived with adult children. One participant lived with a niece, and one other with a live-in home care worker. Some participants discussed very positive relationships and received consistent, high levels of support from family and friends, while others had very few family members or friends who helped them, and sometimes had experienced conflicting or abusive relationships with family.

Findings

The core concept derived from the data analysis was reconciling tensions between care needs and concerns about burdening others, in the context of available home and community care. Contrasting with policies that encourage partnerships with family members, findings suggest that participants' experiences of care were shaped first and foremost by their strong desires to retain a sense of independence and to avoid placing too many demands on family and friends. As the following quotes illustrate, these concerns were often framed in terms of the responsibilities that younger generations faced as they balanced careers, childcare,

and sometimes health problems of their own (see also Peters, Hooker, & Zvonkovic, 2006):

> I don't want to go with my children. It's not because my children aren't nice; no, I don't want to bother … they have their own life, their own family. (Celia, 71)

> But she is also working and she found out she has a blister in the brain, too. So I don't want to aggravate her … you know, elderly people have to realize, you can only so much ask the children. (Lise, 81)

> My nieces live far away … I sometimes wish they lived closer and could do a little more shopping for me. I don't like to call them where, you know, they're so far away … but I survive. I have enough. (Beth, 82)

Although concerns about burdening others were common, participants had diverse formal and family/friend care arrangements. As illustrated in Figure 1, the following four processes account for diversity in experiences of care, and demonstrate variations of the core concept reconciling tensions: (1) turning to formal home care as a first choice, (2) coordinating networks of formal and family/friend support, (3) engaging in relations of reciprocity, and (4) struggling with unmet needs. Against the backdrop of available home and community care, contextual dimensions that framed experiences of care included access to financial resources as well as support from family or friends. These contextual dimensions highlight the opportunities afforded to some older people with financial means and strong networks of support, as well as the constraints that some older people with low incomes and limited social support may experience. Taken as a whole, the core concept reconciling tensions and the related processes underscore the emotional and practical challenges that older people may encounter vis-à-vis policy discourses that emphasize family responsibility for care.

Turning to Formal Home Care as a First Choice

Although participants often enjoyed close and supportive relationships with family members, they did not want established family relationships to spill over into the work of care. Participants attempted to use formal home care services as much as possible, and given the limited availability of publicly funded home care, they often relied on private home care services to complement or serve as an alternative to public home care. The process of turning to formal home care as a first choice was therefore typically only available to participants who had access to financial resources and/or insurance plans to purchase home care services privately. As such, this process highlights inequities in access to care within the current policy context. Social locations of privilege, and in some cases life course experiences that resulted in increased coverage for health and

Table 2: Demographic profile of participants

Pseudonym	Gender	Age	Marital Status	Country of Origin	Education	Work History	Living Arrangement	Type of Formal Care (public/private)	Main Source of Family/ Friend Caregiving
Alice	F	92	Widowed	Canada	College	Secretary, stay-at-home mother	Alone in apartment	Public	Son, granddaughter, some friends occasionally
Andy	M	75	Married	Holland	University	Engineer	With wife in condominium	Public	Wife
Angela	F	65	Single, never married	Canada	University	Nurse	Alone in apartment in retirement community	Public	None
Anne	F	100	Widowed	United States	Some university	Philanthropist	Alone in condominium	Private	Friend's daughter occasionally
Beth	F	82	Widowed	Canada	College	Nurse	Alone in apartment	Public	Nieces, sister-in-law, friends occasionally
Carol	F	98	Widowed	England	High school	Stay-at-home mother, volunteer	Alone in apartment in retirement community	Public	Daughter
Celia	F	71	Widowed	Italy	Some high school	Factory work, retail	Alone in house	Public	Sister, neighbours, daughter, and son
David	M	82	Widowed	Scotland	Some college	Communication technician	Alone in house	Public	Daughters
Diana	F	79	Single, never married	Canada	University	Financial industry	Alone in apartment	Public	Friend
Donald	M	70	Single, never married	Canada	Some high school	Unemployed due to disability, some work in office	Alone in apartment in subsidized seniors' housing	Public	Family occasionally
Doris	F	78	Divorced and widowed	Canada	Elementary school	Factory work, housekeeper, server	Alone in apartment in subsidized seniors' housing	Public	Daughter occasionally
Earl	M	92	Widowed, now lives with partner	Hungary	Some college	Draftsman	With partner in condominium	Public	Intimate partner, daughter, son
Ellen	F	89	Married	Canada	High school	Beautician, dance instructor	With husband in house	Public	Husband; daughter occasionally
Fannie	F	83	Married	Hungary	Some high school	Stay-at-home mother	With husband in condominium	Public and subsidized private	Daughter and son occasionally
Hannah	F	90	Single, never married	Germany	High school	Government administration	Alone in house	Public	Neighbour occasionally
Ingrid	F	91	Widowed	Estonia	Some high school	Custodian	With daughter in condominium	Public and private	Daughter
Joe	M	89	Married	Czech Republic	Some high school	Store owner	With wife in condominium	Public and subsidized private	Wife; daughter and son occasionally
Josie	F	82	Widowed	United States	College	Secretary	Alone in apartment in subsidized seniors' housing	Public	Daughter

Table 2: Continued

| Pseudonym	Gender	Age	Marital Status	Country of Origin	Education	Work History	Living Arrangement	Type of Formal Care (public/private)	Main Source of Family/ Friend Caregiving
Judy	F	75	Divorced	Canada	Some elementary school	Did not specify; some unemployment	With son in apartment in subsidized seniors' housing	Public	Son
Kate	F	77	Divorced	England	University	Social worker	With daughter and granddaughter in house	Subsidized private	Daughter
Lise	F	81	Widowed	Germany	College	Factory work, accountant	Alone in apartment in retirement community	Public	Daughter and son-in-law
Louisa	F	74	Divorced	Canada	Some university	Financial analyst	With son in apartment	Public	Son
Maggie	F	89	Widowed	Canada	College	Secretary, housekeeper	Alone in house	Public	Daughters and sons-in-law
Marion	F	89	Widowed	Canada	University	Doctor	Alone in condominium	Private	Sister, daughters and son
Martha	F	67	Divorced and widowed	Canada	Some high school	Stay-at-home mother, call centre	Alone in apartment in subsidized housing	Public	Daughter
Norah	F	68	Single, never married	Canada	College	Early childhood educator	Alone in apartment in attendant care building	Public	Friends
Phillip	M	84	Married	Canada	High school	Owner of construction company	With wife in condominium	Public and private	Daughter
Ray	M	66	Common-law partner	Canada	University	Interior decorator, music producer, disc jockey	With partner in house	Public	Intimate partner
Robert	M	89	Married (wife lives in long-term care)	Canada	High school	Steel mill worker	With niece in house	Public	Niece
Rosa	F	93	Widowed	Canada	Elementary school	Factory work, retail	Alone in apartment in retirement home	Public	Daughter
Ruth	F	73	Single, never married	Canada	University	Teacher, president of computer company	Alone in condominium	Public	Friends
Sarah	F	68	Divorced	Canada	University	Dental hygienist	Alone in condominium	Public	Son and daughter-in-law
Suzanne	F	80	Divorced	Canada	University	Actress, activist	With live-in care worker in house	Public and private	None
Yolande	F	72	Divorced	Canada	Some university	Truck driver, singer, waitress, owned convenience store	Alone in apartment in subsidized seniors' housing	Public	None
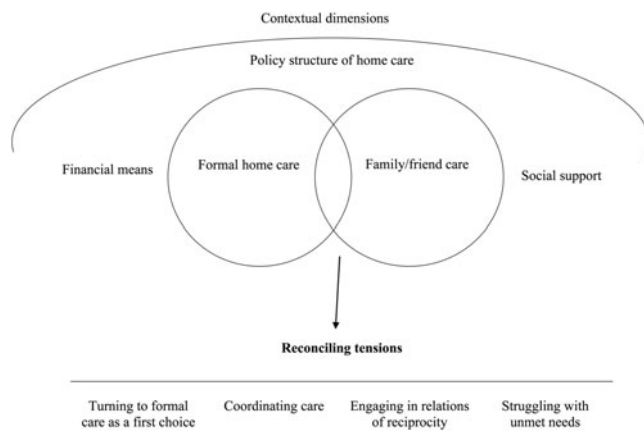
Figure 1: Experiences of formal and family/friend care

social care, afforded some individuals access to formal care that extended beyond publicly provided services. These participants tended to consider support from family members to be a choice rather than a necessity.

The examples of Joe and Fannie, and of Suzanne, illustrate how participants turned to formal care to mitigate the perceived burdens that their care needs placed on family. Joe and his wife Fannie clearly asserted that they preferred to receive formal care, and food from Meals on Wheels, rather than to ask their children to help with cooking and cleaning. As Holocaust survivors, the costs for additional home care services such as Meals on Wheels were covered by compensation claims from the German government (Claims Conference, 2012). Joe and Fannie's adult children lived nearby, and the couple enjoyed regular visits with them. Yet, when asked if there were things they liked, or things they would like to change about their relationships with their children, Fannie replied:

> And, with the kids, I mean, if I would tell them that, "Please cook us meals," they would, but it's not the same. We love them, okay, and they love us and I don't think it's reasonable to ask them to do that, okay? (Fannie, 83)

Suzanne also turned to formal home care as first choice, and to do so she drew on her considerable financial means and hired a live-in companion to help with various tasks that ranged from bathing and dressing to cleaning her home, to walking her two dogs, to driving her to appointments and events. Although Suzanne (twice divorced) enjoyed occasional visits with her children and grandchildren, she clearly asserted her preference to pay for someone to provide care. She felt that it was unfair and unrealistic – for both older people and for their adult children – to expect families to take on caring responsibilities. Yet, Suzanne recognized that most people did not have the financial means to pay privately for a live-in companion and had few

options but to turn to family; perhaps moving in with them and relying on them for financial support:

> You see I'm really one of the very few fortunate people. I have a person that lives here with me. And so I have all the help I need to get from A to B … you know, this thing of the family's looking after their parents … many of them are not in the same city. And they may not have room. And also the worst part is that the parent often, I would say, doesn't want to go. I mean I just think that would be a nightmare to be made to go and live with the children, and think you'd have any independence at all. It's something that should be much more in the hands of the sick person than in the hands of the family. And because often people treat elderly people very, very badly and very rudely, especially when they're all of a sudden in their house. That awful thing of money becomes "Well, who's paying for you?" You know, "Who's doing this?" (Suzanne, 80)

Coordinating Formal Home Care and Family/Friend Care

When participants coordinated care, the complementary relationships or partnerships between formal and family care that are espoused in policy discourses did indeed exist in practice. Here, participants actively engaged in relations of support with formal care providers as well as family or friends. To reconcile their care needs with their concerns about burdening others, participants carefully made choices about when, where, and from whom they received care. In doing so, participants maintained a sense of autonomy and independence even as they received support from others. Similar to examples where participants turned to formal care as a first choice, participants tended to coordinate care when they were in relatively privileged social locations: They often drew on social advantages related to their knowledge of community resources, strong and supportive relationships with family and friends, and sometimes financial resources that enabled them to pay for additional supports. Moreover, participants tended to coordinate care when they had the physical, cognitive, and social capacity to play a more active role in their care arrangements.

Consider, for example, Ruth's and Phillip's experiences of care. Although Ruth was technically allotted publicly funded home care for bathing, she directed her own care: Because she could bathe alone, Ruth arranged for the home care worker to use the time allotted for bathing to help with household tasks, such as cooking and cleaning, that were difficult for her to do alone since she had lost her vision. Complementing this formal support, Ruth relied on a wide circle of very supportive friends for help with transportation, shopping, and chores. Ruth also had the financial means – acquired

throughout the course of her career as a business professional – to pay someone to clean her condominium. As the following quote demonstrates, Ruth expressed a sense of autonomy at the intersections of formal home care and relations of support with friends and family members:

> They [home care worker] can do some shopping for you … It's very rare that I ask her to do that but today I forgot to ask anyone [friends] to pick it up … she would have run out and done it. She does whatever I need … even my cleaning lady who of course, I pay … she knows that I have a thing about my place looking really good. (Ruth, 73)

Coordinating care also involved thinking and planning ahead to ensure that one would have access to sufficient care in the future if changes in health status, ability, or access to care were to arise. Ruth's words illustrate her active involvement in arranging her own care, and her efforts to avoid relying too heavily on friends:

> I'm already thinking, for instance, if I lose the [publicly funded] support worker … what will I do for food when my vision gets worse. I'm already thinking, if this friend, you know, moves or goes somewhere … I'm starting to work it all out. … . (Ruth, 73)

Phillip similarly expressed considerable autonomy when he explained how he was actively involved in coordinating care to mitigate the perceived demands that his care needs and those of his wife placed on others. Phillip needed support for some physical health problems, but he also considered himself to be a carer for his wife Kathryn, who had dementia. Phillip felt that various individuals – including his daughter and both publicly and privately paid care providers – worked well together to ensure that he and Kathryn received the support they needed to continue to live together at home. Through the use of both public and private home care, Phillip avoided placing too many demands on his daughter even though he appreciated the support that she regularly provided. Phillip pointed to the convergence of family and formal care when he explained the support that he and his wife, Kathryn, received from their daughter and from formal care workers:

> My nurse daughter is a fabulous help to us. She gives one day a week; every Thursday, she gives her day to come here and she's a very practical girl, being a nurse. She sees things to do, she helps us every Thursday and usually we go out and have lunch with two of the girls [home care workers] and Kathryn on that day, as well. (Phillip, 84)

To negotiate this complex, intersecting network of care, Phillip saw himself as a manager and drew on the skills as well as the financial means that he had gained throughout his career as the owner of a construction company:[4]

> I was a builder all my life, forty-one years, I told you; so my whole life has been managing … managing … and now, with all that management experience, I'm managing a flock of girls; I've got about seven girls and I'm managing everything and it's my nature. (Phillip, 84)

Phillip's care arrangement illustrates the blurred boundaries that sometimes exist between paid and unpaid, or family and formal care (see also Allen & Ciambrone, 2003; Ward-Griffin & Marshall, 2003). On the one hand, Phillip's daughter used her professional nursing skills to provide family care, while on other hand Philip regarded the privately paid home care workers as family. Phillip's experiences of care were shaped by the relationships that he developed with these individuals and the extent to which he felt he could rely on them. Phillip relied heavily on formal care workers because he paid them and was in a position of relative power, whereas he restricted support from his daughter to one day a week out of recognition that she had other work and family responsibilities.

Engaging in Relations of Reciprocity

Participants also explained how they engaged in relations of reciprocity or gave back to family members to mitigate the perceived burdens associated with their care needs (see also Allen & Wiles, 2014; Lewinter, 2003). Reciprocating enabled participants to conceptualize care as a part of the "give and take" of family relationships that are based on mutual support and exchange (Martin-Matthews, 2000, p. 75). The experiences of Maggie and Martha illustrate reciprocity in terms of both financial and social support. Maggie paid her son-in-law to drive her to run errands. This allowed her to accept help without feeling guilty about asking too much of her son-in-law, and to retain some control over when she received assistance with transportation:

> And my son-in-law is excellent and I just give him a cheque the first of every month because then I don't feel so embarrassed. He's embarrassed taking the cheque but I would much rather give him something per month and then say "Oh, I really need to go to Wal-Mart. Would you just drive me up there?" And we have that errand done, and I don't have to be concerned about it. (Maggie, 89)

Martha lived on a fixed income and, unlike Maggie, did not have the means to pay family for assistance. Still, she demonstrated reciprocity through the provision of social support. While Martha's family helped to clean her apartment and run errands on a regular basis, she looked after her great-granddaughter every day after school. Although Martha's mobility was limited due to

cellulitis and chronic obstructive pulmonary disease, she could still look after children in her family:

> From four 'til seven, I sit here and read then my great-granddaughter comes and I look after her … because she's six so she pretty well does everything for herself; it's just having somebody in the house with her. (Martha, 67)

Struggling with Unmet Needs

The three processes identified thus far underscore participants' autonomy and active involvement in care arrangements. Through the process of struggling with unmet needs, however, some participants expressed a sense of powerlessness and constraint. These individuals had needs that exceeded the publicly funded home care services they were allotted, yet had few economic or social means to access additional support. As these participants contended with mental and physical health conditions, restricted access to publicly funded home care, and small networks of support from family and friends, it was often difficult for them to make meaningful choices regarding their care arrangements. When participants had unmet needs, some felt that they had no choice but to turn to family to fill in gaps in care provision. Here, some participants expressed a sense of guilt or ambivalence about relying on family and friends for significant help and would have preferred to receive more formal home care. Some participants also discussed how they struggled to care for themselves when they had needs that exceeded both the formal home care they were allotted as well as the caring capacities of their families and friends. In a context where policy discourses emphasize family responsibility for care, participants who were contending with worsening health problems and impairments, and lacked family support as well as the financial means to purchase care privately, experienced certain disadvantages and constraints in their care arrangements.

Consider the experiences of Rosa and Yolande. Rosa felt that the formal home care she received was inadequate, and therefore relied heavily on her daughter Megan for support:

> Megan does all of it; she does all my shopping; she does all my medication and she's always busy bringing me pads and diapers and toilet paper and Kleenex and she does all she can do … she's very worn out … She can be angry, too, but I don't blame her. (Rosa, 93)

Rosa felt guilty about the demands that her care needs placed on Megan, but felt that she had no other choice due to the limited availability – and sometimes the poor quality – of the publicly funded home care she received. When asked if she needed more help with anything, Rosa replied, "you know if I say anything my daughter will kill me … it's the cleaning." Rosa felt that she could not ask for more help because Megan was already doing so much, and that she could not voice complaints about home care services for fear that she would sound too demanding. Rosa faced challenges with regards to her relations of support with formal and family care providers because of her various physical and mental health problems, with which she struggled on a daily basis, and because of limited social support. Unlike some other participants who had large, complex networks of support, Rosa only had regular assistance from her daughter. In cases such as Rosa's, family members took on significant responsibilities for care – not because these participants preferred to receive support from family, but simply because no other options were available to them, given restricted access to publicly funded home care.

Yolande also had needs that exceeded the formal home care she was allotted and lacked the financial means to purchase additional care. Yet, unlike Rosa, Yolande did not have strong support from family or friends. In the face of limited support, Yolande struggled to clean her apartment and run errands:

> Yolande: Every two weeks, they [home care workers] come in for twenty minutes.
>
> They wash my floors and they clean the bathroom and if there's a few dishes, they'll do the dishes and that's it.
>
> I: Okay.
>
> Yolande: I don't get anything else. I've asked for more help but … see, I don't know if you'll notice on the floor, there's a lot of marks.
>
> I: Hmm.
>
> Yolande: That was all black marks and I had … I had to get down on my backside and scrub them because they won't do that. Yeah. She [case coordinator] said I'd get an hour every two weeks but they're in and out of here like nothing. Because I keep things clean; I don't like dirt.
>
> I: Sure, yeah.
>
> Yolande: I keep clean as much as I can and usually, after I've done what I did here, I'd be in bed for three days. (Yolande, 72)

In addition to limited access to home care services, Yolande could not turn to family in times of need. She had raised five children alone after leaving an abusive husband, but only three of her children were still alive and none provided regular support. Yolande also lived on a fixed income and could not pay for additional help herself. Despite policy discourses that both assume and encourage family involvement in care, Yolande indicated that she had no other choice but to clean her

own apartment and to run errands alone. Engaging in these tasks actually exacerbated the physical pain that Yolande experienced.

Discussion

Reconciling Tensions: Contributions to Previous Research

The purpose of this grounded theory study was to theorize older people's experiences at the intersections of formal and family/friend care arrangements. The core concept derived from qualitative interviews with older persons receiving home care was reconciling tensions between care needs and concerns about burdening others, in the context of available home and community care. Through four processes – turning to formal home care as a first choice, coordinating networks of formal and family/friend support, engaging in relations of reciprocity, and struggling with unmet needs – participants attempted to reconcile the tensions between their needs for care and their concerns about placing undue demands on family and friends. Although the findings presented here underscore older people's profound concerns about relying on family for care, it is important to note that many participants had close relationships with family and friends. Still, participants wanted to maintain some boundaries between established family relationships and the work of caring. This finding is consistent with other Canadian and international research, which suggests that older people typically prefer formal care for long-term care needs (Kemp & Denton, 2003; Pinquart & Sörensen, 2002).

The concept of reconciling tensions builds on research that explores the relationship between formal and family/friend care in important ways. Consistent with the few other studies that similarly consider the perspectives of persons receiving care, findings suggest that participants engaged support from various sources, beyond the specific tasks that are commonly associated with either formal or family/friend care (see also Allen & Ciambrone, 2003; Porter et al., 2004). For example, some participants developed family-like relationships with formal care providers, although in other cases family members took on the roles that are typically the responsibility of formal care providers. Yet, while Porter et al. (2004) suggested that dichotomies between formal home care and family/friend care are artificial because they do not reflect the perspectives of older people in need of care, participants in this study clearly considered formal home care and family/friend care to be distinct systems.[5] They were well aware of the limited availability of publicly funded home care, and they perceived that younger generations were facing challenges as they balanced multiple work and family responsibilities. As such, participants accounted for

the potential and actual limits of both formal and family/friend care as they reflected upon their care arrangements.

The concept of reconciling tensions accounts for the subjective meanings and practical challenges that older people may encounter at the intersections of formal and family/friend care arrangements, against the backdrop of home care policies that encourage partnerships with family members. In doing so, this concept reaches beyond conventional models that consider the impacts of formal care on family/friend care and vice versa (i.e., the hierarchical compensatory, substitution, task specificity, and complementary models). Insofar as the concept of reconciling tensions accounts for sociostructural contexts that frame expectations and experiences of later life care, it aligns with, and extends, critical models of the relationship between formal and family/friend care (i.e., the socialist feminist and convoys of care models).

Providing an important critique of policies that emphasize family members as "partners in care", Ward-Griffin and Marshall's (2003) socialist feminist model considers how cutbacks to formal home care can result in a transfer of care work to family members. Yet, while Ward-Griffin and Marshall's (2003) research focusses on the experiences of community nurses and family care providers, the concept of reconciling tensions considers the experiences of persons receiving care themselves. Current policies might indeed represent a transfer in care work to family members, yet the findings presented here suggest that older people receiving care may resist this emphasis on family care due to profound concerns about the perceived demands that their care needs place on others. Given the stigma and shame often associated with dependency (Breheny & Stephens, 2012), participants' attempts to reduce demands on family and friends may be understood as a way to maintain a sense of independence in the face of chronic health conditions and impairments.

The concept of reconciling tensions also aligns with Kemp et al.'s (2013) convoys of care model. Both studies consider people who are receiving care, as well as formal and family/friend care providers, to be active participants who engage in care relationships in sociostructural contexts. Kemp et al. (2013) outlined several factors that influence the experiences and actions of convoy members, including broader values about personal and family responsibility for later life care, policies that guide the delivery of home and long-term care services, and socio-structural relations of inequality associated with age, class, gender, and race/ethnicity. To date, however, the convoys of care model has been developed and applied through research on assisted living in the United States – a context that differs

substantially from that of home care in Canada (Kemp et al., 2013; Perkins, Ball, Kemp, & Hollingsworth, 2013). The concept of reconciling tensions may be used to extend the convoys of care model through an in-depth consideration of the contextual dimensions that frame older people's experiences of formal and family/friend home care arrangements, in Ontario, Canada.

In this study, contextual dimensions that framed participants' experiences of care included access to financial and social resources. With financial means, as well as strong networks of support from family and friends, many participants were able to find a balance of formal and family/friend care that reflected their needs, preferences, and timelines. In some cases, however, participants' experiences of care were marked by a sense of powerlessness and constraint. They either struggled to care for themselves, or turned to family to fill in gaps when formal home care was insufficient. These participants' experiences illustrate how "old age" and "impairment" can intersect and lead to particular challenges for those with limited financial means and social support. In the context of restricted access to home and community services, it was especially difficult for participants on low incomes, or with small or nonexistent networks of family support, to access the kinds of care they needed or wanted. As such, findings suggest that the neoliberal emphasis on family and individual responsibility for care may be especially detrimental to older people in disadvantaged social locations.

Implications for Policy and Practice

The findings presented in this article point to some of the gaps that currently exist in Ontario's home care system, and may be used to support the development of policies and practices grounded in the experiences of older people. Other research has considered the challenges and constraints that family carers often face as they attempt to balance care for older relatives with paid work, childcare, and other responsibilities (Hooyman, Browne, Ray, & Richardson, 2002; Keefe, 2011), coupled with the distress associated with unpaid care work (Health Quality Ontario, 2016). Extending this critique, the findings presented here suggest that the heavy emphasis on family care may also be problematic for some older people in need of care. Policies that assume family members' involvement in care may result in challenges and constraints in particular for some older people with small or nonexistent networks of family support, and who lack the financial resources to purchase additional care services privately. Accordingly, this research provides evidence for the development of home care policies that do not assume high levels of family support but ensure consistent, continuous home care services for all people who are in need.

At the level of direct service provision, these findings have implications for the development of person-centred and relationship-centred care – approaches that increasingly guide the delivery of home care services in Ontario and across Canada (Brookman, Jakob, DeCicco, & Bender, 2011). Key aspects of person-centred care include sharing power among individuals involved in care relationships; respecting and accommodating the needs, perspectives, and interests of persons receiving care; and involving them in decision-making. Relationship-centred care, moreover, hinges on strong, mutually beneficial relationships between and among persons receiving care, family members, and care providers (Beach et al., 2006; Brookman, Jakob, et al., 2011). Research findings may inform practice guidelines that are person- and relationship-centred insofar as they account for the meanings that older people attribute to formal and family/friend care, and their subsequent experiences and actions within socio-structural contexts. Recent research illustrates how case managers in Ontario's home care system consider the availability of family care providers when designing care plans (Peckham et al., 2014). It could be useful for case managers to account not only for the objective availability of family care, but also to consider older people's subjective perceptions about relying on family. This could help to ensure that formal care services are provided in ways that reflect the needs and desires of older people in need of care.

Limitations and Future Research Directions

Although the concept of reconciling tensions has important implications for theory, policy, and practice, its usefulness is limited should we apply it to theorize the intersections of gender, race, and class for experiences of care. This study was limited in terms of ethnic and racial diversity. Some participants had migrated to Canada from various part of Europe, but all participants were White. Although I have devoted attention to the significance of social and financial resources, which may be considered in relation to class, this study did not fully explore class differences in experiences of care. Finally, gender and sexuality were not focal points in this analysis.

To address these limitations, several lines of inquiry could be developed on the basis of findings from this study and explored in future research. It is notable that all of the participants who expressed a sense of powerlessness in their care arrangements were women. Older women tend to have lower incomes than men (Denton & Boos, 2007; McDonald & Robb, 2004) and are also more likely to live longer with chronic health conditions and disabilities. By consequence, older women are more likely to be widowed and lack support from a spouse. Having often provided care throughout their lives,

older women might also be more sensitive to the challenges that their family members are facing as they balance multiple roles and responsibilities. It is therefore unsurprising that some older women experienced challenges and constraints with regards to their care needs. Future research could further explore the salience of gender relations, and their intersections with other social locations of inequality such as class and race or ethnicity, for experiences of later life care.

This study finds that participants did not want to place too many demands on family and friends, but it is noteworthy that family/friend carers do continue to play an important role in supporting older people (Keefe, 2011). In fact, estimates suggest that approximately half of older people receiving care in Canada rely entirely on family, friends, or neighbours (Hoover & Rotermann, 2012). This study explored the experiences of people currently receiving formal home care; older people who receive only family/friend support may express different opinions and concerns regarding their care arrangements. It is also possible that older people with dementia would express different concerns about the demands that their care needs place on family. Further research is necessary to better understand the viewpoints and experiences of individuals with diverse care arrangements and with varied health conditions and impairments. Finally, in addition to considering greater diversity in experiences of care, the findings presented here could also be extended through a critical analysis of home care policies. This could contribute to greater insights into the tensions and contradictions that can exist between policy discourses and lived experiences of care.

Conclusion

The core concept of reconciling tensions between care needs and concerns about burdening others, in the context of available home and community care, was developed to theorize older people's experiences at the intersections of formal and family/friend care arrangements. Participants' experiences of care may be understood at least in part as an outcome of their efforts to reconcile conflicting expectations surrounding later life care – between self-sufficiency on the one hand, and family responsibility on the other hand. The four processes outlined in this article illustrate how participants' access to financial and social resources can lead to opportunities and constraints in experiences of care. These findings give insight into the socio-structural and policy contexts that frame older people's experiences of care and, in turn, have implications for the relationships that exist between and among individuals involved in care relationships. Moreover, these findings highlight the limitations of policy discourses that take for granted older people's capacity and willingness

to access family support, and point to where policy adjustments can be directed to equalize access to care. Home care policies that ensure more consistent levels of formal home care, and practices that carefully consider older people's concerns and challenges with regards to family support, may help to mitigate the challenges and constraints that some older people face at the intersections of formal and family/friend care arrangements.

Notes

1   Some family/friend carers reject the term "informal" because they feel that it has negative connotations (Brookman, Holyoke, et al., 2011). It can imply that family/friend care work is "casual or intermittent" whereas in reality it is often "intense and long term" (Lero, Keating, Fast, Joseph, & Cook, 2007, p. 2). In recognition of this critique, I use the term "family/friend care" instead of "informal care" throughout this article.

2   According to the Ontario Home Care Association (2013), approximately 150,000 people in Ontario purchase 20 million visits or hours of home care privately every year. An estimated 653,730 people received 34.5 million visits or hours of publicly funded home care in 2012 and 2013.

3   Three of the eight participants who had never graduated from high school experienced disruptions to their education as a result of war or global conflict.

4   Phillip's managerial approach was consistent with other research on older husbands' care work (King & Calasanti, 2013). Older men often draw on skills gained in paid work settings when they care for spouses, and Phillip clearly connected his paid work experience to his role as a carer and as a person receiving care.

5   This discrepancy is perhaps because *receiving* formal home care was not an eligibility criterion in Porter et al.'s (2004) study. Participants simply classified the various people who helped them, regardless of compensation, according to the types of help they provided. By contrast, all participants in this study used either publicly funded or privately paid formal home care. Participants were asked directly about their experiences with formal home care as well as their relations of support with family and friends.

References

Allen, S. M., & Ciambrone, D. (2003). Community care for people with disability: Blurring boundaries between formal and informal caregivers. *Qualitative Health Research*, *13*(2), 207–226.

Allen, R. E. S., & Wiles, J. L. (2014). Receiving support when older: What makes it OK? *The Gerontologist*, *54*(4), 670–682.

Armstrong, P. (2010). Neoliberalism in action: Canadian perspectives. In S. Braedley & M. Luxton (Eds.), *Neoliberalism and everyday life* (pp. 184–201). Montreal, QC: McGill-Queen's University Press.

Aronson, J., Denton, M. A., & Zeytinoglu, I. U. (2004). Market-modeled home care in Ontario: Deteriorating working conditions and dwindling community capacity. *Canadian Public Policy*, *30*(1), 111–125.

Barken, R. (2015). *Age relations and care: Older people's experiences of self-care, family/friend caregiving, and formal home care* (Unpublished doctoral dissertation). McMaster University, Hamilton, ON.

Beach, M. C., Inui, T., Frankel, R., Hall, J., Haidet, P., Roter, D., … Williamson, P. (2006). Relationship-centered care: A constructive reframing. *Journal of General Internal Medicine*, *21*(Suppl. 1), S3–8.

Breheny, M., & Stephens, C. (2012). Negotiating a moral identity in the context of later life care. *Journal of Aging Studies*, *26*(4), 438–447.

Brookman, C., Holyoke, P., Toscan, J., Bender, D., & Tapping, E. (2011). *Promising practices and indicators for caregiver education and support programs*. Markham, ON: Saint Elizabeth. Retrieved from https://www.saintelizabeth.com/getmedia/ec3bb66f-6ec9-4f53-b0b8-c3030361d1e7/Promising-Practices-and-Indicators-for-Caregiver-Education-and-Support.pdf.aspx?ext=.pdf.

Brookman, C., Jakob, L., DeCicco, J., & Bender, D. (2011). *Client-centred care in the Canadian home and community sector: A review of key concepts. Final report*. Markham, ON: Saint Elizabeth. Retrieved from https://www.saintelizabeth.com/getmedia/4aba6e8e-0303-4b9c-9117-a8c22a43f8bd/Client-Centred-Care-in-the-Canadian-Home-and-Community-Sector.pdf.aspx.

Canadian Home Care Association (2013). *Portraits of home care in Canada. Executive précis*. Retrieved from http://www.cdnhomecare.ca/content.php?doc=274. Mississauga, ON: Author.

Cantor, M. (1979). Neighbors and friends. *Research on Aging*, *1*(4), 434–463.

Cantor, M. (1991). Family and community: Changing roles in an aging society. *The Gerontologist*, *31*(3), 337–346.

Chappell, N. L., & Blandford, A. (1991). Informal and formal care: Exploring the complementarity. *Ageing and Society*, *11*, 299–317.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Los Angeles, CA: Sage.

Claims Conference (2012). *Worldbook: A guide to claims conference programs worldwide*. Retrieved from http://forms.claimscon.org/worldbook12.pdf. New York, NY: Author.

Corbin, J. M., & Strauss, A. L. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. Los Angeles, CA: Sage.

Creswell, J. W. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: Sage.

Davey, A., & Patsios, D. (1999). Formal and informal community care to older adults: Comparative analysis of the United States and Great Britain. *Journal of Family and Economic Issues*, *20*(3), 271–299.

Denton, M. A. (1997). The linkages between formal and informal care for the elderly. *Canadian Journal on Aging*, *16*(1), 30–50.

Denton, M. A., & Boos, L. (2007). The gender gap in wealth: Structural and material constraints. *Journal of Women and Aging*, *19*(3-3), 105–120.

Erlandson, D. A., Harris, E. L., Skipper, B. L., & Allen, S. D. (1993). *Doing naturalistic inquiry: A guide to methods*. Newbury Park, CA: Sage.

Funk, L. M. (2013). Home healthcare and family responsibility: A critical discourse analysis of talk and text. *Healthcare Policy*, *9*, 87–97.

Gee, E. M. T. (2000). Population and politics: Voodoo demography, population aging, and social policy. In E. M. T. Gee & G. M. Gutman (Eds.), *The overselling of population aging: Apocalyptic demography, intergenerational challenges, and social policy* (pp. 5–25). Don Mills, ON: Oxford University Press.

Glaser, B. G. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory*. Mill Valley, CA: Sociology Press.

Glaser, B. G., & Strauss, A. L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine de Gruyter.

Greene, V. L. (1983). Substitution between formally and informally provided care for the impaired elderly in the community. *Medical Care*, *21*(6), 609–619.

Health Quality Ontario (2016). *The reality of caring: Distress among the caregivers of home care patients*. Toronto, ON: Queen's Printer for Ontario.

Hoover, M., & Rotermann, M. (2012). Seniors' use of and unmet needs for home care, 2009. *Health Reports*, *23*(4), 3–8.

Hooyman, N., Browne, C. V., Ray, R., & Richardson, V. (2002). Feminist gerontology and the life course: Policy, research and teaching issues. *Gerontology & Geriatrics Education*, *22*(4), 3–26.

Kahn, R. L., & Antonucci, T. C. (1980). Convoys over the life course: Attachment, roles, and social support. In P. B. Baltes & O. Brim (Eds.), *Life span development and behavior* (*Vol. 3*, pp. 254–283). New York, NY: Academic Press.

Keefe, J. (2011). *Supporting caregivers and caregiving in an aging Canada*. Montreal, QC: Institute for Research on Public Policy.

Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies*, *27*(1), 15–29.

Kemp, C. L., & Denton, M. (2003). The allocation of responsibility for later life: Canadian reflections on the roles of

individuals, government, employers and families. *Ageing and Society*, *23*(6), 737–760.

King, N., & Calasanti, T. (2013). Men's aging amidst intersecting relations of inequality. *Sociology Compass*, *7*(9), 699–710.

Lero, D. S., Keating, N. C., Fast, J., Joseph, G., & Cook, L. (2007). *The interplay of risk factors associated with negative outcomes among family caregivers: A synthesis of the literature* (Centre for Families, Work & Well-Being, University of Guelph; & Research on Aging, Policies and Praxis, University of Alberta). Retrieved from http://www.worklifecanada.ca/cms/resources/files/718/The_interplay_of_risk_factors_associated_with_negative_outcomes_among_family_caregivers_2007.pdf.

Lewinter, M. (2003). Reciprocities in caregiving relationships in Danish elder care. *Journal of Aging Studies*, *17*(3), 357–377.

Litwak, E. (1985). *Helping the elderly: The complementary roles of informal networks and formal systems*. New York, NY: Guilford Press.

Martin-Matthews, A. (2000). Intergenerational caregiving: How apocalyptic and dominant demographies frame the questions and shape the answers. In E. M. T. Gee & G. M. Gutman (Eds.), *The overselling of population aging: Apocalyptic demography, intergenerational challenges, and social policy* (pp. 64–79). Don Mills, ON: Oxford University Press.

Martin-Matthews, A., Sims-Gould, J., & Tong, C. E. (2013). Canada's complex and fractionalized home care context: Perspectives of workers, elderly clients, family carers, and home care managers. *Canadian Review of Social Policy*, *68/69*, 55–74.

McDonald, L., & Robb, L. (2004). The economic legacy of divorce and separation. *Canadian Journal on Aging*, *23*(S1), S83–S98.

Neysmith, S. M. (2000). Networking across difference: Connecting restructuring and caring labour. In S. M. Neysmith (Ed.), *Restructuring caring labour: Discourse, state practice, and everyday life* (pp. 1–28). Don Mills, ON: Oxford University Press.

Oleson, V. (2007). Feminist qualitative research and grounded theory: Complexities, criticisms, and opportunities. In A. Bryant & K. Charmaz (Eds.), *The SAGE handbook of grounded theory* (pp. 417–435). Thousand Oaks, CA: Sage.

Ontario Association of Community Care Access Centres (2014). *Making way for change: Transforming home and community care for Ontarians*. Retrieved from http://www.home-careontario.ca/home-care-reports/other-home-care-publications/home-and-community-care.

Ontario Home Care Association (2013). *Private home care—A vital component of the health care continuum in Ontario*. Retrieved from http://www.homecareontario.ca/docs/default-source/position-papers/position-papers/private-home-care--a-vital-component--oct-2013e81a79fdc99c68708e32ff0000f8dac8.pdf?sfvrsn=10.

Peckham, A., Williams, A. P., & Neysmith, S. M. (2014). Balancing formal and informal care for older persons: How case managers respond. *Canadian Journal on Aging*, *33*(2), 123–136.

Penning, M. J. (2002). Hydra revisited: Substituting formal for self- and informal in-home care among older adults with disabilities. *The Gerontologist*, *42*(1), 4–16.

Perkins, M. M., Ball, M. M., Kemp, C. L., & Hollingsworth, C. (2013). Social relations and resident health in assisted living: An application of the convoy model. *The Gerontologist*, *53*(3), 495–507.

Peters, C. L., Hooker, K., & Zvonkovic, A. M. (2006). Older parents' perceptions of ambivalence in relationships with their children. *Family Relations*, *55*(5), 539–551.

Pinquart, M., & Sörensen, S. (2002). Older adults' preferences for informal, formal, and mixed support for future care needs: A comparison of Germany and the United States. *The International Journal of Aging & Human Development*, *54*(4), 291–314.

Porter, E. J., Ganong, L. H., Drew, N., & Lanes, T. I. (2004). A new typology of home-care helpers. *The Gerontologist*, *44*(6), 750.

Rose, N. (2000). Government and control. *British Journal of Criminology*, *40*, 321–339.

Sims-Gould, J., & Martin-Matthews, A. (2010). We share the care: Family caregivers' experiences of their older relative receiving home support services. *Health & Social Care in the Community*, *18*(4), 415–423.

Sinha, M., & Bleakney, A. (2014). *Receiving care at home*. Ottawa, ON: Statistics Canada, Ministry of Industry.

Ward-Griffin, C., & Marshall, V. W. (2003). Reconceptualizing the relationship between "public" and "private" eldercare. *Journal of Aging Studies*, *17*(2), 189–208.

Weicht, B. (2013). The making of "the elderly": Constructing the subject of care. *Journal of Aging Studies*, *27*(2), 188–197.