






## Sustaining care for a parent with dementia: an indefinite and intertwined process

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### ABSTRACT

This study aimed to understand how adult children sustain caring for persons with dementia (PwDs) within their family and formal care contexts in Canada. Half-day focus groups were conducted with adult daughters and adult sons in Toronto, Canada. Using constructivist grounded theory, we examined both substantive concepts and group dynamics. Sustaining care was interpreted as an indefinite process with three intertwined themes: *reproducing care demands and dependency*, *enacting and affirming values*, and *“flying blind” in how and how long to sustain caring* (i.e., responding to immediate needs with limited foresight). Family values and relationships, mistrust toward the institutional and home care systems, and obscured care foresight influenced care decisions and challenged participants in balancing their parents’ needs with their own. Positive and negative aspects of care were found to influence one another. The implications of these findings for research and policy are discussed.

### ARTICLE HISTORY

Accepted 5 October 2017

### KEYWORDS

Alzheimer; dementia; caregiving; adult child; informal care; relational care; family care; formal care; grounded theory; focus group

### Introduction



As our population ages, the problem of how and by whom older adults will be supported is both pressing and complex. Conceptually, aging in place has garnered increasing attention in efforts to align the priorities of older adults, families, care providers, and policymakers (Vasunilashorn, Steinman, Liebig, & Pynoos, 2012). However, reports that unpaid family members and friends provide 70–80% of community-based care in Canada (Sinha et al., 2016), and save the public systems \$25 billion in Canada (Hollander, Liu, & Chappell, 2009) and \$470 billion in the U.S.A. (National Alliance for Caregiving & AARP Public Policy Institute, 2015, p. 3), question how equitably the responsibility of care is currently distributed between the public system and its citizens.

Problematically, the caregiving literature has been dominated by prevailing narratives of caregiver stress, burden, and health hazards (Roth, Fredman, & Haley, 2015). Important social and structural forces known to influence care experiences (Chappell & Funk, 2011; Lilly, Robinson, Holtzman, & Bottorff, 2011) have been marginalized, along with evidence of the positive aspects of care (e.g., accomplishment, enhanced relationships) (Carbonneau, Caron, & Desrosiers, 2010), despite a recent majority (83%) of family care partners who view care as a positive experience

(National Opinion Research Center, 2014, p. 4). A more balanced view of caring is therefore needed to provide targeted support to those family care partners who are most vulnerable to stress and strain, and to enhance the positive aspects of care that encourage and support family care partners as valued partners in care (Roth et al., 2015). To this end, a richer contextualized understanding of how care of persons with dementia (PwDs) is currently sustained is needed.

### *Sustaining care for persons with dementia at home*

For persons living with dementia and cognitive impairment, who comprise the majority of residents in long-term residential care settings (Prince, Prina, & Guerchet, 2013), sustaining care in the home is particularly complex and challenging, and increasingly depends on formal care services. In Ontario, Canada’s most populated province, care is primarily managed by informal care partners (e.g., family members, friends), who may or may not access subsidized home care services (i.e., personal support and home-making, nursing, therapy, and social work) by a local Community Care Access Centre (Health Quality Ontario, 2016, p. 9). Individuals and families may also hire private care through a community agency or

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independently. Ontario's Local Health Integration Networks provides additional programs, including adult day programs, transportation, and meal delivery services (Health Quality Ontario, 2016, p. 9).

Previous work that examined home care services highlighted fundamental incongruences between the formal care services and actual needs. A critical ethnographic study found that dementia home care services in Canada assumed inexhaustible familial care, but which diminished as care needs increased over time (Ward-Griffin et al., 2012). Service inaccessibility also derives from a mismatch between formal and informal care priorities. Formal care is provided based on objectivity and efficiency (Lloyd & Stirling, 2011), where lineal time allocations (e.g., 2 h of personal care service) are incongruent with "unshiftable" care tasks, such as personal care (Hassink & van den Berg, 2011, p. 1510). Such a structure of formal care services tends to neglect important priorities held by informal care partners, such as the quality of their interactions and relationships with service providers (Singh, Hussain, Khan, Irwin, & Foskey, 2014). Moreover, current representations of caregiving have typically assumed a single primary care partner, which is challenged by work that has illustrated complex informal care networks (Lingler, Sherwood, Crighton, Song, & Happ, 2008) and changes to these networks over time (Szinovacz & Davey, 2007). Thus, it remains unclear how care is sustained within the context of informal-formal care interactions and relationships.

### **Adult children as care partners**

Examining how adult children sustain caring is timely, based on population demographics and sociocultural trends. Adult children and adult children-in-law together represent the largest group (48%) of informal care partners in Canada (Sinha, 2013) and (49%) in the U.S.A. (National Alliance for Caregiving and AARP Public Policy Institute, 2015). Caregiving in the U.S, 2015, p. 6). They are known to experience care differently from spouses, typically balancing numerous roles—such as adult child, parent, and employee (Bastawrous, Gignac, Kapral, & Cameron, 2014); use more informal supports (Pinquart & Sörensen, 2011); and tend more toward managing care (e.g., arranging services) than providing hands-on assistance (Brodsky & Donkin, 2009). With the majority of females employed in the labour market, caregiving is increasingly viewed as "work" beyond normative family expectations, which has created greater demands for public services (Guberman, Lavoie, Blein, & Olazabal, 2012). As the extent of filial obligation remains an open philosophical and policy question (Stuifbergen & Van Delden, 2010), care responsibilities tend to be unequal among adult child siblings (Connidis & Kemp, 2008) with inconclusive explanations of how various

factors (e.g., employment, geographic proximity, family relationships (Egdell, 2012)) influence certain adult children to sustain care responsibilities over others.

### **Aim**

In an effort to better understand and support adult children in their care experiences, this study aimed to understand the processes through which they sustain caring for persons with dementia (PwDs), and how these processes are shaped by their family and formal care interactions.

### **Methodological approach and method**

This study adopted a constructivist grounded theory (CGT) approach (Charmaz, 2014) in two, half-day focus groups. The approach is rooted in pragmatism and relativist epistemology and assumes that data are co-constructed by researchers and participants. We employed this methodology in order to explore the depth and complexity of a phenomenon through group interactions (Carlsen & Glenton, 2011). As related work has commonly used individual interviews with family care partners, focus groups were employed to explore and clarify views and experiences of caring as an adult child; encourage explanations of how and why these views are held; and facilitate critical discussion about structural factors (Kitzinger, 1995) that influence care experiences. The two focus groups were gender-segregated (i.e., one with adult daughters and one with adult sons) based on literature that highlights gender-based differences in how adult children experience caring (e.g., males tend to approach care as tasks to be completed, while females take a more emotional approach) (McDonnell & Ryan, 2013).

### **Setting and participants**

With open sampling followed by purposive sampling, we recruited a sample to explore a range of experiences (Hallberg, 2006; Kitzinger, 1995). Initially, we recruited through public advertisements (print, radio, website), word-of-mouth, and a participant database at the University of Toronto that included family care partners who had expressed interests in participating in rehabilitation research. Participants were recruited based on the criteria that they lived in the Greater Toronto Area, provided unpaid care for at least 6 months to a community-dwelling parent (or in-law) with dementia (self-reported), and identified themselves as primarily responsible for their parents' care and care arrangements. The first author telephoned each prospective participant and collected descriptive data on age, marital status, employment

status, parent's diagnosis, duration of care, and living and care situations (e.g., co-residing, informal and/or formal care arrangements, nature of care work). These data identified important similarities and differences between participants (Table 1), which both guided the recruitment of a varied sample and sensitized us to the variations to expect between participants in focus group discussion. Referred by two recruited participants, we also managed to recruit two full-time, homebound adult children that we believed could add important perspectives. As expected for a hard-to-reach group (Navaie, 2011), focus group coordination with the recruited participants proved to be challenging. Scheduling constraints arose between participants who had competing responsibilities (e.g., spousal care, child care), and those who were unemployed and providing homebound care had limited respite care resources that would be required for them to participate. For this reason, we decided to design each focus group as one half-day session and amended our study protocol to compensate all participants for 6 h of respite care, which was accepted by all but one participant who participated without claiming this compensation.

Descriptive data were collected at the time consent was obtained (Table 1). All participants were assigned pseudonyms, which will be used to refer to each participant. As listed in Table 1, all four sons reported that their mothers (-in-law) had been diagnosed with dementia. Two daughters reported that their parents had been diagnosed with dementia, while the other three had assumed dementia. Our participants also reported wide variations in their parents' functional limitations, which are also summarized in Table 1 (see three columns, entitled "Parent's activities"). In the daughters' group, functional limitations ranged from functional independence in basic activities of daily living (Hilary's mother) to full assistance with every basic activity (Denise's mother). The functional range was similarly varied in the sons' group from David's mother-in-law, who still lived independently without any formal caregiver support, to Timothy's mother, who had recently been institutionalized due to her full-time care needs.

### **Data collection**

Both focus group sessions extended over an afternoon (i.e., approximately 4 h), including lunch and refreshment breaks (Kitzinger, 1995). This duration afforded a comfortable pace for participants to establish rapport and discuss a set of open-ended themes (Table 2). Participants were encouraged to discuss with each other and explore issues they felt most important to them (Kitzinger, 1995). The daughters' group was co-facilitated by a hired facilitator and the first author (i.e., who was new to focus group methodology). The sons' group was facilitated by the first

author after debriefing with the hired facilitator and discussing respective field notes, reviewing the audio from the daughters' group, and generating early analytic memorandums. A research assistant took observational field notes during the sons' group discussions and similarly debriefed with the first author immediately after the session, which generated additional analytic memos, including comparisons and contrasts between discussed content and the social dynamics observed between the two groups. In both groups, these research team members were discussion facilitators, where they explored with participants their perspectives and experiences (as per the focus group guide and their own observations noted in their own researchers' field notes). Our dataset includes descriptive data (Table 1), focus group audio recordings and transcripts, researchers' observational field notes, and any typed or handwritten notes voluntarily submitted by participants before or after the focus group sessions.

### **Ethical considerations**

The study was conducted with the approval of the Health Sciences Research Ethics Board at the University of Toronto (Protocol #29,463). All participants provided written consent after obtaining verbal and written information regarding the study, data privacy and security protocols, and how and to which audiences the study results would be disseminated. Participants were offered compensation for transportation and respite care expenses.

### **Data analysis**

Taking a social constructivist perspective, data analysis focused on examining the processes through which our participants sustained caring, and their social and structural conditions. We viewed "processes" in Charmaz's terms—as 'unfolding temporal sequences that may have identifiable markers with clear beginnings and endings and benchmarks in between...and lead to change.' (Charmaz, 2014, p. 17). Moreover, the researchers brought their own theoretical perspectives to their interpretation of the data—in particular, the perspective that care and caring is highly complex and should not be reduced to the narrow parameters of stress and burden. Preliminary analysis of the daughters' group guided but did not restrict topics to further explore with the sons' group. These included: ambivalent feelings toward caring; differences in care values and care approaches; the influence of sibling relationships on care arrangements, and vice versa; participants' attitudes toward and behaviours resulting from their formal care experiences; and shifts in the meaning of caring over protracted care journeys. After each focus group, the

Table 1. Description of study participants.

Participant (pseudonym)	Age	Occupation	Parent receiving care & diagnosis?	Length of care at study	Living arrangement in relation to parent	Parent's activities – without assistance	Parent's activities – assisted by participant	Parent's activities – assisted by formal caregiver	Formal care arrangement (PSW = personal support worker)
Eric	67	Retired; photographer & politician (part-time)	Mother, diagnosed dementia	7 years	Separate; mother lives in own house	TL, HW, DR, MD, CM (needs prompting)	TP, SH, FN	BT, MP, MD	24/7 private care: 2 live-in caregivers + 1 day shift Subsidized PSWs, 2 hours per day
Timothy	57	Puppeteer (part-time, self-employed)	Mother, diagnosed mixed dementias	10 years (7 co-residing)	Partial co-residence in adjacent units; mother institutionalized 2 months prior	HW (sanitizing wipes)	TL, DR, MD, CM (translation)	BT, TL, TB, DR, MP, MD	Subsidized PSWs, 2 hours per day
David	70	Retired health services consultant	Mother-in-law, diagnosed dementia (Note: Wife did not participate in study)	10 years	Separate; mother in her own condominium	TL, DR, MP (simple), MD (with prompts), CM	DR, MP, MD, CL, TP, SH, SC, FN; BT (wife only)	No formal caregiver	No formal care arrangements
Patrick	55	Semi-retired; part-time paper route & volunteering	Mother, diagnosed dementia	4 years	Co-residing in Patrick's house	TL (diapers), HW, DH, DR, CM	DH, MP, MD, CM, SC, EX, PF, HC	BT	Subsidized PSW 2 days a week, 1 hour per day
Florence	47	Senior manager, consulting firm	Father, diagnosed dementia	3 years	Separate; parents in own house	None	HW, DH, DR, MP, MD, CM, FN, SH	HW, DH, DR, MD, BT, TL	24/7 PSW coverage; subsidized & private
Carla	58	Retired (early)	Mother, assumed dementia	7 years	Co-residing in Carla's & husband's house	None	BT, TL, HW, DH, DR, MP, MD, CM, FN, SC	Same as Carla	Subsidized PSW 1 day per week, day program
Denise	56	Retired (early)	Mother, diagnosed dementia	12 years (with late father)	Co-residing in Denise's house with Denise's son & daughter	None	BT, TL, HW, DH, DR, MP, FD, MD	"96%" co-assistance with Denise	3 subsidized PSWs per day, 7 days per week
Thema	50	Unemployed, on social assistance	Mother, assumed dementia	4 years	Co-residing in Thema's apartment with Thema's daughter	HW, DH, TL	DR, MP, MD, CM (translation), EX	BT, DR, MP, MD, EX	4 subsidized PSWs, 12 hours/4 days per week; day program
Hilary	69	Retired (motor vehicle accident)	Mother, assumed dementia	11 years	Separate; mother in her own apartment	TL, HW, DR, MD, CM (needs prompting)	TB, DR, MP, MD, SH, FN	BT, TB, MP, MD, CL	3 subsidized PSWs, 20 hours per week; private housekeeper, bi-weekly

Notes: For activities, HW = handwashing, DH = dental hygiene, BT = bathing, TL = toileting, DR = dressing, MP = meal preparation, FD = feeding, MD = medications, CM = verbal communication, FN = personal finances, SH = shopping, SC = socializing, HC = household cleaning, TP = transportation, EX = exercise accompaniment (e.g., walks).

**Table 2.** Focus group discussion themes.

1. Tell us about how it is you came to care for your parent.
2. What does being a “caregiver” mean to you?
3. What do you want the world to know about what it is to care for your parent?
4. What is it like being a [daughter or son] who is a caregiver?

first author generated early memos based on the notes that participants voluntarily wrote and submitted; researchers’ field notes; and debriefing discussions (i.e., with the hired facilitator from daughters’ group and the research assistant from sons’ group). The first author then listened to and transcribed both audio recordings, generating analytic memos throughout. Using NVivo 10 software, the first author conducted initial line-by-line coding of the daughters’ focus group transcript, then grouped the codes into broad topic-oriented categories (e.g., interacting with formal care providers, navigating family dynamics, implementing care strategies). Throughout coding and categorizing, the first author continuously compared data in a back-and-forth fashion, between participants and between group discussion at different points in the session, to look for substantive similarities and differences (Charmaz, 2014, p. 132). After the first author coded, three authors (AH, LR, and LN) met multiple times to discuss substantive categories, where the data from salient codes and categories were shared and scrutinized. When these co-authors had different interpretations of the data, which were occasionally based on authors’ respective prior perspectives (Charmaz, 2014, p. 132), the first author routinely re-checked and compared the data (i.e., transcript and, as needed, audio) again. Subsequently, the three co-authors then reconvened to reach consensus about which interpretation(s) was best substantiated by the data. Group interactions were also analysed in order to examine how participants co-constructed their views within these ‘social spaces’ (Lehoux, Poland, & Daudelin, 2006, p. 2092), and highlighted knowledge claims on which ‘common ground’ was established (e.g., avoiding institutionalization) or contested (e.g., strategies for negotiating care with siblings). For group-level analysis, the first author re-coded the transcript based on an analytic template for group interactions (Lehoux et al., 2006, p. 2101) and then, through the same collaborative process with the second and last authors, prioritized the codes that were salient across substantive and group-level analysis. These analysis processes were repeated for the sons’ focus group transcript, and earlier codes and categories were treated as tentative topics (Charmaz, 2014, p. 16) while remaining open to generating new codes. Later analytic meetings between the three authors (AH, LR, and LN) refined topic-oriented categories by comparing and contrasting newer categories with those created earlier in the analysis process. Charting and

**Table 3.** Summary of analytic themes and sub-themes.

Themes	Sub-themes
Reproducing care demands and dependency	Resigning to care responsibilities and family conflict Mistrusting and limiting utilization of “the system”
Enacting and affirming values	Preserving one’s parent and family relationships Deriving and cultivating personal meaning from caring
“Flying blind” in how and how long to sustain caring	Bootstrapping care through one’s own resources Focusing on present needs—obscuring consequences

diagramming facilitated the mapping of processes (Charmaz, 2014, p. 219) across participants’ varied care durations, family contexts, and formal care access experiences. During this iterative team process, different interpretations between the three co-authors were scrutinized (Charmaz, 2014, p. 118), which led to their agreement on important similarities shared between gender-segregated groups (e.g., possessing an intrinsic ‘need to care’, sibling and formal care tensions, protracted care journeys), which were more salient in the data than the noted gender differences (e.g., the daughters’ group described caring more in terms of scheduling and ‘case management’, while the sons’ group discussed more personal relational aspects of caring). These three authors also agreed that the quantity and quality (i.e., rich rigour (Tracy, 2010)) of focus group data were adequate (Carlsen & Glenton, 2011). To achieve credibility (Tracy, 2010), working interpretations were presented for critical scholarly discussion at research seminars with dementia and caregiving experts at Karolinska Institutet (Sweden), University of Toronto (Canada), which included other co-authors, and an international dementia conference. All other co-authors contributed to two final iterations of data analysis, which generated the final three analytic themes (see Table 3), their embedded subthemes, and the relationships between themes.

## Findings

Findings from two focus groups with nine participants (described in Table 1) are summarized by the themes and subthemes in Table 3. The three themes are interrelated and together construct the core theme, which interprets sustaining care as an indefinite and intertwined process.

### *Sustaining care as an indefinite and intertwined process (core theme)*

Sustaining care within participants’ family and formal care contexts was understood as an indefinite process characterized by three intertwined themes



(summarized in Table 3). Reproducing care demands and dependency captures how participants' own care negotiations and conflicts when relating to parents and siblings, together with their fostered mistrust of the formal care system, created a dynamic wherein the care demands and dependency placed on them was further sustained. Shouldering these demands, however, led to positive outcomes, which participants invoked to justify and reinforce their care commitments through enacting and affirming values. Guided by these values, as care demands precipitated over uncertain trajectories, participants relied on their intuition and own resources to meet immediate care needs—i.e., “flying blind” as the magnitude of their responsibilities and opportunity costs (i.e., personal, social, and financial opportunities) accumulated over protracted care journeys.

In the forthcoming quotes, the square brackets house terms that are inserted into or altered from the direct quotation to clarify the speaker's meaning (e.g., “[my mother]” may be inserted to clarify who the participant is referring to when using “her”). When a participant's pseudonym is indicated in the square brackets (e.g., “[Carla: ...]”, this indicates an interjection by another participant(s) during the speaking participant's quote.

### ***Reproducing care demands and dependency***

For our participants, sustaining care within their family and formal contexts tended to reproduce care demands and care dependency. First, negotiating care arrangements with parents (PwDs) and siblings tended to stir relationship conflicts between family members, which resigned our participants to disproportionate care dependency and social isolation in caring. Secondly, mistrust in both institutional and home care services led participants to limit their service utilization and continue shouldering complex care demands.

### ***Resigning to care responsibilities and family conflict***

Both groups discussed the demands of negotiating care arrangements with their parents (PwDs) that they deemed in their parents' and their own best interests. David and his wife, for instance, had been struggling to convince his mother-in-law to accept a hired caregiver. They hoped this would alleviate some of his wife's hands-on care tasks, since it was felt to compromise their enjoyable mother-daughter time together. This discussion led the sons' group to establish common ground on the “aging-in-place” argument that they would invoke when negotiating new care arrangements with their parents. As reasoning and recall capacities varied between

participants' parents, some participants across groups would persist in their attempts to reason with their parents when discussing practical care arrangements, and obtain their parents' consent to implement arrangements. Other participants, however, asserted the need to circumvent or override their parents' resistance to such arrangements. Florence aptly describes this tension:

So...we've, we do it I think, it is, it is hard—sometimes it breaks my heart 'cause my mother wants to sleep in, but we have someone showing up at seven o'clock to get her washed, but if she doesn't wash at that time...she won't go out because her hair wasn't washed... So it's...it's for our sanity as well, and ... where my mom is at any given time, and um, and then it gives us the flexibility to spend time with my father. .... and I'm always the first point of contact... [so] when somebody isn't cooperating ... I would have to calm the situation down with the caregiver and, or try to get [the parent] on the phone so that I could talk them through it ... and if I can't, I would have to jump in my car ... and get over there. (Florence)

For some participants, care dependency expanded to social dependency. Denise's and Patrick's full-time homebound arrangements meant including their mothers in their limited social visits or outings with friends. As care demands increased, Carla and David also attested to including their mothers (-in-law) in all family holiday gatherings and vacations, which transformed the nature of their social and leisure time because of their continued care efforts. This was juxtaposed with their siblings, whom they reported to maintain clearer nuclear family boundaries, for which several participants shared a feeling of resentment.

Caring with and without sibling support produced demands, despite participants' differing expectations of care involvement from their siblings. Some daughters, for instance, described how they did not expect care involvement from their brothers; their traditional gender and ethnocultural values prescribed caring as a female responsibility. Other participants described battling with siblings over care matters, which strained or estranged their sibling relationships, and ultimately relegated participants to shoulder care responsibilities with reduced social support. In some cases, participants resigned from “fighting” with their siblings and accepted their siblings' lesser care involvement, in an effort to restore their sibling relationships or manage their own emotional stress. Others, however, severed relationships with siblings due to unresolvable care conflicts. In all instances, without the possibility of sharing care responsibilities, our participants' personal sacrifices mounted as care demands increased over time, and threatened their pursuits of education, employment, and personal leisure.

For some participants, strained sibling relations and disproportionate care responsibilities were reproduced by legal and financial arrangements. In particular, participants described how their appointments to, or family negotiations of, power of attorney and legal executorship not only fueled sibling conflict, but also discouraged care involvement from non-appointed or non-beneficiary siblings. For example, Eric described feeling discouraged from requesting more care involvement from his siblings. This derived from his appointment as his mother's legal decision-maker, which stirred conflict with his siblings, led them to scrutinize and subsequently withdraw their care involvement, and, in turn, limited their understandings of his day-to-day care challenges and decisions. Eric writes in a typed note he brought to the focus group session:

As the primary caregiver, I have gone through a painful process that has led to me accepting these [responsibilities]. I have also seen my siblings struggle with this as they question my acquired control and then see the need for it when they have exposure to the issue. They usually start by accusing me of cruelly grabbing power then come to realize that I had no choice. For me, it is a repetition of the process that I went through making the decision as I have to justify my methods and see their slow acceptance of my methods. (Eric)

Those participants whose siblings were involved in care arrangements reported enacting "quarterbacking" roles—i.e., leading, delegating, and sharing care responsibilities—which reproduced a different set of demands. This was most evidenced by Florence, who was adamant in demanding consistent efforts from two siblings, and deeply resented her eldest sister who was reportedly uninvolved in their parents' care arrangements. While managing complex care arrangements (e.g., family members, formal caregivers, care decisions, schedules), Florence had learned to temper her demands in order to maintain harmonious sibling relationships. She felt, however, that this balancing act had enabled her siblings to rely on her fully and precluded her from any real respite.

Like I, I would never put my ... guard down ... [my siblings] will take advantage of that. They are ... all of our mothers and fathers, so I don't, I ... it's my struggle and it's something I have, I should actually work harder at (...) and I will get to the point where I have to be careful because I don't want to [Carla: Sever]. ...ruin my relationships with them, and it's gotten very close with, in some situations because I just don't understand it. (Florence)

### ***Mistrusting and limiting utilization of the "the system"***

The most pronounced reason constructed by both groups for sustaining care was their shared mistrust of the care offered by "the system"—a term that

participants in both groups used to refer to the formal care services offered in both institutional and home care settings.

With respect to institutionalized care in long-term care homes, discourses of risk and fear were prominent among the daughters who cited security and physical risks, presumed accelerated health decline, social isolation, and limited opportunities for meaningful engagement for their parents.

Carla: {Recalling when her late father lived in nursing home} So we lived in the long-term care with my dad for 3 years .... those workers are really worked off their feet and they can only do things physical, like uh, change their diapers, move them to the cafeteria, put them in front of the T.V. [Thema: Yeah] ... I think I'm giving [my mother] a life sentence [by putting her in a home].

...

Thema: I felt the same thing, um... in my, like my mom...she cannot interact with other people [in a home] because of language barrier, and .... when I did my [nursing] practical in a ... long term care facility, I realized sometimes [the staff] want to make things as much easier as possible, so they can put a diaper on somebody who doesn't need [right, right], and they will leave that diaper for a whole day [Florence: Oh my God] ... and eventually the person went in as a healthy person, but within a time the person develop a whole lot of ... like you push your loved one in the facility and then it's like you kiss the person bye, you know [Florence: Yeah, I feel, I feel sick to my stomach].

The sons' group shared similar attitudes, citing media expositions of unethical care practices and criminal incidents to frame their commitments to sustaining care at home, despite its precipitating demands (e.g., medical appointments, transportation, home care services, community and respite programs, family care coordination).

Avoiding institutional care entailed accessing public home care services that most participants also grew to mistrust, which created more care work and influenced some to limit service utilization and rely on their own resources. Participants experienced more work and worry when new or substitute personal support workers (PSWs) arrived to the home without any knowledge of their parents or care routines. This led our participants to "stick around" in order to supervise and give instructions to new or untrusted PSWs. Doing so prevented those with limited alternative resources from fulfilling other personal obligations, such as education, employment, and childcare.

Participants with greater financial resources acquired private care resources for more control and flexibility in the nature of care provided (e.g., tasks supported, care schedules). However, private services also reproduced a different set of demands on our participants. Hilary, Florence, and Eric bore substantial

managerial and personal responsibilities to their private care staff, including recruiting and managing trusted private caregivers. This entailed administrative responsibilities (e.g., taxes, immigration); managing caregivers' workloads to mitigate stress; scheduling between private and subsidized home care, community care services, and health care appointments; resolving day-to-day care problems; and maintaining positive personal relationships and working environments (e.g., housing for live-in caregivers).

### **Enacting and affirming values**

Sustaining care was also characterized by a spiral process through which our participants continuously enacted and affirmed their values, which, in turn, reinforced their care commitments over time. Enacting values captures how participants embodied certain values through their actions or behaviours, and often came to prioritize caring over their other social roles, employment, and personal leisure. Affirming values captures the complementary process of how participants reconciled such "value conflicts" (e.g., between filial, family, gender, ethnocultural, personal/moral, vocational, and financial values) by deriving affirmation from positive aspects of care, which, in turn, reinforced their value enactments. This spiral was constructed in both groups and was most evident in two ways: how participants' beliefs that they were preserving their parents (PwDs) and their family relationships reinforced their continued care efforts, and how participants cultivated and derived personal meaning through caring.

### **Preserving one's parent and family relationships**

Sustaining care enacted participants' shared value orientation toward preserving their parents' health, well-being, and social relationships, which they believed not to be possible in institutional care settings. Sustaining home care arrangements, however, competed with other held family values. For example, Carla admitted that her decision to retire early and move her mother into her home had compromised her family financially, competed for quality time with her husband, and socially distanced her from her sisters who now excluded their mother and Carla from social events and vacations. The latter consequence, which resonated with multiple participants, derived from a value conflict between siblings over whether or not it was time to institutionalize their parents.

One way in which participants reconciled these value conflicts was through a shared belief that their care arrangements were "working" insofar as they delayed their parents' cognitive and functional losses, extended their longevities, or maintained their happiness and social engagement. While some participants

attributed their parents' continued wellness to the schedules or "programs" (e.g., Hilary), they had established between their PSWs and community services, Patrick felt that his homebound care arrangement was keeping his mother and their relationship well. This included the shared routines he had established with his mother (e.g., daily walks together, co-attending a weekly seniors program), which were made possible by his decisions to forego other personal opportunities (e.g., full-time employment, romantic relationships) in order to care for her on a full-time basis.

So [my mother is] ... she still has some, you know, mental cognitiveness, um ... and ... it's, it's you know, it's working ... and it's just because of the way my life is. You know, I have no kids, I've, I've...it's basically, you know I [laughs]—it's going to sound sad if I said I have nothing but my mom [laughs] ... but it's okay (...) now my priorities are different." (Patrick)

Caring also afforded frequent opportunities for participants to nurture their own relationships with their parents, such as adapting new and enjoyable communication strategies. Florence, for instance, had created "special games" using specific words, gestures, and eye contact with her father, which her siblings and formal caregivers emulated in their own interactions. The sons also discussed learning to relate to their parents through a "slightly risqué" sense of humour and the shared enjoyment derived by fostering this:

My mother-in-law and I enjoy our laughs ... and usually that's when we're alone [mhm]. You know, she'll go into her apartment and I'll say, "Don't pick the guy up outside the door," and I'll say, "Give you a call when I get home," and she'll say, "Well, I may not be done then!" [others laugh] [laughs] ... and, and you know, we both laugh about it and ...those are the rewards. (David)

Preserving and strengthening other family relationships also constituted both reason for and reinforcement of their care commitments. Some connected these to their previous family experiences, reasoning based on promises made to late family members to care for the living parent, or atoning for regrets about the care of a late parent (e.g., accelerated decline in institutional care, neglected health events). Bonds with spouses were also fostered through sharing the day-to-day joys and challenges of caring. Lastly, intergenerational solidarity also strongly affirmed participants' value orientations toward sustaining care. They believed that sustaining their care arrangements instilled good family values in their children, made evident by their children's demonstrated compassion and empathy toward their parents, and by their own confidence that their children would, in turn, care for them in future. Eric also underscored the continued reciprocity that he believed his mother's home care arrangement preserved.



Other people are involved in [my mother's] life, still... and well you think, what's best for her? What about them? They need this contact, they need to see her... So, it's more than just, just her quality of life. It's other people's quality of life...which she's part of. (Eric)

### ***Deriving and cultivating personal meaning from caring***

Sustaining care both enacted participants' personal values and affirmed these values as they ascribed personal meanings to caring over time. Although most participants described forgone personal opportunities (e.g., education, employment, financial health, personal goals), different forms of validation affirmed these sacrifices. For instance, both groups discussed receiving social validation and praise for their care efforts from friends, acquaintances, and service providers. Some participants also described upholding their ethnocultural values, which reinforced their commitments to sustaining care. Thema, for example, was validated by her ethnocultural, family, and gender values that were enacted through caring, which reinforced her decision to abandon her nursing education and intended financial independence from social assistance.

With my experience with others ... in [my West African community] ... they call me and they tell me, "Oh, you are doing a wonderful job, to care for your parents!" ... [but others outside my community] tell you, uh, to put your mom [in a nursing home] because she really qualifies to be in a ... long-term [Carla: Home] facility. But, in my culture, if you do that, it's like you, uh, you are very, very mean ... like even though, like it's something that I really wanted but ... [I told the doctor], "No, I want to keep her in the house." (Thema)

Our participants also attested to enacting and cultivating their inherent affinities, aptitudes, and skills through caring. Most felt that caring enacted their intrinsic empathetic nature, which they contrasted with their siblings' natures. For example, both Carla and Timothy emphasized that their decisions to sustain caring were "in the heart" and owing to their personal natures rather than being forced extrinsically. Florence also recognized her inherent "need to care and take care" of others, which Patrick echoed in his expressed "passion" for helping others, now fulfilled by his full-time caring role. Sustaining care also created opportunities for participants to apply and foster skills and interests, from which they derived mastery or achievement. Some examples included exercising one's management skills with private PSWs and applying business and technology skills to the development of mobile applications to support PwDs.

### ***"Flying blind" in how and how long to sustain caring***

"Flying blind" characterizes how, amidst uncertain and indefinite care trajectories, participants responded to immediate care demands through intuitive and adaptive problem-solving, and reliance on their own resources (e.g., learning, knowledge, time, money, new support relationships)—or "bootstrapping". Doing so, however, demanded a present orientation, which obscured the personal consequences that participants accumulated over protracted care durations.

### ***Bootstrapping care through one's own resources***

Participants continuously adapted to the growing demands of caring. Reducing working hours, retiring early, leaving the workforce, forgoing educational opportunities, "gaming" with service providers, and hiring private caregivers evidenced how participants negotiated between time and money to sustain caring through their own resources. Adapting also involved continuous learning, problem-solving, and seeking ad hoc support resources, often outside of one's strained sibling relations and mistrusted "system" resources, from neighbours, community organizations (e.g., church), casual hired help (e.g., babysitters), and peers. The latter was evidenced by Carla and Denise advising Thema on how to request consistent PSWs from the agency, and in this exchange of home modification ideas between the sons:

Timothy: Uh...your point about the learning...I mean, I would certainly say that 10 years ago I had no clue what caregiving was about, and everyday you're learning, learning, learning, learning. And one of the great things about [caregiver] support groups is how if you say something, it {snaps his fingers} ... it happened here [in today's focus group] too when I said motion-sensitive switches [and it gave Eric the idea] (...) That's happened to me a couple times [in other groups]: everyone goes, "Ye ah! Of course that's what!" And that whole learning process is a big part of it.

Eric: I'm going to install one tomorrow ... in [my mother's] washroom.

### ***Focusing on present needs-obscuring consequences***

Bootstrapping, as described, entailed meeting present needs with limited foresight into the durations and trajectories of caring. Florence recalls her family's decision to move her father to a transitional care unit when he became aggressive and was thought

to place their mother and their formal caregivers at risk. With some regret, she recounts making the decision based on then-present circumstances and the agency's recommendations, without anticipating that her father could no longer move back home due to unsuccessful interventions to manage his aggressiveness. For Denise, flying blind encompassed successive "short-term" decisions that enabled her to sustain caring for her late father and mother. According to Carla (Denise's friend), however, this eventually left Denise's home "completely transformed" with hospital beds, nursing stations, and assistive equipment, and complex care responsibilities that came to eclipse most aspects of her personal life.

No one expected this is where you're going to be in 5 or 10 years, but you think short term, and it becomes long term (...) until you're actually hands on, you do not get it (...) the scope of things (...) it's just at the emotional, the physical, it's the day to day, like you've got not just paperwork, you might have [an occupational therapist] coming in, you might have [a physiotherapist] coming in, you may have a case manager coming in, uh, social work—it just goes on and on...and these are added things that come into your life. (Denise)

Such hindsight realizations revealed to our participants how focusing on the present obscured the cumulative magnitude of their care responsibilities and personal opportunity costs. This raised important political discussion in both groups, including such consequences as indefinite suspensions of employment income, health benefits, pension contributions, and diminishing employment opportunities due to age and time away from the labour force. Timothy and David also grappled with the possibility of being outlived by their mothers (-in-law), which both felt would deprive them of opportunities to fulfill their own later life goals. Where David admitted that he felt "cheated" by the seemingly irreconcilable situation, Timothy explained that these feelings led to his decision to institutionalize his mother in an effort to "restore a life of my own". For this, he was conflicted between feelings of guilt and justification, having eventually realized he could not singlehandedly sustain his mother's care indefinitely.

In a perfect world, where everyone is a perfect human being, we don't [put our parents in homes] ... you know? We carry on to the bitter end ... [I] would've been able to stick it out indefinitely and learned enough to be able to cope and...blah-blah-blah. This is fantasy that we're in now ... because the reality is where she is now [in the nursing home] ... there's a staff of 20 people who interact with her on a daily basis, each with their own specialties ... and of course, there's no way I can have that base of knowledge of 203 different people, never mind the stamina of 20- different people, never mind the adaptive technology and the facilities. (Timothy)

## Discussion

Our study contributes a situated understanding of how (i.e., the processes through which) adult children may sustain caring for PwDs within their familial and formal care contexts. Two extended-duration focus groups afforded rich debates and establishments of common ground, from which we interpreted sustaining care as an indefinite process with three intertwined themes. These themes illustrate how care demands and dependency are reproduced on "primary" adult children, who rely largely on their own resources to meet immediate care needs, and are affirmed and reinforced in sustaining their care commitments by positive aspects of caring.

Our findings of how family and formal care relations reproduce care demands underscore the important influence of social and structural interactions on an adult child's care experiences and decisions. Where prevailing notions assume that caregiver stress and burden are the results of providing PwDs with functional assistance (critiqued by Roth et al., 2015) and managing PwDs' "behaviours" (critiqued by Dupuis, Wiersma, & Loisel, 2012b), our study asserts an alternative explanation that stresses the consequences of limited family support and inadequate home and institutional care supports. Others have similarly charged the dominant construction of burden as imprecisely understanding the sources of stress (Roth et al., 2015) and burden (Bastawrous, 2013), and neglecting important structural factors that produce negative consequences for family care partners (Lilly et al., 2011; Singh et al., 2014; Ward-Griffin et al., 2012). While the mismatched logics between informal and formal care systems (Singh et al., 2014) and diminishing formal care support (Ward-Griffin et al., 2012) have been documented, our study adds two novel insights. First, a more fundamental issue of "value conflicts" can exist not only between systems but also within informal care networks, including family members who might be expected to share the same ethnocultural values. Moreover, conflicting values between "primary" adult children and their siblings (e.g., if and when to institutionalize a parent), and between family care partners and formal care providers (e.g., personal relationships between care providers and parents vs. time- and activity-specified assistance, respectively), may explain why adult children limit seeking support from either stakeholders. Family conflict and ineffective care collaboration that ensues may explain why care responsibilities tend to be disproportionate between adult children (Connidis & Kemp, 2008). Secondly, our findings not only confirm that dementia care demands increase over time (Ward-Griffin et al., 2012), but emphasize that these demands increase *unforeseeably* and *indefinitely*. Primary adult

children consequently have limited foresight with which to make care decisions and arrangements, and may accumulate direct and opportunity costs when care journeys extend longer than expected without responsive support from informal or formal care resources. Amidst growing recognition of caregiver needs (e.g., Sinha et al., 2016), our study elucidates a temporal dimension of how adult children may become increasingly vulnerable insofar as financial insecurity due to unforeseen care costs and care demands that threaten their employment, and political disenfranchisement when they lack the wherewithal (e.g., time, knowledge, language, social status) to access formal care services, or when utilizing services threatens their held values. Mistrust in and limited utilization of public home care and institutional care also adds to previous evidence (Singh et al., 2014; Ward-Griffin et al., 2012) that has called for systemic reforms that build trust with informal care partners by responding to their values and priorities (e.g., greater social opportunities and connectedness for PwDs, family care collaboration, financial security). Future work to drive such change may longitudinally examine care journeys and relationships, and the personal, social, and financial impacts to care partners once they are no longer caring for their parents. Moreover, we advocate for the use of broader contextual frameworks when investigating care and caring. Adopting a citizenship lens (Bartlett & O'Connor, 2007; Kontos, Miller, & Kontos, 2017; Kontos, Grigorovich, Kontos, & Miller, 2016), for example, would recognize the political nature of dementia care and promote the rights and opportunities of PwDs and adult children who experience different forms of vulnerability as care is sustained.

Secondly, our study confirms related work that has conceptualized the positive aspects of caring for PwDs, and further theorizes how positive and negative aspects of providing care are interrelated. Carbonneau et al.'s (Carbonneau et al., 2010) three domains of positive aspects of caring (i.e., caregiver-care recipient relationships, caregivers' feeling of accomplishment, and meaning of caregiving role) were evident in our findings. The development of skills (e.g., management skills) that adult children foster through sustaining care, for example, demonstrates one way in which complex care management is not solely experienced as stressful or burdensome. Our study also adds that positive relational aspects can extend to the enhancement of multiple family relationships, including spousal and intergenerational relationships. Moreover, our findings suggest that positive aspects of caring not only provide uplifts (Carbonneau et al., 2010); they may also be invoked to justify and reinforce an adult child's care commitments despite negative consequences. In this way, our study conceptualizes positive aspects of caring

as a "double-edged sword"; these aspects enhance care experiences but can also obscure an adult child's need to balance her parents' needs with her own. From this view, we caution decision-makers from interpreting and translating positive aspects of caring into policies and practices that shortsightedly encourage adult children to sustain caring irrespective of cumulative costs to their own security and well-being. Rather, it is crucial that reforms prioritize and facilitate care foresight and informed decision-making, to promote positive outcomes over the care journey and mitigate the aforementioned vulnerabilities that adult children may experience.

Thirdly, our study advances challenges to the dominant conceptualization of caring as support that is unidirectionally given by a "caregiver" and passively received by a "care recipient" (Lingler et al., 2008). First, our findings emphasize that care partnering by adult children entails more than assisting parents in everyday tasks per se; it also involves the complex management of time, resources, relationships, and ongoing changes to care circumstances. Secondly, our study adds to previous work (Chappell & Funk, 2011; Lingler et al., 2008) that has highlighted the interdependencies—often between several care stakeholders—on which care decisions and arrangements are based, and which are inherently overlooked by the person-centred care paradigm (Bartlett & O'Connor, 2007; Dupuis, Gillies, Carson, Whyte, & Genoe, 2012a; M. Nolan, Ingram, & Watson, 2002). For example, our findings elucidated how strained sibling relations can resign an adult child to sustaining care with little to no family support, and explain greater needs for informal community-based respite resources (e.g., neighbours, church, friends) when home care support is inadequate or inaccessible (e.g., cost prohibitive). In contrast, cooperative care coordination by multiple family members may reduce home care and institutional care needs, but create greater needs for family education, mediation, and legal and financial planning. Thirdly, our findings demonstrated that personality and value differences shaped these interdependent relationships between care stakeholders, particularly between adult children siblings, and between adult children and their parents (PwDs). We therefore encourage future research to examine the nature and quality of care relationships through relationship-centred frameworks which promote equitable, synergistic care relationships that reconcile the needs of all partners in care (Dupuis et al., 2012a; M. R. Nolan, Davies, Brown, Keady, & Nolan, 2004). Moreover, it is crucial that policy and services aim to be value-sensitive and flexible to accommodate a wide range of personalities, values, and care arrangements, from no adult child involvement to active care collaboration with multiple adult child siblings.

## Limitations

Several limitations and trade-offs of this study were recognized. One limitation common to any focus group study is that group norms and viewpoints may discourage individuals from voicing deviant viewpoints (Kitzinger, 1995). The advantage offered by group dynamics, however, is that individuals have the opportunity to concur or challenge others' views, thus eliciting depth, range, and complexity of experiences across participants. Given the constitutive role of the researcher in data collection (Charmaz, 2014, p. 27), a second limitation was the difference in facilitators between the two focus groups. The presence of the first author at both groups, and analytic debriefs with the hired facilitator (daughters' group) and research assistant (sons' group), was intended to mitigate this limitation. Another trade-off was the recruitment of two participant dyads—one within each group—that had pre-existing relationships. Practically, this snowball sampling afforded the recruitment of homebound participants who otherwise would have been difficult to recruit. Moreover, these relationships promoted naturalistic interactions between the two dyads who could relate to and share observations about each other's experiences (Kitzinger, 1994). Conducting two single-session, extended-duration focus groups also had both advantages and disadvantages. We note that conducting longer half-day focus groups may have fatigued our participants; however, these extended durations accommodated our participants' resource constraints, and we observed that longer sessions strongly promoted rapport-building in both groups. Moreover, we recognize this study's small sample size, and posit that our findings offer insights that may have important conceptual or qualitative generalizability (Morse, 1999) to adult children, care partners, or other persons in comparable contexts or conditions, which we encourage future work to further explore. Lastly, our final interpretations emphasized experiential similarities between our gender-segregated groups. Although we initially attended to both similarities and differences between genders, after multiple iterations of analysis, all authors concurred that the variations not explicitly attributed to gender were most salient in our dataset. While we certainly cannot conclude from this small study that adult sons and daughters sustain caring in similar ways, our findings can inform future work that explores how care experiences compare and contrast between genders.

## Conclusions and recommendations

This focus group study elucidated the processes through which adult children of PwDs sustain caring within their familial and formal contexts. Overall, both

singlehandedly caring and seeking care support (i.e., from siblings and/or service providers) tended to reproduce care demands and dependency placed on primary adult children. The indefinite and ambiguous trajectories of dementia care precluded longer-term care planning, which exacerbated these consequences insofar as they accumulated direct and opportunity costs to adult children. While our findings confirmed positive aspects of caring, these affirmations can simultaneously reinforce commitments to challenging care arrangements in spite of negative, cumulative personal consequences. Together, our findings necessitate longitudinal, relational, and sociopolitical frameworks through which to conceptualize care and caring. In culturally diverse contexts (e.g., Canada), where the roles and expectations of adult children vis-à-vis parental care are difficult to prescribe, more flexible support schemes are needed to accommodate a wide variety of informal-formal care arrangements. At a minimum, policy should not assume the availability, willingness, and wherewithal of adult children and family networks to provide care for their parents. However, adult children who wish to and have the means to sustain caring should receive adequate and value-sensitive support that enhances positive aspects of caring while mitigating risks to their own health and financial security—both present and future. We recommend streamlined case management resources that are sensitive and responsive to diverse values (e.g., ethnocultural) and care arrangements, which may include different combinations of family and formal care resources; hands-on care vs. care management arrangements; and co-residence vs. local care vs. caring from a distance. Resources are also needed to facilitate access to public and private services offered within home, community, and institutional settings, and provide family education and holistic (e.g., health, social, financial, legal) advance care planning. Additional support schemes that may promote financial stability for adult children may include flexible work time, leave policies, and telecommuting technologies; universal tax benefits and continued pension contributions; and direct payments to replace reduced or foregone income. Importantly, schemes should be available to adult children irrespective of their mix of care resources (e.g., other family members, neighbours, friends, community groups or programs, formal home care). It is promising that several of these recommendations to better support informal care partners—including adult children—have been proposed in recent aging and dementia strategies (e.g., (Alzheimer's Society of Canada, 2015; Prince et al., 2013; Sinha et al., 2016)). To these proposals, our study stresses the need for such schemes to be accessible over highly unpredictable and indefinite care durations, and irrespective of workforce participation and living arrangements vis-à-vis PwDs. Moreover,



strategies should incentivize care involvement and collaboration by adult children siblings and other informal care partners (e.g., tax benefits to multiple adult children providing care, rather than only a co-residing care partner). These may promote the distribution of care demands within families who choose to provide care and, in turn, facilitate ongoing social support for adult children as care demands increase over time. Such reforms are expected to improve the equitability and sustainability of systemic reliance on the continued care efforts by adult children care partners, who experience the benefits and challenges of balancing their parents' needs with their own.

## Acknowledgements

The authors would like to thank Karen-Lee Miller and Bing Ye for their assistance during the focus groups, and Hans Jonsson and the research groups at the Division of Occupational Therapy at Karolinska Institutet (Sweden) who provided valuable feedback during data analysis.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## Funding

This work was supported by the Canadian Institutes of Health Research (Grant #: 278311) and various doctoral student awards, which were sponsored by Canada's AGE-WELL Network of Centres of Excellence, Toronto Rehabilitation Institute (University Health Network), and the Rehabilitation Sciences Institute at University of Toronto in Toronto, Canada.

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