



Mitigating Caregiver Distress in South Western Ontario: Perspectives on Role, Community, and Care

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Article

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Résumé

L'ancien Réseau local d'intégration des services de santé (RLISS) du Sud-Ouest de l'Ontario, une région essentiellement rurale, affiche régulièrement les taux les plus bas de détresse des aidants dans la province. Les aidants des communautés rurales sont régulièrement confrontés à des défis liés à l'accessibilité, la mise en œuvre et la disponibilité du soutien et des services. Cette étude de cas qualitative décrit les points de vue des aidants de la région et explore comment la conception de leur rôle et leurs attentes peuvent à la fois atténuer leur détresse et influencer leur utilisation des services de soutien. L'analyse thématique a permis de dégager cinq thèmes : l'accompagnement anticipé, la prise en charge genrée, les hypothèses sur le soutien des services, la confiance en la communauté et la définition de limites dans les décisions relatives à l'aidance quand les besoins évoluent. À travers le prisme de la théorie de l'identité de l'aidant, les résultats suggèrent que ces personnes conçoivent cette identité comme un élargissement de leur rôle principal pour inclure des obligations et responsabilités d'aidance. Nous avons également constaté une confiance inébranlable en la communauté et des perceptions de soutien des services dans l'ensemble de la région, et ce sans écart notable entre les régions rurales et les régions urbaines.

Abstract

The former South West Local Health Integration Network (SW LHIN) of Ontario, which is in a predominantly rural region, regularly reports the lowest rates of caregiver distress in the province. Caregivers from rural communities regularly face challenges related to the access, applicability, and availability of supports and services. This qualitative case study describes perspectives of caregiving from the region, and explores how role construction and expectations of caregivers might both mitigate distress and influence service support use. Thematic analysis identified five themes: anticipated care, gendered caring, service support assumptions, confidence in community, and the "line in the sand": care decisions for evolving needs. Using the lens of caregiver identity theory, the findings suggest that these caregivers conceptualize identity as an extension of their primary role, to include caregiving obligations and responsibilities. We also noted a steadfast confidence in community and perceived service support assumptions across the region, with no notable rural–urban divide.

Filling the gap in formal care for older people has generally been the responsibility of family and friend caregivers. Today, one quarter of Canadians provide care to a family member or friend (Hango, 2020), and the need for unpaid caregivers is projected to double over the next 30 years (Fast, 2015). Unpaid caregiving for older adults has become an expected role in the life course, with family and friend caregivers providing between 70 and 75 per cent of all care in the community (Health Council of Canada, 2012). Now, with the shortage of personal support workers, the largest labour pool among community care human resources, arguably destabilizing the community care sector in the wake of COVID-19 (Hopwood & MacEachen, 2021; Marani et al., 2021), unpaid caregivers are depended on more than ever to address gaps in care (Ontario Caregiver Organization, 2020).

Caregiving can be unrelenting. Ontario, Canada, has seen a steady rise in caregivers expressing feelings of distress, anger, or depression. Many feel that they are unable to continue with their caring activities (Health Quality Ontario, 2016). The provincial average shows that 26.1 per

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cent of Ontario caregivers report distress, with the number rising to 41.3 per cent in the former health authority¹

known as North Simcoe Muskoka Local Health Integration Network (Health Quality Ontario, 2018). One region, the former South West Local Integrated Health Network (SW LHIN), consistently documents the lowest rates of caregiver distress (17.1%) across the province (Health Quality Ontario, 2017, 2018). This presents a paradox.

The former SW LHIN is in a predominantly rural region, with approximately 1,000,000 people spread over 22,000 km², challenging the design and delivery of health and social care services. The impact of distance, lack of transportation, inclement weather, and isolation is considerable in rural and remote communities (Chappell, Schroeder, & Gibbens, 2008; Sims-Gould & Martin-Matthews, 2008). It is well established that caregivers from rural communities regularly face challenges related to the access, applicability, and availability of supports and services (Brannen, Johnson Emberly, & McGrath, 2009; Crosato & Leipert, 2006; Crouch, Probst, & Bennett, 2017; Ehrlich, Emami, & Heikkilä, 2017). Rural family caregivers, in general, are likely to sustain the care recipient far longer in the community than urban family caregivers (Ehrlich et al., 2017). This could be because more frequent connection with family and friends in rural communities brings expectations of care (Ehrlich et al., 2017; Kirby et al., 2016).

The aforementioned challenges and contextual norms may explain why rural caregivers are both less likely to seek formal support, including visits to health care professionals, and more likely to under-use available services and supports (Buckwalter, Davis, & Talley, 2011; Keating, Swindle, & Fletcher, 2011; Stockwell-Smith, Kellett, & Moyle, 2010). Perhaps unsurprisingly, reports of caregiver burden and distress continue to grow and are high in rural and remote communities (Chappell et al., 2008; Cohen, Kunicki, Nash, Drohan, & Greaney, 2021; Crouch et al., 2017; Hango, 2020; Keating et al., 2011).

It may be reasonable to expect higher levels of caregiver distress to have emerged in the former SW LHIN region and yet, caregivers there seem insulated from distress. The purpose of this research was to describe perspectives of caregiving from caregivers living and caring in the region, and to explore how role construction and expectations of caregivers might both mitigate distress and influence service support use.

Theoretical Influence

Caregiver identity theory (CIT), developed by Montgomery and Kosloski (2009), offers a valuable mechanism to explain the occurrence and extent of caregiver distress. The theory grew out of identity theory, with roots also in the sociology of the family. Philosophically, caregiver identity theory, used in this study to frame the understanding of the caregiver distress experience, accepts the premise that identity is socially constructed through interaction with others, institutions and, societal expectations (Carroll, Chippior, Karmali, Sriram, & Ysseldyk, 2019; Eifert,

Adams, Dudley, & Perko, 2015). CIT is built around three central tenets: the caregiver role is acquired systematically, informed by culture and social norms; caregiving is a dynamic process that evolves with the needs of the care recipient; and third, role evolution leads to identity change (Montgomery & Kosloski, 2013).

The caregiver role typically emerges from the primary familial role and posits that identities and subsequent relationships are shaped by societal norms, family rules, rituals, and boundaries. As the care needs of the recipient evolve with disease trajectory, the caregiver must either assimilate, integrating the new activities into their existing role and identity, or accommodate, shifting the caregiver's primary identity to incorporate the changes in care demands (Montgomery & Kosloski, 2013). A significant source of distress is the incongruity brought forth by the caregiver needing to take on new and unfamiliar roles, such as assisting with personal care or providing supervision, that unconsciously break family rules (Montgomery & Kosloski, 2013). Distress is further compounded when socialized gender norms are factored into identity discrepancy, such as adult sons caring for mothers (Eifert et al., 2015; Friedemann & Buckwalter, 2014; Holstein, Parks, & Waymack, 2011).

The metamorphosis of the new identity happens in tandem with the care trajectory. Montgomery and Kosloski (2009) have conceptualized this progression as a five-phased process, from onset to institutionalization. Phase I is classified as the onset of caregiving, most likely defined by assistance with instrumental activities such as banking and shopping. In Phase II, the caregiving role begins to extend beyond the usual familial identity. Phase III is said to occur when the care needs of the recipient increase to the point at which the caregiver identifies him/herself in the role and is struggling to straddle both identities. Phase IV is dominated by the caregiver role, with family possibly contemplating long-term care. Phase V sees the return of the primary role as the major source of identity, as the recipient is typically institutionalized. Throughout, the caregiver is forced to determine whether they will accept the new role expectations and tasks, thus establishing a new equilibrium, or change the situation by seeking alternative supports or applying for long-term care placement (Miller, Killian, & Fields, 2020; Montgomery, Kwak, & Kosloski, 2016).

Methods

This article presents data drawn from a subset of a larger qualitative case study that examined how the policies, practices, and geographic culture of the former SW LHIN interconnected in a manner to insulate caregivers from distress. The goal of a case study is to optimize the understanding of the phenomenon under study, rather than to make broad generalizations or build theory (Stake, 2003). The research is underpinned by a constructionist paradigm. We believe that how caregivers construct their reality is deeply influenced by the contextual conditions of the SW LHIN; namely, the socio-economic history, culture, and geography of the region. Constructionism is based on social exchange, rather than on the internal cognitive processes and perspectives accepted by constructionists, and emphasizes the role and importance of culture on our world-view (Crotty, 1998). Individual and collective action generates knowledge and shapes perceived reality, and contributes to our identities (Berger & Luckmann, 1967). Finally, the tenets and phases proposed by CIT influenced the recruitment strategy and data analysis of our study, particularly the framing of concepts within the themes and the interpretation of the findings.

¹Healthcare in Ontario was regionalized by the Dalton McGuinty Liberal government in 2005. The establishment of the Local Health Integration Networks (LHIN) divided the province into 14 regional health authorities mandated with the responsibility of planning, integrating, and distributing public funding for all regional health care services. The LHIN structure has since been replaced by the Ontario Health Team reforms introduced by the Doug Ford Conservative government; however, all data collection for this study was completed under the LHIN structure prior to the reforms.

Recruitment

The Health Sciences and Affiliated Teaching Hospitals Research Ethics Board of the Queen's University granted ethical approval for the study. We used a purposive maximum variation sampling strategy described by Patton (2015), chosen to capture common patterns among a heterogeneous group of caregivers. Recruits were screened and recruited across a matrix of factors including relationship, living situation, care tasks, and location within the SW LHIN (rural or urban and across the five sub-LHIN geographies). The goal was for the sample to reflect the variability of caregiving relationships and situations, as well as to potentially represent caregivers from the various phases of caregiver identity described by Montgomery and Kosloski (2009). Recruitment posters seeking unpaid caregivers for one-time interviews were put up across the region in public spaces, banks, seniors' centres, pharmacies, libraries, and shopping locations. Advertisements were also placed in faith-based institutions' announcements and bulletins across the region.

The eligibility criteria were: (1) being 18 years of age or older; (2) providing unpaid support for at least 3 months to a spouse, parent, other family member, or friend who was over the age of 65; (3) both the care recipient and caregiver being residents of the former SW LHIN; and (4) the care recipient living in the community and requiring assistance and/or supervision with at least one of the following: instrumental activities (banking, errands, grocery shopping or activities of daily living (ADL) (personal care, medication).

Participants

Recruitment achieved a sufficiently diverse sample to match the heterogeneity matrix. Potential recruits contacted J.W. by e-mail or phone. Of the 18 people screened, total of 14 individuals were eligible to participate. One participant cited increased caregiver demands during the COVID-19 pandemic and withdrew from the

study. The final study cohort consisted of 13 caregiver participants, all caring for older adults. Three participants were spousal caregivers, seven caregivers were providing care for parent(s), one participant was both a spousal and parental caregiver, and two were caring for other extended family members. The sample had representation across the three distinct geographies within the LHIN boundaries: rural, small population centre, and large urban centre. Statistics Canada defines "rural" as small towns, villages, and other populated places with less than 1,000 people, which may contain estate lots, as well as agricultural, undeveloped, and non-developable lands, as well as remote and wilderness areas (Statistics Canada, 2022). The participants from small population centres, considered to be areas with populations of 1,000–29,999 by Statistics Canada (2022) were largely from towns with populations of under 8,000 that were in fact surrounded entirely by agriculture. As such, a decision was made to consider our small population centre respondents as being rural for this study. Table 1 provides a description of the participants and their care recipients.

Data Collection

A background questionnaire was completed by each eligible participant prior to the scheduled interviews, which provided the information for Table 1. The purpose of the questionnaire was to gain a deeper understanding of the attributes of the caregivers themselves. Semi-structured interviews, held both in person and virtually, explored topics such as the meaning of caregiving, service and support use patterns, and caregivers' thoughts on their community. See the interview guide in Table 2. All interviews were conducted by J.W. over a 7-month timespan between the fall of 2019 and the summer of 2020.

In all interviews, participants were urged to speak freely regarding their relationship and experience with their care recipient and were encouraged to share positive and negative thoughts about the

Table 1. Caregiver characteristics

ID	Caregiver Type	Care Recipient	Living Arrangement	Duration of Care	Support type (IADL, ADL or both)	Geography	Occupational Background
CG001	Daughter	Mother	Live-out	1-2 years	Both	Rural	Nurse
CG002	Daughter	Parents	Live-out	3-5 years	IADLs	Small population centre	Bookkeeper
CG003	Niece Grandmother	Uncle Granddaughter	Live-out Live-out	≥6 years	IADLs	Rural	Teacher
CG004	Daughter	Mother	Live-in	3-5 years	Both	Rural	Customer service provider
CG005	Daughter	Father	Live-out	3-5 years	Both	Rural	Teacher
CG006	Husband	Wife	Live-in	3-5 years	Both	Small population centre	Small business owner
CG007	Son	Parents	Live-out	3-5 years	IADLs	Rural	Training and development
CG008	Wife Daughter	Husband Mother	Live-in Live-out	6 + years 1-2 years	IADLs	Rural	Retail
CG009	Daughter	Mother	Live-out	3-5 years	IADLs	Rural	Social worker
CG010	Husband	Wife	Live-in	3-5 years	Both	Small population centre	Post-secondary education
CG012	Daughter	Father	Live-out	≥6 years	IADLs	Urban	Pharmacology
CG013	Wife	Husband	Live-in	≥6 years	Both	Urban	School secretary
CG014	Brother	Sister	Live-out	≥6 years	IADLs	Urban	Account sales

Notes. Duration of care = participants responded from pre-set selection (35 months, 6 months to a year, 1-2 years, 3-5 years, or ≥ 6 years) IADLs = instrumental activities of daily living (meal prep, medication assistance, shopping, laundry, financial management); ADLs = activities of daily living (washing, dressing, grooming, toileting, feeding); rural = ≤ 1000 people; small population = 1000-29,999 people; urban = > 100,000 people.

Table 2. Semi-structured interview guide

<ol style="list-style-type: none"> 1. What does the term caregiver mean to you? <ol style="list-style-type: none"> a. To what extent do you see yourself as a caregiver? 2. How is being a caregiver different from being a spouse/child/friend? 3. In your family, is family help an assumption/expectation? 4. Tell me about the things you do to support [care recipient]? <ol style="list-style-type: none"> a. What tasks, activities do you help with? b. What does a good day [or week, depending on the intensity of support previously established] supporting [care recipient] look like to you? 5. How does supporting [care recipient] impact your life? <ol style="list-style-type: none"> a. Who picks up the slack if you can't be there? 6. How do/would you know if you needed a break? What would a break look like to you? 7. What causes you stress in supporting [care recipient]? 8. If you needed help outside of the family, how would you arrange it? <ol style="list-style-type: none"> a. What support do you have around you? 9. Have you ever felt you couldn't provide the care you wanted to [care recipient] because of barriers or limits to services? 10. What good things are happening here, in this community, for older adults (both in general, and for those who need care)? What is your community good at; what are its strengths?

caregiving role and their community. The interviews lasted between 30 and 60 minutes. Responses were probed and followed up with prompts to capture rich and robust data. The face-to-face interviews were audio recorded digitally and then transcribed verbatim. Virtual Zoom interviews were both audio and video recorded before being transcribed (audio only). Transcriptions were then read and verified for accuracy by J.W., as well as de-identified to maintain confidentiality.

Data Analysis

The interview data were analyzed using the six-stage process articulated by Braun and Clarke (2006) for thematic analysis, with CIT components used as sensitizing concepts in theme generation. Thematic analysis provides a rich detailed account of the data and looks for patterns across the interviews (Braun & Clarke, 2006). This approach, although similar to content analysis, is better suited at uncovering why and how certain factors, processes, or beliefs shape and influence behaviour (Guest, MacQueen, & Namey, 2012). Thematic analysis allows for the coding of direct semantics, but also affords researchers the flexibility to code latent meaning as it aligns with existing theory (Sun, 2014).

In Phases 1–2, transcripts were closely read and reread several times by the research team independently for familiarization and then to inform the development of inductive codes. This process occurred concurrently with the data collection phase. Transcripts were then grouped by sub-LHIN region and uploaded into the qualitative data management software, NVivo 12, for further coding and data mining. In Phase 3 we collaborated as a research team on early theme development and thematic maps. Phases 4 and 5 saw themes greatly revised and refined before being finalized for manuscript writing in Phase 6 (Terry, Hayfield, Clarke, & Braun, 2017).

Qualitative rigour was supported through several strategies. The research team met regularly to discuss codes and explore initial themes and sub-themes relevant to the aims of the research (Terry et al., 2017). The findings were compared with previous works on the experience of rural aging and rural caregiver help-seeking patterns for alignment. J.W. maintains a strong personal connection with many of the rural communities researched, through both

family background and caregiving connections. As such, she was conscious of the need to challenge self-evident responses from interviewees. The other members of the research team had no connection with the people or the place. To maximize the *sincerity* of the research (Tracy, 2010), predetermined assumptions and unconscious biases were uncovered and discussed through the use of a reflexive journal and meetings with members of the research team. Member checks were also used to enhance trustworthiness. All participants were sent a summary of the findings and were invited to offer input. No changes were suggested by participants.

Findings

Five overarching themes were identified during analysis: (1) anticipated care, role extension and expectations; (2) gendered caring; (3) service support assumptions; (4) confidence in community; and (5) the “line in the sand”: care decisions for evolving needs. The first four themes we interpreted with the first central tenet of CIT: the caregiver role is informed by culture, social norms, gender, and boundaries. The final theme is reflective of the second tenet of CIT: caregiving is a dynamic process that evolves with the needs of the care recipient. The themes will be presented with accompanying, illustrative quotes.

Anticipated Care: Role Extension and Expectations

Within this theme there was a tacit understanding that “caring” would fall within the boundaries of the primary role. Beliefs about caregiving were closely tied to a caregiver’s understanding of the meaning of “daughter” or “spouse”. Participants conceptualized caregiving responsibilities as part of the relationship, a natural extension of their existing role. A daughter caregiver, CG005, never questioned new responsibilities, “The question of whether I was going to be a caregiver or not never even arose. It’s just what you do.” CG014, a caregiver to his sister, summarized it as “It’s my sister, so I want her to have the best things that she can have for the rest of her life.... I think that is an extension of being a brother.”

The transition to caregiver, although acknowledged as stressful, was accepted as a normal aspect of having aging family and friends. Adult child caregivers foresaw the need for caregiving, anticipating and accepting care responsibilities with a “just do it” attitude, even if they had incorrectly estimated the timing of onset. Consider two caregivers’ experiences: “If you’re doing something for somebody you love, you just shut up and do it” (CG008), and CG002, “It’s just something I do now because that’s ... Yes, I feel that’s my responsibility now, and it’s what I need to do... If they [parents] need help, you help.”

A different picture emerged for some spousal caregivers. As partners aging together, having to take on the caregiving role had not been as readily expected, though was still considered to be within the scope of the primary role: “Because I wasn’t ready for it and that was the main thing.... I hadn’t anticipated it at all. So, I missed signs” (CG010). Recently retired, CG006 became tearful as he explained about caring for his wife with early-onset dementia, “I can’t say there’s been a line of demarcation that one is one and one is the other. It’s all one role.... It never even occurred to me that this was going to happen, that this would be the way it was” (CG006).

Some participants implicitly carried their professional experiences with them to their extended role, thus expanding their

capacity to fulfill their duties. The skills and knowledge from the professional background were regarded as significant assets, especially for those with careers in health and social care as CG009 describes:

I think because I am a social worker, and because I've worked in community supports, because I have supported seniors, I understand. I get it. I understand. I understand the isolation that seniors have. And their losses. Right? The loss of dignity, the loss of independence, the loss of cognition.

For CG012, her professional background, and that of another of her siblings, positioned them well to lead the care of their parents: "We tend to have a different perspective just innately than our other two siblings because of the different therapeutic areas that we've studied, not only in our education, but also in our careers." And for CG001, a nurse with experience both in hospital and community health, caregiving was anticipated, "I am the daughter, but I also expect this sort of thing." Expectations pertaining to caregiving were not usually fully expressed, but both silently understood and internalized as well as normalized.

Gendered Caring

Care responsibilities and the division of labour among caregivers, especially when larger families were providing the care for an aging parent or parents, were typically divided along traditional gender norms. Women – daughters, nieces, wives, sisters – were still performing most of the hands-on care care, in addition to the management and coordination. This was regardless of whether or not there was a male relative to share the responsibility. When asked about the sharing of care among siblings, one daughter explained the division of labour:

And we do try to take turns [providing care] Like, my brother's the one that calls almost every day to talk to my dad. I don't call every day, but we have my dad to our place more often just for a visit. So, we all kind of have a different role. And the nice thing is that the four of us kids communicate, so there's no friction. We kind of just divide and conquer... it's nice to have siblings (CG012).

Participants described different expectations of sons and daughters, "It's so different. It's very, very different. And he just sees what he wants to see...they don't see that day-to-day stuff, which is, that's nice for them I guess" (CG001). Spousal caregiving was described in gendered terms.

CG009 felt that she had been abandoned by her brother to manage all the care herself while balancing the needs of her own life:

J.W.: What about your brother? Where is he?

CG009: Useless? Did I say that too quickly? He'll never know. So, my brother is single. He lives in [city]. My brother does not drive. My brother rarely comes to my mom and dad. I don't know the dynamics of their relationship. It's not for me to ask, but I'll be honest with you, it's very frustrating. Because I feel that I'm the one who's getting all the questions, either myself or my husband. And my brother is totally oblivious.

When asked about distribution of care responsibility this participant explained that her freedom of movement was compromised because of her brother's choices.

No, just my brother and he's away half the year, so it mainly ... I do all the helping and he's gone now until May. I won't go away, because I know my brother is away. Yeah, it's just not an option, because there's nobody else (CG002).

One male caregiver, trying to make a pre-emptive care plan for his wife, acknowledged that their daughter, the youngest of their five children and only daughter, would be in charge.

I talked to all of them about what happens if something happens to me type of thing. And of course, an organizer of everything is our daughter, and she says ... When it comes down to it, she says, really, she thinks she should be the one that takes the initiative portion of it anyhow (CG010).

Service Support Assumptions

Experiences with support services and program availability were discussed in the interviews. Rural and urban caregivers alike expressed pride in local health and social care organizations. Participants were confident that supports could be arranged and that they knew how to access those supports, articulating even whom they would call and engage. The reality of what support was available and the knowledge about how to arrange services was not always factual; caregivers were often incorrect, in terms of both availability and access, but their self-confidence provided comfort in challenging times. Consider this quote from a spouse caregiver discussing Home and Community Care:

They've been wonderful to me. They're accessible, really accessible, responsive. And I can get *anything* I need, if I ask for it. I'm thinking home care, I'm thinking practical assistance around the house. I'm thinking transportation. Or the Day Away Program is community services... (CG006).

Pride in healthcare was abundant. CG005 trusted that her family doctor would know how to arrange services, "We have an excellent doctor who makes sure that we get the resources that we need."- Pride also extended to additional social care resources such as the Alzheimer's Society and community support services, "Give me a diagnosis and I can tell you the support" (CG013), and "Mom did, last year, find a homemaker. I don't even know what program it is. Maybe you could go ask her. And this young lady would come into the house once a week and exercise her for an hour, which was fabulous" (CG004).

Despite some understanding of services and supports, many caregivers, particularly spousal caregivers, were wary of outside help, putting it off if possible and instead relying on their own efforts and capacity; for example, two husband caregivers, CG010 and CG006. CG010 failed to see the need, "So, it's [outside help] not something that I'm averse to, but it's not anything that I see any need of as yet." And CG006, already providing round-the-clock care for his wife, felt that formal help might make things worse, "I haven't made any move to bring anybody in from outside because I think at this point in time, it'll be more of an intrusion than anything."

For some participants, accessing services was limited by the care recipient's self-reliant values. This created tension at times between what the caregiver needed, and what the care recipient wanted. Several caregivers knew of programs worth investigating, but suggesting those programs to the care recipient met with refusal.

Well, to be honest, I haven't explored all those things because she's so resistant. So, there's a few things that we're trying to encourage her to do, and she refuses. I don't know what day, maybe today, they have a senior's program at the Legion ... and there's all this stuff. But she won't go (CG001).

Individual autonomy and independence were described by many participants as generational values and characteristics of care recipients. As CG002 explained about her own parents, both in their nineties: "They would complain that there was no help, but they wouldn't pay for help, or more or less accept help." Others eschewed assistance out of pride.

Because my mom is such a strong person, and I mean that in a positive way, I think sometimes we don't always realize when she needs the extra support because she's been able to compensate and manage so much for so many years. And she also has that character and pride, right (CG012)?

It was difficult for caregivers to accept help from sources outside their immediate circle, either because of their belief that caregiving was their responsibility or out of recognition for the care recipients' values.

Confidence in Community

There were similar beliefs expressed by rural and urban caregivers from the SW LHIN that the community could be relied upon and trusted for helping with life's challenges during times of need. Participants tended to have lived in and around their community for most of their adult life, if not their whole life. There was a sense of a shared accountability, born out of place and space. Duration alone was revealed as a strength.

I think the one strength that they have in their community is my dad was born and raised there, so they're from [town]. They live in [town]. So, Dad was born and raised in [town], so Mom was born and raised in [city], which is just a hop, skip and jump (CG009).

There was a feeling shared among all participants that their communities were good places to come from: "It's a community where I grew up in, went away to school and ended up coming back to live in. So, it's just a place that's a good place to be" (CG005). Participants believed that the community could be counted on to adapt and respond to the changing needs of its residents.

A sense of belonging was enhanced by membership in service groups or volunteering, or through recreational activities. Religious affiliations and faith-based groups also provided additional opportunities for caregivers to maintain a connection to community, "Our church family has been really good to look after us" (CG006). Churches offered a place of respite and a familiar routine, and were also a source of counsel, "My minister has been very good" (CG003), and "I said I've got to talk to the minister because he visits around, and I know him fairly well, because he knows our situation" (CG010), are both good examples of the continued importance of religion in these rural communities.

Strong connections meant that multiple networks could be enlisted to offset the responsibility of caregiving. In drawing from different circles across the community, distress was minimized.

So, we have a very strong family community and then our neighbours ... So, it's a very strong neighbour thing. And then this place where she lives now, all those people surround anybody that they know is not managing. So yesterday to go to this church meeting, two of the neighbours had

called to see if they could take her, kind of thing ... We've had a lot of friends too that have offered to go in like once a week just to visit (CG001).

It was very common for participants, in discussing their connection to their community, to reinforce traditional views of rural communities: "Oh, just that small town rural feel of helping your neighbour and just being resilient and strong to be there for your family and friends" (CG005). CG002 highlights the variety of help people can expect when part of a rural community.

Rural communities all seem to be the same. People here want to help. If something happens to somebody, it's overwhelming, the support from the town, and you don't get that in the cities, that's for sure. Everybody pretty much knows everybody. So, when you go through something, then yeah, there's all kinds of support. Whether the people bringing food to your house, or calling, or emailing, or texting, or dropping in (CG002).

Overall, caregivers felt confident that their community could be counted on to meet their changing needs. Information regarding services and supports for caregivers was transferred through long-held connections and existing networks built over the long tenure of residence and a deep sense of belonging.

The "Line in the Sand": Care Decisions for Evolving Needs

Even though participants rejected the concept of "caregiver" as a separate and distinct role, there was an acknowledgement that care evolved over time on a continuum and sometimes provoked major life decisions. We interpreted these decisions as a caregiver's "line in the sand" for making a transition. New demands required adaptation; decisions needed to be made about how best to meet increasing needs.... There was an acknowledgement that previous boundaries would need to be re-evaluated, such as living arrangements.

I just found myself spending more time going between the houses. So, I was at my place looking after my stuff and my girls. And then I would have to go out and do the shopping for mom, and I would have to go and change a light bulb or do whatever. It was just so much back and forth. At that time the girls were in school. My sister and I have vowed that we would like to never have to put our mother in a nursing home. So, I was like, you know what, I live in the same town as her, so I'm making the move and I'm going to bunk in with her (CG004).

With the end of the continuum in mind, many participants had conceived of a turning point of caregiving, anticipating an accumulation of small changes or declines in the care recipient's health or function that might eventually result in a significant care turning point. For CG008, the "line in the sand" with her mother was "If she starts wandering ...". For CG009, caring for both parents, her father's driver's license was pivotal, "The license will be key. And if something happens to dad." A husband caregiver, just days after his wife had had a traumatic fall down the stairs, was reluctant to say the words "long-term care", but implied them in the following quote: "This situation is starting to deteriorate to the point where I'm going to need to make some hard and fast decisions one of these times" (CG006).

The "line in the sand" was highly individual to each caregiver. The most experienced, or longest-serving caregivers were the least rigid about definitive decisions or an absolute end point.

And for me the "line in the sand" is if she's not getting up, getting bathed and getting dressed and eating, then that's sort of, otherwise I think she's

safe even though she is starting to lose some of her mental capacity, I feel she's still quite safe (CG001).

The “line in the sand” was the future care point or task that would provoke a major decision by a caregiver. It represented the limit or the boundary of the caregiving role.

Discussion

The overarching goal of this study was to describe perspectives of caregiving from caregivers living and caring in the former SW LHIN area, and to explore how role construction and expectations of caregivers might both mitigate distress and influence service support use. The existing literature on caregiver distress and burden suggests certain factors, particularly gender, relationship type, ADL care tasks, care recipient cognition, living situation, and employment status are all associated with an increase in caregiver burden (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014; Health Quality Ontario, 2016; National Institute on Ageing, 2018; Pauley, Chang, Wojtak, Seddon, & Hirdes, 2018; Riffin, Van, Wolff, & Fried, 2019). These same factors were common among the majority of caregivers in this study. Caregivers did acknowledge the inherent difficulties in providing care and the many ways that they struggled. However, participants described an acceptance of the caregiving role and a “you just do it” attitude that may have contributed to their ability to mitigate some of the distress associated with caregiving.

Second, researchers have noted significant place-based differences among people living in different geographies (urban, rural) on many key issues such as the economy, climate change, politics, values, and traditions (Speer & Loewen, 2021). A rural–urban divide has also been noted in the use and requirement of community health care supports (Keating, 2008) and in some of the existing literature on geographic differences in caregiving (Buckwalter & Davis, 2011; Cohen et al., 2021; Crouch et al., 2017; Ehrlich et al., 2017). Across the themes of this qualitative study, differences in perspectives and expectations between rural and urban caregivers were not found, despite disparities in community characteristics and resource access suggesting a gap in our understanding of meso-level or regional identities (Paasi, 2011; Pohl, 2001). Future research may consider how regional identities are constructed and sustained, as regional identity may contribute to improved health outcomes for caregivers.

Caregiver identity theory was adopted in this study as the theoretical lens through which to conceptualize the experience of caregiver distress and inform the findings. Existing CIT literature has previously addressed a multitude of relationship dyads (Eifert et al., 2015; Miller et al., 2020; Montgomery et al., 2016; Montgomery & Kosloski, 2009; Rurka, Sutor, & Gilligan, 2020; Savundranayagam & Montgomery, 2009), all of which reinforced the occurrence of identity discrepancy and role incongruity in caregiver distress.

Our findings are consistent with the tenets of CIT, and substantiate the theory from the inverse experience: a lack of distress fostered through identity maintenance. Caregivers described the incorporation of care activities into their lives and their routines as something that had to be done and was normal among their peers and communities. This integration of care into the existing role is consistent with the definition of assimilation by Montgomery and Kosloski (2013). The social norms that informed the identity

construction of what it meant to be a “good” daughter, spouse, or sibling carried unspoken implications of care for caregivers across the SW LHIN. Parental care was normalized among adult child caregivers as an expected, anticipated stage in the life course, in keeping with previous research on care trajectories (Allen, 2019; Brody, 1985; Kirby et al., 2016).

Furthermore, caregivers discussed having a “line in the sand” that guided decisions in the context of caregiving. This concept was similarly described by Pinquart and Sorensen (2007) and is akin to the “tipping point” defined by Crist et al. (2019), which signaled a pivotal change in the caregiving career. This broad scope of role, combined with anticipated care responsibilities, at least by adult child caregivers, seems to have contributed to greater role satisfaction for caregivers and mitigated the distress that Montgomery and Kosloski (2009) would attribute to identity discrepancy.

From a theoretical perspective, our findings also add to previous theoretical work on perceived social support. Social support plays an important role in moderating the potentially detrimental impact of caregiving on the health and well-being of the caregivers (Birtch, 2017; Cohen & Wills, 1985; Del-Pino-Casado, Frias-Osuna, Palomino-Moral, Ruzafa-Martinez, & Ramos-Morcillo, 2018). A perceived availability of social support can significantly decrease caregiver burden, and may mean that caregivers appraise a situation as being less stressful (Del-Pino-Casado et al., 2018). In particular, perceived social support from close relationships, for even the most self-reliant, is a strong predictor of physical health outcomes, quality of life, and life satisfaction (Şahin, Özer, & Yanardağ, 2019). Self-reliance remains a poorly defined construct, particularly in the context of aging and caregiving. Eales et al. (2006) found that stoic, independent older adults in rural communities were unlikely to join activities and were less likely to ask for formal help. In our study, caregivers from across the region were equally likely to describe personal attitudes interpreted as self-reliant, as they were to describe the care recipient as independent or private. The presence of self-reliance as a characteristic, regardless of whether it was a trait of the caregiver or the care recipient, may have some relationship to caregiver distress, and is worthy of future exploration.

Discussions with participants suggested that perceived support should be considered beyond personal relationships to the wider community. Caregiver coping strategies extended beyond the boundaries of family and friends to include wider community resources. There was belief among participants, both urban and rural, that supports could be leveraged through an existing network such as a religious affiliation. Social capital built through social participation and community connection could also be a source of perceived support (Birtch, 2017; Eales et al., 2006; Rozanova, Dosman, & de Jong Gierveld, 2008). And, although caregivers’ understanding of access to service was not always in keeping with the prescribed provincial processes or offerings, the perception of the existence and availability of resources ameliorated feelings of distress. Caregivers believed that a wider array of services was available to them when needed, such as in-home nursing, respite, home help in all forms, adult day programs, and volunteer transportation, and could be accessed immediately. In reality, publicly funded programs in the region, if they existed at all, had lengthy eligibility assessment requirements and extensive wait lists in many communities (R. Griffin, now Director, Planning & Integration, Ontario Health [West], personal communication, May 17, 2021).

A corollary of strong community connection and perceived support was a high level of confidence in community. Caregivers

strongly believed that the necessary resources that enabled and empowered them to manage the caregiver role were present, having been developed over time and fostered by connection. Although never before applied in this manner, there is a future opportunity to use Bandura's Bandura (2000) theory of collective efficacy to help understand the importance of confidence as a protective factor for caregiver mental well-being. According to Bandura, "perceived collective efficacy fosters groups' motivational commitment to their missions, resilience to adversity, and performance accomplishments" (2000, p. 75). As confidence and collective efficacy influence both behaviour and the creation of supportive environments, further study is required to understand the significance to unpaid caregivers of older adults.

Overall, the findings from our study provide new insight into the importance of the meaning of place to caregiver outcomes. Place matters to health, defining access to resources, life expectancy, and well-being (Kulig & Williams, 2012). Place attachment enhances psychological well-being (Scannell & Gifford, 2017) and has been linked with "many positive health and community participation outcomes" (Anton & Lawrence, 2014, p. 451). Place is also key to identity. People are shaped by the social and geographic context in which they grew up, reside, and work, often sharing values, beliefs, history, traditions, and common social space (Raagmaa, 2001). Similar feelings for a place and a shared frame of reference contribute to a meso-level culture that cultural geographers refer to as "regional identity" (Pohl, 2001).

As demonstrated earlier, previous caregiver research and theory have offered valuable insight into how personal identity and social identity influence the caregiver experience (Carroll et al., 2019; Eifert et al., 2015; Hughes, Locock, & Ziebland, 2013). We could speculate that many of the features of each theme – community connections, deep roots, pride in local resources – played an important role in creating social identities that both managed and improved health outcomes (Jetten et al., 2017). Greenaway et al. (2015) and Carroll et al. (2019) noted that caregivers who understood themselves to be members of a wider care group were able to foster a sense of belonging and well-being that buffered them from perceived stress. We suggest that a strong sense of regional identity, arguably itself a social identity with "value and emotional significance attached to membership" (Tajfel, 1978, p. 63), contributed to minimizing the experience of caregiver distress in the SW LHIN region.

Limitations

Several limitations of this study can be identified. Caregivers providing for the most unrelenting and intense care needs may not have been recruited to the study, as they were not available to participate. The impact of the COVID-19 pandemic on this research cannot be minimized. Although recruitment for the study began in the fall of 2019, recruitment was still underway in the spring of 2020. After several months, we failed to successfully recruit any caregivers from one of the sub-regions. A decision was made to continue with the interviews we could arrange. Many unpaid caregivers during the pandemic were stretched and challenged as Ontarians came to terms with enforced isolation. Services that provided much needed help and respite, such as in-home personal support work, adult day programs and transport services were suspended indefinitely, the impact of which was a potential increase in either or both frequency and intensity of care responsibility. This may suggest that cohorts of more highly distressed

caregivers were also unable to participate in the study. Also, the confidence in resources and community felt before the pandemic may no longer be the same given the widespread health human resource shortages in the wake of the pandemic (Hopwood & MacEachen, 2021).

Social distancing requirements necessitated a methodology amendment to allow for the interviews to take place over the Zoom video conferencing platform. Modifications to the inclusion criteria reflected the need for individuals to have Internet connectivity; access to a computer, laptop, or tablet; and a basic knowledge of computers. This undoubtedly impacted recruitment, as broadband was not universally available to all communities in this study. In hindsight, we realized that we were remiss not to offer telephone interviews. We were attempting to stay as true to the face-to-face earlier interviews as possible, but we may have missed out on valuable information from caregivers without access to or knowledge of technology.

Moreover, the Zoom interviews tended to be much shorter than the face-to-face interviews, suggesting perhaps that the online platform, at the time less familiar to people, was not as effective as face-to-face interviews for collecting rich and robust data. It was more difficult to build rapport, and we could not strive for privacy in the same way. The field notes, missing many of the non-verbal observations, were not as rich.

Despite the limitations discussed, the rich qualitative research presented here provides valuable insight into the importance of caregiver role construction and regional identities. There is ongoing need for studies exploring the variety of experiences of caregivers from different geographic areas. Our work may offer a starting point for an expanded investigation into effective caregiver supports and further the applicability of existing theory.

Conclusion

The SW LHIN region has been an anomaly for many years, as the predominantly rural region continually reports the lowest rates of caregiver distress in the province of Ontario. As the need for unpaid caregivers is certain to increase with an aging population, understanding caregivers' perspectives on their role provides insight into expectations and influences of support use.

This study found that unpaid caregivers from the SW LHIN conceptualized identity as an extension of their primary role relationship to include caregiving obligations and responsibilities until a "line in the sand" was drawn. We also found a steadfast confidence in community and perceived service support assumptions across the LHIN, without the notable rural–urban divide that one might expect. When taken together, these elements buttressed caregivers from distress, and contributed to role satisfaction. Given that unpaid caregivers are essential partners in health care, we must continually strive to understand and enhance the caregiver experience in Ontario.

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