



research article

Producing the public caregiver: the discursive politicization of family caregiving by Canadian caregiver organizations

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How are problems of family/friend care framed and politicized, and with what socio-political implications? This feminist rhetorical analysis examines how carers are positioned, how problems and solutions of care are framed, and how carers' social and political rights are supported by Canadian caregiver organizations. Organizations' public materials draw on and expand narratives that foreground individual risk and recognition, decentring the state's role. We elaborate on how carers' citizenship rights are discursively bounded with proposed individualized solutions that support them in continuing to care. Broader narratives could consider carers' human or citizenship rights or otherwise foreground relationality and complex collective care solidarities.

Keywords advocacy • caregiver organizations • citizenship • Canada

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Introduction

Family caregivers are from ‘different walks of life’. They are ‘heroes’ who do the impossible and ‘victims’ who need help. They are at one and the same time a ‘backbone’ of the economy and the labour force’s weakest links; their unpaid care work saves governments billions but places them at risk of jeopardizing their own paid employment. They give more than they are credited or compensated for but find it rewarding.

These are just some of the contradictory assertions that we explore in this article, as we analyse how family/friend carers are positioned by care advocacy organizations across Canada and consider the implications for the politicization of care as a social issue. After surveying dominant, moralizing representations of carers and representations of the problems of family/friend care, we discuss broader relational potentialities and possibilities.

This analysis responds to pressing societal problems related to unpaid family/friend care in eroding welfare states, both in Canada and beyond. Globally, social and economic changes associated with population ageing, neoliberal austerity and the COVID-19 pandemic have coalesced in ways that have increased people’s need for help from friends and family (Estes and Phillipson, 2002; Chappell and Penning, 2005; Armstrong and Braedley, 2023). In Canada, shifting conditions and circumstances of care, including privatization in formal care sectors and public sector cuts, have intensified reliance on unpaid eldercare (Armstrong, 2023), alongside initiatives centred on ‘ageing in place’ (Dalmer, 2019) or direct-managed models of care (Kelly, 2020).

This article extends international feminist scholarship that has long interrogated dominant conceptions of unpaid care work, with a focus on moral, feminine or familial understandings (Aronson and Neysmith, 1997; Dodson and Zincavage, 2007; Klostermann and Funk, 2022; Streeter, 2023). We also engage with scholarship examining how care and carers are discursively positioned in policy (Heaton, 1999; Levitsky, 2014; Davidson, 2015; Morgan et al, 2021). Rhetorical and discursive studies offer generative ways of engaging with questions of citizenship: how carers are positioned as citizens, how problems are framed or politicized, and how carers’ social and political rights and responsibilities are understood. Such questions guide our examination of the rhetorical strategies of caregiver organizations and advocates in Canada.

Since the 1990s, caregiver organizations in Canada have been key discursive actors in policy, news media and research. The most prominent are seven provincial-level organizations (in five provinces) and three national organizations (Carers Canada, PetroCanada CareMakers and the Canadian Centre for Caregiving Excellence [CCCE]). Various receiving funding from governments, fund-raising and private corporations, these not-for-profit caregiver organizations constitute an important part of the patchwork of supports for carers, as they coordinate support groups and act as information and referral hubs. Many of these groups also advocate in the public sphere for carers to influence awareness and policy. These organizations are well positioned to engage in political work to resist and reframe the devaluing of care and to validate carer experiences and contributions.

While we recognize the imperative of these public activities and advocacy by caregiving organizations, our aim here is to reflexively explore the ideas and narratives embedded and reinforced therein. As conceptual resources and road maps, these narratives guide how or whether caregiving realities and carer identities can be interpreted as ‘political’. Our analysis considers how advocacy narratives around late-life family/friend care in particular (1) discursively position carers and their social functions, with

implications for understandings of citizenship, and (2) frame or politicize the problems, with implications for politicized understandings of care and social reproduction. Our analytical approach moves beyond issues of need to examine how rights are recognized and supported through care practices, policies and institutions (see, for example, [Seventhuijsen, 2000](#)). Stemming from this analysis, a more secondary and indirect aim, drawing inspiration from [Banerjee \(2023\)](#) and [Klostermann \(2021; 2023\)](#), is to identify different ways of thinking and talking about carers and care.

Literature review: feminist studies surveying care advocacy

Scholars have analysed the rhetoric, metaphors and framing within caregiver advocacy in countries where caregiver organizations have a long and active history, such as in the UK), the US and Australia. We review some of this work in the following, with attention to socio-political implications and broader issues of choice and responsibility.

The discursive framing of carers has been examined within a range of scholarship. In the UK, [Heaton's \(1999\)](#) classic analysis traced the emergence of the discourse of informal care (and carers as subjects) after the 1970s as it manifested among political interest groups of carers, policymakers and researchers. Heaton ties these developments to structural changes in both the main locus of care (from institutions to community) and the object of the medical gaze (which extended to relationships between the care receivers and caregivers). In doing so, she emphasizes how carers were defined in contrast to paid carers, with the latter positioned as secondary supports or backup for the former. [Heaton's \(1999: 766\)](#) point that needs assessments tend to be more about preventing the caring relationship from breaking down 'rather than, say, empowering individuals to choose whether or not to be carers' informs our analysis of how particular discursive framings work.

Socio-political implications of how the problems of care are framed have also been explored in analyses of UK advocacy materials. [Lloyd \(2006\)](#) argued that an advocacy emphasis on carer recognition has not only been unsuccessful at achieving tangible improvements for carers but also diverted public investments away from publicly funded care services. She argues that carer recognition campaigns can obscure more fundamental redistributive social movement struggles, as the injustices facing carers are not distinct to them 'but reflect a wider range of [distributive injustices]' ([Lloyd, 2006: 957](#)). Writing a decade later, [Larkin and Milne \(2014\)](#) also noted that although the UK carers' movement had increased carer visibility in the public and professional realms and achieved some legislative and policy successes, their efforts had not increased carer empowerment. During the pandemic, [Wood and Skeggs \(2020: 644\)](#) made a similar argument regarding paid care workers when they called for moving beyond symbolic expressions of 'heart-felt appreciation' for and recognition of carers and towards public 'demands for material change' and care justice.

In the US, [Davidson \(2015\)](#) analysed rhetorical frames used by The Rosalyn Carter Institute on Caregiving and the Family Caregiver Alliance. She elaborated how organizational communications, through invoking family and maternal metaphors, subtly 'associate caregiving rhetorics with women and the domestic sphere even as they attempt to challenge those associations' ([Davidson, 2015: 22](#)). Speaking to the significance of this, [Davidson \(2015\)](#) identified how persistent narratives of service and sacrifice, which interweave 'caring for' and 'caring about', do little to engage with

dominant assumptions about family responsibility. Moreover, Davidson (2015: 132, emphasis in original) identified how the family care discourse underpinning advocacy implies that the public ‘only need to support unpaid family caregivers’ *already-made* choices, as opposed to supporting unpaid family caregivers’ right to choose’.

In another example, Levitsky (2014: 167) pinpointed the absence of efforts to ‘mobilize individual grievances into organized political demand making’ around US government responses to late-life social care needs. Yet, she saw potential in the ‘consciousness-raising’ effect of carer discourse for catalysing politicized understandings of care and maintaining people’s self-worth across different identity categories. Of relevance to our study, Levitsky (2014) also speaks to issues of choice and responsibility in exploring how advocacy might transform public understandings of citizenship and social responsibilities for care rather than reinforcing an ideology (and identity) of natural family duty.

Lastly, Knight and Davy (2019) highlighted how Australian carers’ campaigns remain silent on the gendered nature of care and avoid describing carers’ marginalization as a feminist issue. Given recent erosions of carer supports, they suggest carer movements move beyond a ‘non-enforceable’ recognition paradigm ‘predicated on maintaining the sustainability of the valuable – and free – resource of family-based informal care’ (Knight and Davy, 2019: 455). Engaging issues of citizenship head-on, Knight and Davy (2019: 454, emphasis in original) foreground a rights-based approach to advocacy ‘if the lives of the next generation of carers are to be characterized by the full rights of citizenship and participation, *as well as* recognition’.

The collective contributions of these rhetorical analyses invite further reflection on and attention to the discursive politicization of carer issues in the public sphere and the implications and potential of such representations for carer citizenship and social rights, including aspects of choice and responsibility. We examine this through an analysis of several Canadian caregiver organizations’ efforts to call for carer supports in recent years.

Methods

Our methodological approach is grounded in feminist rhetorical theories that explore circulating terms and discourses shaping practices and possibilities (Kock and Villaden, 2017; Klostermann, 2019). It is also informed by our experience of conducting systematic, in-depth content and frame analyses (see, for example, Funk et al, 2020; Sawchuk et al, forthcoming). In the present study, we conducted a rhetorical and discursive analysis of textual materials (2010–22) produced by prominent Canadian organizations engaging in advocacy at provincial and federal levels around family/friend caregiving for older adults. Since our focus was on how unpaid caregiving is politicized in the public sphere, we examined documents (including policy-related papers) and web pages produced by these organizations. Caregiver organizations have played a key role in shaping how caregiving is framed, such as by calling for a national caregiving strategy or expansions of supports for unpaid carers. The highly visible narratives and metaphors used by these organizations are designed to shape perceptions and understandings of caregiving.

We orient to texts as sites of social interaction with the potential to influence actions or ways of thinking (Davies and Harré, 1990). Through active discursive practices, texts often position the producers (in this case, the organizations), the

immediate readers and extended others in connection to larger storylines or cultural narratives (Davies and Harré, 1990; Flowerdew, 2004). While these materials position caregiver organizations, giving the reader a sense of the organization as a social entity (Flowerdew, 2004; Askehave, 2010), our aim is not to critique these organizations or diminish their contributions but to prompt discussion about how relational possibilities are socially organized and can be better supported through care advocacy.

In Canada, key national-level caregiver advocacy groups include Carers Canada (part of the Canadian Home Care Association), the recently established CCCE (funded by a philanthropic foundation), the new grant organization CareMakers (funded by Petro-Canada) and several provincial-level caregiver organizations and coalitions. Only five of 13 provinces and territories have such organizations, with both Québec and Ontario having two (in both provinces, one is a more service-oriented organization and the other is more advocacy oriented).

Materials examined included policy documents, reports, mission statements, fact sheets and websites. We also analysed a prominent 2022 national public webinar series addressing family/friend caregiving in Canada that focused on organizational change within healthcare systems and featured speakers on issues of carer policy and supports more broadly (University of Alberta, 2022). As part of a larger public conversation (Davidson, 2015), these texts provide insight into the discursive and structural context in which carers of older adults (in differing settings and relationships of care) are situated in Canada's welfare state. A full list of reviewed material is available from the authors upon request.

The analysis, led by the first author, with ongoing input from the co-authors, identified key rhetorical themes, theories and narratives while attending to the complexities of the specific forms and genres of materials. Both English- and French-language materials were included, with the latter being analysed and translated by the fifth author. We identified and explored representations and social constructions as they were communicated implicitly (for example, through the symbolic use of language and metaphor) and explicitly.

Findings: the discursive production of family caregiving in care advocacy work

After elaborating on how the rhetorical interventions of care organizations engage with, expand and limit how carers are conceived, we examine how they frame the problems of care. We then explore textual claims about carers' rights and responsibilities and highlight the need to engage conceptions of citizenship and relationality.

In Canada, provincial caregiver service organizations tend to be directed (though not exclusively) towards individual carers. Materials encourage carers to self-identify and access resources to help them feel less isolated. The broader public, policymakers or politicians are secondary audiences in those materials, wherein implicit rhetorical purposes might be to attract funding for the ongoing work of the organization and prompt policy changes to enhance carer supports. Provincial materials frame how carers imagine and actualize themselves as carers.

In contrast, materials produced by federal-level organizations, the two provincial-level advocacy-focused organizations (in Ontario and Québec) and the 2022 caregiver webinar series (featuring researchers, caregiving organization representatives and 'influencers' with lived experience) were more explicitly designed to prompt

organizational and government-level policy changes. Audiences for these materials include not only carers but also healthcare workers, healthcare system and government policymakers, and employers. Here, conceptions of carers also frame and activate assumptions about the Canadian welfare state.

How are the family carers (and their contributions) discursively positioned?

Altogether, organizational materials conceptualize carers as: (1) ubiquitous yet unique; (2) heroic yet needing help; and (3) valuable yet rewarded for their contributions. In highlighting this, we argue that such representations tend to reinforce familialist, gender-silent and clinical understandings of care that can inadvertently obscure broader relationality and close off the potential for carers' political citizenship or consent.

Caregiving is ubiquitous, but each caregiver is unique

As part of broader efforts to emphasize the importance for all Canadians of investing in care, family/friend care is often depicted in advocacy materials as an almost universal experience implicating everyone in some way. With links to dominant public narratives, this manifests within matter-of-fact statements, such as 'it's not if, it's when' you will become a caregiver ([Canadian Caregiver Coalition, 2013](#)) or 'caregiving is a near-universal family experience' ([Vanier Institute of the Family, 2020](#)). This also manifests when broad definitions of caregivers are used in statistical reporting, such as those cited by the [CCCE \(2022\)](#) in their 2022 white paper, for example, one in four Canadians are a caregiver, and half will be at some point in their lives. The idea that caregiving is ubiquitous can serve to bolster awareness of the societal importance of carer issues because, coupled with data on carer needs, one gets an impression of a vast, almost unfathomable service population of carers requiring help from caregiver organizations. However, given that such prevalence statistics typically include people providing care who have provided 'any' level of support over a long period of time, casting such a broad conceptual net may risk losing some precision or scope around the problem. It may even make readers feel helpless about the possibility of offering supports for the entire population, especially since individualized tailored supports (for example, in clinical or service settings) are proffered solutions (see later; see also [Sawchuk et al, forthcoming](#)). With homogenizing statements, readers lose a sense of both who is doing the most intensive forms of care and the variation in carers' conditions or circumstances.

Claims about the universality of caregiving often occur in tandem with broad statements about family/friend carers coming 'from all walks of life' ([CCCE, 2022: 2](#)). There is an emphasis on the diversity of carers' demographic characteristics (for example, age, race/ethnicity, sexual orientation, having young children or not, and so on) and stage of caring and care recipients' health needs or conditions, alongside an emphasis on the diversity of carers' needs. That said, apart from some materials from Québec organizations, variations in terms of willingness or ability to provide help, or in terms of relationship quality, are typically not mentioned, nor are differences in carers' material resources or geographic distance from those they are helping.

The idea that every carer is different or unique appears to contradict efforts elsewhere in materials to make generalizing claims about carers' experiences or to

discuss either the gendered nature of care work or important structural inequities. The CCCE does prioritize ‘underserved communities’ by referencing how racialized and immigrant carers struggle more with system navigation and featuring case stories of Lesbian, Gay, Bisexual, Transgender, Queer, and Two-Spirit communities (LGBTQ2S) or young carers in text boxes. For the most part, however, gender and racial inequities or the structural roots of those inequities are rarely discussed in Canadian advocacy materials. Broad comments about carers in ‘different walks of life’ at times gloss over and obscure the racialized and transnational histories and relations shaping how poor women, primarily immigrant women of colour, become carers for older parents or spouses, including after extensive histories of paid care work or with different cultural pressures (Glenn, 2010; Ferrer et al, 2017). A frequent focus on individualized solutions to support carers (for example, clinical needs assessment tools or person-centred care approaches) may also implicitly undercut arguments for broad structural and policy changes, as noted further in the following.

Caregivers are heroes who sometimes need help

Depictions of carers in organizational materials draw on and reinforce both hero and victim narratives. Most prominently, carers are identified as self-sacrificing superhumans, a sort of ‘hidden army’ working tirelessly and against all odds to ensure people can live at home (Young Caregivers Association by Powerhouse, 2020). Metaphors like the hummingbird represent the carer as someone who ‘performs the impossible, works at lightning speed, survives extremes, and often flies solo’ (Caregivers Nova Scotia, 2023). Likewise, the 2022 CCCE report refers to the ‘heroic work’ of carers and paid care providers, in this way moralizing and naturalizing carer contributions (CCCE, 2022: 77).

Carers are not only cast as heroes but also positioned as victims or patients at risk of ‘breaking’ (particularly from health effects). Descriptions of carers’ vulnerabilities are often linked to the need for supportive services, especially in those reports published during the early years of the pandemic. A commonly used phrase is ‘the helpers need help’. Carers are also at times positioned as patients when organizations and advocates recommend that carers be assessed by healthcare providers in clinical interactions (a prominent theme in the 2022 webinar series [University of Alberta, 2022]).

Caregivers Alberta appears to directly acknowledge the tension between hero and victim narratives when it explicitly states that caregivers are ‘heroes not victims’ (Global News, 2023), which is a move in line with efforts to promote a strengths-based approach. Even here, however, the tension is evoked to be resolved in favour of the heroes narrative.

The Petro-Canada CareMakers Foundation (2020–21) identifies supporting carers as a kind of patriotic community service: ‘caring for those who care for others, it’s the Canadian way’. Following this logic, caring for carers extends beyond the care of the individual to the care of the state and its institutions.

Carers give more than they are compensated for but find it rewarding

Echoing recent news media representations (Sawchuk et al, forthcoming), most organizational materials establish carers as economically valuable by using dollar-value estimations of the equivalent of their contributions. In the CCCE white paper,

for instance, carers are described as helping the ‘economy tick’, fuelling economic prosperity, filling important gaps in health and social systems, and undertaking work that ‘previously cost governments billions of dollars to co-ordinate and deliver’ (CCCE, 2022: 2, 5, 8).

There is a subtle tension, however, between the idea that carers save the government money and keep our economy going and other claims that caregiving represents ‘a major loss to the Canadian labour force and economy’ or ‘dragging down our economic potential’ (CCCE, 2022: 16), with impacts on labour force participation from absences or early retirement due to care work. Labour force shortages are the unspoken problem, as carers are implicitly encouraged to remain in the workforce and workplaces are encouraged to accommodate carer-employees. This is at times represented as an equity issue given the economic disadvantage to carers of discontinuing or limiting paid work.

That said, in the absence of material compensation for carers, carers are further positioned as experiencing intrinsic (non-material) rewards and enjoyment. Such non-material rewards include feelings of fulfilled reciprocity, a sense of purpose, feelings of pride and competence, and personal growth, including greater empathy and compassion (Charles et al, 2012; Vanier Institute of the Family, 2018). In the CCCE (2022) report, family/friend caregiving is identified as both rewarding and challenging, with vignettes presented that highlight people who found the role rewarding and were fully committed, even as they struggled. Although acknowledging rewards tells a fuller story, the rhetorical or political effect can be to inadvertently undercut political arguments for tangibly supporting carers while further moralizing their work. This can also subtly position carers as fully motivated and committed to their ‘choice’ to provide care.

Although carers are frequently depicted as struggling, it is also noteworthy that these texts rarely refer to care as a form of labour or work. Instead, care is depicted as tasks, responsibilities, roles, contributions, time or effort. Although the CCCE report makes a few exceptions – noting that care ‘can be described as the work that makes all other work possible’ or that ‘the cost and labour of supporting care recipients has essentially been outsourced to caregivers’ (CCCE, 2022: 12, 29) – more frequently, they use the term ‘work’ to refer to carers’ paid employment or careers. Having explored the complex and contradictory ways family/friend carers are positioned, in the next section, we analyse how the problems of care are understood and politicized as public issues.

What are the problems of care, and to what extent are the issues politicized?

As explored earlier, advocacy materials problematize issues of economic sustainability, especially as related to carers exiting the workforce when they can no longer manage both paid employment and care. Further, care advocacy materials articulate the core problem of care in relation to (1) negative outcomes, impacts or effects on individuals and (2) related issues of carers’ invisibility and exclusion, particularly within healthcare systems. Both problems are identified as having been amplified during the COVID-19 pandemic.

Here, we argue that foregrounding individual risk and recognition as the problem of care decentres state responsibility. With few exceptions, there is little direct centring of the state as having primary responsibility for preventing or addressing impacts of family/friend care work, except perhaps indirectly through funding caregiving organizations or healthcare professionals. One example of how these representations can decentre the

state is through an emphasis on shared responsibility, as in the 2013 Canadian caregiver strategy document, which states: ‘government alone cannot achieve [the] vision ... all elements of society, including the public and private sectors, and individual Canadians, must work together’ ([Canadian Caregiver Coalition, 2013](#): 3). In addition, CareMakers emphasizes the role of non-profit/charitable community-based organizations, alongside a vaguely defined mutual aid in ‘caring communities’ ([Petro-Canada CareMakers Foundation, 2020–21](#): 17), and implies that public dialogue has overly focused on the responsibility of formal systems or institutional support. This discursive decentring of the state can be considered a strategic ‘hook’ in Canadian care organization advocacy, with most organizations relying on state funding. In this way, mobilizing for carer recognition can involve activating assumptions that rationalize retrenchment.

In contrast, Proche-aidance Québec (not funded by the government) takes a more active role in calling for state investment and resource allocation (see, for example, [Proche-aidance Québec, 2021](#)). We also note that the [CCCE \(2022\)](#) report calls for national state leadership through a coordinated strategy that would prompt provincial investment in carers and care recipients. Although not produced by an organizational source, ‘The care economy statement’ was an example of public advocacy written by a group of established academics, that highlights the need for social infrastructure and federal responsibility ([Armstrong et al, 2021](#)). Despite these exceptions highlighting the government’s role, the framing of the central problems of care in other materials, including those noted earlier, decentre the state.

Adverse effects on individuals

National and provincial organizations frequently present qualitative and quantitative depictions of carers’ struggles, primarily through convenience samples of self-identifying carers. Both before and after the onset of the COVID-19 pandemic, reports from the Ontario Caregiver Organization (2019; 2020; 2021), the British Columbia Seniors Advocate ([Office of the Seniors Advocate British Columbia, 2017](#)) and other advocates ([Le Regroupement des aidants naturels du Québec, 2020](#); [Anderson et al, 2021](#); [Family Caregivers of British Columbia, 2021](#); [Funk et al, 2021](#)) delineate the challenges of care work in various life domains, depicting carers overall as at the ‘breaking point’. Typically, these texts connect the individual-level impacts of care (on isolation, mental and physical health, finances, and so on) to role stresses and demands or a lack of training, information and preparedness. Inadvertently, at times, carers are subtly positioned as bringing negative outcomes upon themselves (for example, where carers are encouraged to seek help, prepare or self-identify as a caregiver). In these instances, the genre of carer as a hero who needs help is evoked as a kind of self-destructive anti-hero.

Advocacy materials also identify broader contextual factors as contributing to population-level increases in caregiver stresses and potentially negative outcomes. Such factors include: trends towards people remaining home for longer before entering institutional care (that is, with increasingly complex and medical needs); fragmented health and social care systems (a particular emphasis in the last decade); the exclusion of carers within healthcare interactions/organizations (which we consider in the next section); and, in recent years, policy and service responses to and the effects of the COVID-19 pandemic.

A lot is left unsaid, including the inequitable distribution of both the need for care and the negative impacts of care ([Chappell and Penning, 2005](#)), as well as

political-economic changes that have limited public care supports and increased carer responsibilities. That said, the [CCCE \(2022\)](#) and some of the 2022 webinars do identify adequate public supports for persons requiring care as a form of carer provision, signalling a more solidaristic emphasis in this regard. We also note that, to some extent, emphasizing public services for care recipients sits in tension with claims about how much money the government saves because of the efforts of carers.

Framing individual impacts as a problem, care advocacy materials consistently emphasize the need to protect carers from negative effects yet overwhelmingly frame this around the ultimate goal of carers continuing in their caregiving roles. There is an emphasis on preventing burnout and helping carers cope with managing their care and paid employment. Helping carers is typically positioned as more about ensuring future sustainability, or protecting those who require care than about a dominant concern for carers' wellbeing – and never, it seems, as a human or citizenship right of carers. Carer support is framed as a way to mitigate potential societal risk, with the [CCCE \(2022: 15\)](#), for example, evoking fears about the collapse of the healthcare system in the absence of carer support: 'hospitals, long-term care settings and other models of care cannot absorb a surge of people whose caregivers and [paid] care providers find themselves at a breaking point'.

Importantly, carers are framed as needing protection from the adverse consequences of 'having to care too much' ([Canadian Caregiver Coalition, 2013](#)) rather than, for instance, being protected from overload in the first place, with respite as an exception. That carers might limit or bound their involvement in some way is absent. Reflecting the scope and goal of caregiver organizations, carers are positioned as requiring more preparation and training for their role and for navigating services, more respectful and sensitive interactions with healthcare professionals, and tangible supports (for example, respite, counselling and vaguely identified 'community supports'). Caregiver organizations and healthcare professionals are typically positioned as most able and/or responsible for mitigating the negative impacts of caring on carers. Thus, proposed solutions typically focus more on micro-level interactions and meso-level interventions, despite some growing attention elsewhere to issues like integrated health and social care systems or broader policy change ([World Health Organization, 2015](#); [Funk, 2019](#)).

Aligning with the idea that carers are diverse and that, as such, 'one size does not fit all' ([Petro-Canada CareMakers Foundation, 2020–21](#)), advocacy organizations call for individualized or clinical solutions, which can express and extend a neoliberal logic. Although well intentioned, such solutions may also inadvertently reflect and reinforce an expansion of the clinical gaze and professional power ([Heaton, 1999](#); [Sadler and McKeivitt, 2013](#)) and subtly erode advocacy for broader policy solutions, as well as obscure attention to systemic or structural issues.

Caregiver invisibility and exclusion

A key factor highlighted in various advocacy materials as contributing to the stress or negative impacts of care provision is the problem of carers' invisibility and lack of voice, input or accommodation in the public sphere and particularly at the meso level within organizations (healthcare, workplaces and so on). This problem is framed as contributing to feelings of isolation and helplessness, with calls for greater public awareness and recognition to validate caregivers' experiences or encourage them to seek help to improve their well-being. At times, caregivers' invisibility is implied as extending from their moral virtue; for instance, one employer featured by CareMakers

stated, ‘they’re folks who give without keeping score, who ask for nothing in return and don’t talk about it either’ (PetroCanada CareMakers Foundation, 2021).

Carers’ exclusion from fulsome involvement in care planning and provision is typically identified as a key source of stress, worry or frustration that also impacts the persons receiving care. Since the COVID-19 pandemic, the focus on family/friend carers’ involvement in institutional settings has gained traction, which was again especially evident in ‘essential family caregivers’ campaigns that responded to pandemic-related visitor restrictions. A few years prior to the pandemic, however, caregiver and patient organizations had begun advocating for carers’ involvement in individual care planning, health system improvement planning (for example, advisory councils and co-design) and other collaborative learning and research opportunities.

In sum, these texts take issue with carers not being empowered to be more fully involved in different forms of care or in decision making to reshape the systems that impact them. The problem of carer invisibility (and lack of power) is most often framed not as a structural or gendered problem but as a problem of the mindset of a large number of people who do not see what carers can and do contribute. It is hoped that meso-level policy and practice changes (carers’ needs assessments, visual identification badges and so on) could shift these mindsets and presumably increase carer power (if not lessen their workload). In recent years, advocates have likewise argued that carers desire and need to be fully included in respectful, ‘caregiver-friendly’ or ‘caregiver-centred’ interactions with clinicians and in healthcare organizations. The focus is on training for and culture change among healthcare providers, who should pay more attention to carers.

Although involving carers is important, such narratives around their involvement also seem to decentre the role of the state (or the need for structural changes) while reinforcing images of carers as universally willing to provide any and all types of care, if only they were more fully welcomed or accommodated into closed systems. As we have explored, this was also the case when responding to the ‘impacts’ or issues of economic sustainability. Broader implications of these framings will be addressed in the next section.

Thinking about caring rights and responsibilities

Our analysis raises questions about how carers’ social/political rights and responsibilities are represented and how their options to consent or make choices are supported. We look at how rights-based language has been used, before considering other relational possibilities for understanding these issues. With such a focus, we note Banerjee’s (2023: 4, emphasis in original) criticism of solutions that involve establishing rights in the abstract, without explaining ‘*how* these rights would translate’ into or materialize in desired outcomes. In attending to consent and choice, we also observe that advocacy narratives rarely talk about the choices of older adults who rely on care, presuming that they prefer to be cared for by family or friends.

A narrow focus on supporting people’s inclusion in their role as carers has implications for citizenship. The full citizenship and social participation rights of people who provide care for family or friends requires attention to the socio-political relations structuring people’s experiences of caring (Knight and Davy, 2019). Yet, in this regard, we observed that advocacy narratives about caregiving typically reinforce

familialist, gender-silent and clinical understandings of care that can obscure this, closing off the potential for carers' political citizenship or consent.

One of the many critiques of the term 'caregiver' is that it can imply a sense of voluntariness and choice in the role (that is, that it is freely given). Reinforcing this idea, as noted earlier, are images of carers as always or completely committed and in close, caring relationships with the person for whom they are providing care. In one text, for example, carers are positioned as freely choosing to provide care even if 'many do not feel like they have a choice' ([Petro-Canada CareMakers Foundation, 2020–21](#)). Carers are understood as responding out of love and as a natural response to the needs of the other. In line with this image, the framing of carers' needs in advocacy materials is almost wholly limited to supporting them to keep going in their (desired) roles and only rarely about recognizing that some may need to step back in some situations or have choices in the matter.

The 2001 'Charlottetown declaration on the right to care' ([The Care Economy, 2001](#)) articulated the importance of people's choice 'to provide or not to provide unpaid care', but the document is now difficult to locate online and not widely cited by caregiver organizations. Roughly a decade later, the Canadian Caregiver Strategy ([Canadian Caregiver Coalition, 2013](#)) mentions carers' rights to choose their degree of involvement (as does a 2015 policy brief from the [Canadian Caregiver Coalition \[2015\]](#)), but this idea is not widely reproduced in subsequent materials or public narratives of caregiver organizations. Instead, these texts orient to formal carer rights in terms of securing supports to keep them in their role and for inclusion and respect within meso-level institutions. With regards to the latter, institutional pledges employing rights-based language exist but typically with a limited focus on accessing care facilities or affirming that carers are more than visitors (such as in the 'Declaration of family caregiver rights and responsibilities' [see [Canadian Hospice Palliative Care Association, 2020](#)]).

Websites of caregiver organizations in British Columbia, Alberta and Nova Scotia include similar versions of a caregivers' 'bill of rights'. While not a legally binding agreement, the bill is more of a motivational or affirmational tool to prompt carers to see their own needs and advocate for themselves. Importantly, the bill includes the right to seek help through the affirmative statement: 'I recognize the limits of my own endurance and strength' ([Caregivers Nova Scotia, nd](#): 1). Given the motivational focus, however, the social function appears to be more about reassuring the carer to ask for help rather than about prompting the state to provide assistance. Moreover, the bill is also implicitly oriented to supports needed to remain in the role rather than about stepping back, sharing responsibility or otherwise 'bounding' their work ([Klostermann, 2023](#); [Klostermann and Funk, forthcoming](#)).

Proche-aidance (formerly Le Regroupement des aidants naturels du Québec [RANQ]) does foreground the issue of carer rights, including educating carers on how to advocate for these rights and identifying situations where carers should set limits. The organization acknowledges carers' right to support, as well as rights to set limits and to prioritize themselves, including in situations where they might be mistreated by people they are caring for, by other family members or by institutions (which among other things, might impose the caregiver role [[Le Regroupement des aidants naturels du Québec, 2021](#)]). This promising portrayal ([Sawchuk et al, forthcoming](#)) offers an alternative framing that moves beyond encouraging carers to keep caring.

Another place where rights-based language is found or implied is in how the Vanier Institute of the Family and other groups identify the need for organizational accommodations around ‘family status’, addressing people’s rights to provide care without being discriminated against by their employer (identified in some materials as an issue of gender equity [Battams, 2016]). There is also some minor attention to leave benefits or accommodations throughout the materials we reviewed. Options to quit paid work entirely to provide care while being supported appropriately through an allowance are not a strong focus in these materials.

Concluding remarks

Our feminist rhetorical analysis of Canadian advocacy materials has identified how carers are represented in advocacy materials as: (1) ubiquitous yet unique; (2) heroic yet needing help; and (3) valuable yet rewarded for their contributions. These texts reproduce broader cultural metaphors, including that of carers as ‘heroes’ saving the state money (Chivers, 2018; Sawchuk et al, forthcoming) and of older adults as ‘problems’ requiring management through clinical interventions (Ceci et al, 2020). The problems of care are framed as economic impacts, individual impacts and needs for support (for example, from service organizations and health professionals), as well as carers’ invisibility and exclusion. Such framings decentre the role of the state while serving to support carers to keep going – ideally, without compromising their ability to remain in paid employment.

We acknowledge that these materials position advocacy groups themselves, which often seek a credible ‘seat at the table’ to influence social policies (an aim that may shape their communications). These dominant rhetorical moves, however, discursively bound carers’ citizenship around their right to be involved and recognized within health systems and by professionals, as opposed to their rights not to care or to choose the level and type of their involvement – or, indeed, for care recipients to choose something other than family care. For the most part, carer choice and commitment seem presumed and carers’ rights to inclusion in broader dimensions of civic and social life are typically absent, except for paid work or schooling.

A recent review of Canadian media representations of family carers (Sawchuk et al, forthcoming) identified how ‘the carer [was] consistently turned and being turned towards the person who needs support’. Likewise, the narratives of caregiving organizations in the present analysis often prompt carers to take responsibility for, or ‘turn towards’, those they support through various services and policy initiatives. Although perhaps in part politically strategic, such rhetorical conventions can contribute to a broader problem. Care scholarship has indicated the dangers for relationships and people’s well-being when carers have no options to step back, make choices or share responsibility (Klostermann, 2021).

These discursive framings of family/friend carers and the problems of care provide a broader glimpse into how family/friend care is configured in Canadian society, as well as the human potentialities of certain framings (Symonds-Brown and Ceci, 2022: 14). The material importance of thinking differently about both caregiving and care is underscored in particular by Klostermann (2021; 2023), who calls for ‘conceptions and configurations of care that enable carers to resist or renegotiate inequitable care work arrangements as needed’ (Klostermann, 2021: 232). Further discussion of carers’ rights and citizenship might be one way that care advocacy organizations might

move beyond dominant framings, and in this regard, we see promising portrayals in material from Proche-aidance that promotes attention to the limits of family/friend care and that calls for structural changes. As a broader possibility, advocacy could speak in fuller ways to alternative conceptions of collective solidarity or recognize relational complexity. Such conceptions emerge in scholarship that foregrounds the changing, relational nature of care or the complexities of meaning making, creative expression, joy, pleasure and belonging (Kontos et al, 2017; Stevens, 2018; Banerjee, 2023; Braedley et al, 2023), even alongside the disorientation, alienation and distress (Titchkosky and Aubrecht, 2017) that can unfold through caring.

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Conflict of interest

The authors declare that there is no conflict of interest.

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