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Relieving the Burden of Navigating Health and Social Services for Older Adults and Caregivers

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FACES OF AGING

ABOUT THIS STUDY

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SUMMARY

Canada's aging population faces a harsh reality: growing numbers of older Canadians with chronic illnesses, disabilities and cognitive impairment are regularly discouraged by the efforts required to access and coordinate fragmented health and social care services. These challenges are often most profound for those who cannot rely on help from family members or friends, but they add greatly to caregivers' burden as well.

In this study, Laura Funk argues that navigation problems are rooted in the structures and operations of existing care systems, as well as the downloading of administrative and coordination tasks to individual patients and their families. In her view, navigation work must be transformed from a private struggle into a public responsibility.

According to the author, navigation challenges and caregivers' burden are compounded by health and social care systems that are difficult to access due to overly restrictive eligibility criteria, convoluted application processes and other gatekeeping mechanisms. The lack of transparency due to limited or conflicting information on how to access public services is particularly problematic. The work involved in overcoming these obstacles – the search for information about available services, the effort needed to access them, and the ongoing monitoring and advocacy required to ensure health and social needs are met – is far from negligible. It generates important economic and social costs, including time that caregivers might have spent on other care activities, in paid employment or in social activities.

Although there has been an expansion of navigation supports in recent years, existing programs, whether provided by nonprofit organizations or by government agencies, are often specific to particular care-setting transitions, such as from hospital to home, or to people with particular health conditions, such as cancer or dementia. Availability varies greatly across regions and locations of care. A dedicated, comprehensive policy strategy is needed to reduce the navigation burden for broader patient and caregiver populations.

The author proposes a three-pronged patient-centred approach to alleviate navigation problems. It consists of improving service information, expanding public navigation programs and better integrating care services for older adults. Removing the navigation hurdles faced by older persons and their caregivers is key not only for improving their health and well-being, but also for preventing exhaustion among caregivers and reducing inequities in service access. Doing so could also make it possible for older adults to remain at home longer if they wish to do so.

There is still much policy-makers need to learn about which specific elements of navigation programs – be they administrative, organizational or financial – provide the largest benefits in terms of improved health and well-being and reduced caregiver burden and service access inequities. Systematic and thorough evaluation of navigation programs and initiatives for older adults – involving researchers, providers, service users and caregivers – is essential if we are to tackle this problem effectively.

RÉSUMÉ

La population vieillissante du Canada fait face à une dure réalité : un nombre grandissant d'aînés souffrant de maladie chronique, d'incapacité ou de déficience cognitive se heurtent à de multiples obstacles lorsqu'ils cherchent à accéder à nos services de santé fragmentés et mal coordonnés. Ces problèmes sont plus graves encore pour ceux qui ne peuvent compter sur le soutien de leur famille ou d'amis, sans compter que le fardeau des proches aidants est aussi alourdi.

La difficulté de se retrouver dans notre système de santé découle en bonne partie de la structure et du fonctionnement même de nos services de soins, qui obligent les patients et leurs proches d'assumer de nombreuses tâches d'administration et de coordination. Selon Laura Frank, ce fardeau devrait plutôt relever de la responsabilité publique.

L'auteure soutient que les problèmes d'accès au système sont exacerbés par des contraintes administratives, notamment des critères d'admissibilité trop restrictifs, des processus de demande inutilement complexes et des mécanismes de contrôle dissuasifs. Et c'est sans parler du manque de transparence en raison d'informations insuffisantes ou contradictoires sur les modes d'accès aux services publics. Il faut ainsi consentir de sérieux efforts pour surmonter ces obstacles, de la recherche sur les services offerts aux démarches à effectuer pour y accéder, en passant par les suivis nécessaires pour obtenir les services requis. Cette situation entraîne d'importants coûts économiques et sociaux, y compris pour les proches aidants, qui ont moins de temps à consacrer aux soins, à un emploi rémunéré ou à des activités sociales.

Si le soutien aux patients s'est récemment amélioré (meilleure information, coordination des soins, ressources à leur disposition), les programmes à cet effet, qu'ils soient offerts par des organismes sans but lucratif ou gouvernementaux, servent le plus souvent à faciliter la transition entre milieux de soins, de l'hôpital à la maison par exemple, ou sont réservés à des patients souffrant de maladies spécifiques comme le cancer et la démence. Et leur disponibilité varie grandement selon les établissements et les régions. Seule une stratégie globale et ciblée permettrait de réduire les obstacles à l'accès pour un plus grand nombre de patients et de proches aidants.

Pour pallier ces problèmes, l'auteure propose une approche en trois volets axée sur le patient : améliorer l'information sur les services, élargir les programmes d'accompagnement des patients et renforcer l'intégration des services destinés aux personnes âgées. Faciliter l'accès aux soins pour les aînés et leurs proches serait non seulement bénéfique pour leur santé et leur bien-être, mais contribuerait aussi à prévenir l'épuisement des proches aidants et à diminuer les inégalités d'accès. Cela pourrait même permettre aux aînés qui le désirent de vivre plus longtemps à la maison.

Nos décideurs doivent déterminer quels aspects administratifs, organisationnels et financiers des programmes d'accompagnement sont les plus susceptibles d'avoir des répercussions positives en matière de santé et de bien-être, tout en réduisant le fardeau des proches aidants et les inégalités d'accès aux services. Pour s'attaquer efficacement au problème, il est donc indispensable de mener une évaluation rigoureuse des initiatives et programmes d'accompagnement destinés aux aînés qui mettra à contribution aussi bien les chercheurs et les prestataires de soins que les usagers et les proches aidants.

INTRODUCTION

Organizing health and social care services to support Canadians as they age is a major challenge. Current care systems are poorly suited to address older adults' complex, wide-ranging and changing needs, which can involve multiple chronic conditions and transitions between different care settings. These transitions are especially problematic because many older adults have difficulty navigating access to fragmented systems. Services are often siloed and uncoordinated. Those who need support in finding and accessing services often struggle unassisted or have to rely on family caregivers.[1]

These challenges can be insurmountable for ailing older persons without family or friends to support them. The hard work required of caregivers to seek out professionals and services for help with their loved ones' needs also generates economic and social costs, including time that caregivers might spend on other caring activities, paid employment or social activities. Navigation challenges can also hamper access to resources and services, complicate transitions between care settings, cause dissatisfaction and undermine support for public health and social systems. Ensuring easier access to social services and health care could prevent or delay caregivers' burnout by reducing their stress while freeing up time to focus on other aspects of care provision. It could also make it possible for older adults to remain at home longer if they wish to do so.

Navigation difficulties are rooted in the structures and operation of existing care systems: the lack of integrated health and social services for older Canadians generates serious costs in terms of the time and energy required of older adults and their families to find and access appropriate care. And because these costs are borne by patients and their caregivers – not by the governments or organizations that provide services – policy-makers have little financial incentive to better integrate and coordinate services. As such, navigation work must be transformed from a private struggle into a public responsibility. In response to these concerns, some governments, nonprofits and for-profit providers have begun offering navigation services. Despite growing pressure on governments to do more, there is still little knowledge regarding the best way to design public navigator programs to assist service users and their caregivers.

This paper proposes three policy directions to alleviate the problems families face in navigating care access: providing better information about available services, creating more formal navigation supports and improving service integration. Ensuring easier access to services can increase the well-being of both older adults and caregivers. Furthermore, advocating for governments to bear some of the costs of barriers to access by instituting formal navigator programs may generate broader benefits. In particular, it might lead to greater recognition among decision-makers of the obstacles associated with accessing care for older adults and provide the impetus to better integrate services. Although the ultimate goal should be to improve the system so that navigators are no longer needed, in the short run this may be unrealistic given the complexity of older adults' needs across social and health domains.

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[1] In this study, a broad definition of "family caregiver" is adopted that can include friends and extended kin.

SYSTEM NAVIGATION FOR OLDER ADULTS: INVISIBLE WORK AND CAREGIVERS' BURDEN

At present, the onus is on individual patients and their families to navigate complex care systems. With the exception of cancer care, navigational outreach and clearly presented service information are rare. Older people and their caregivers often need to learn as they go, relying on their resourcefulness to navigate and access health and social services. The following are common examples of the tasks involved (Funk, Dansereau and Novek 2019):

- Searching for information about services and how to access them
- Pushing through and working around barriers to accessing services
- Coordinating the receipt of formal help and resources (including administrative work)
- Ongoing monitoring and advocacy to ensure that the services provided are adequate

Navigation work entails dealing with multiple providers, filling out forms, making appointments, contacting professionals, prompting providers for feedback and mitigating the risk of errors (Funk, Dansereau and Novek 2019).

Patients and their caregivers must be highly resourceful, literate and persistent to successfully navigate siloed and fragmented health care and social service systems. They need to know the right questions to ask and to whom to ask them. They must also develop the ability to negotiate and be assertive with professionals (Wuest 2000). Doing this effectively requires not only time and energy but confidence, good connections and a balance between "being nice" and "getting angry" (Funk, Dansereau and Novek 2019).

Navigation challenges and caregivers' burden are compounded by health and social care systems that are difficult to access due to overly restrictive eligibility criteria, convoluted application processes and other gatekeeping mechanisms (Crooks et al. 2007; Dixon Woods et al. 2006). The lack of transparency due to limited, vague or conflicting information on how to access public resources is particularly problematic (Funk, Dansereau and Novek 2019). Caregivers consistently ask for more timely, user-friendly guidance and information (Meyer 2017; Bookman and Harrington 2007; Brookman et al. 2011). In a survey by the Change Foundation (2018) in Ontario, 32 percent of caregivers reported the lack of information as the biggest barrier to getting support in their role.

Finally, placing the onus on patients and their families to navigate systems and access care themselves can give rise to inequities due to disparities in income, education and other characteristics that affect their capacity to succeed in these tasks. Low-income families are less able to access private forms of navigation support, such as paid consultants and advocates. Ailing older adults without family or friends who can provide support can be seriously disadvantaged. And navigation challenges can be greater for patients with cognitive impairment and for families who are Indigenous, live in remote or rural areas or are less familiar with Canadian service systems and official languages.

What do caregivers say about navigation responsibilities?

Until recently, there was little awareness of the emotional and economic burden experienced by caregivers in their navigational work, because these issues were rarely measured or analyzed. However, the challenges facing caregivers are slowly being recognized, as a growing body of scholarly research highlights their navigation struggles, including studies conducted in the US (Bookman and Harrington, 2007), the UK (Meyer 2017; Peel and Harding 2014), New Zealand (Williams et al. 2018) and Canada.[2]

In consultations for the Manitoba government, 36 percent of caregivers of adults aged 65 and over reported needing either quite a bit or a lot more help with system navigation (Funk 2012). These findings are echoed in a more recent survey of Ontario caregivers, who expressed a strong sense of responsibility for organizing health care, including accessing services, financial support and equipment: 54 percent of them felt overwhelmed by this aspect of their role (Change Foundation 2016a, 2018). Ontario caregivers also said they felt ill equipped to ensure cross-provider communications and continuity of health information across different parts of the system (Change Foundation 2016a). Even health care providers and clinicians themselves were shocked by the challenges of system navigation when they became personally involved with supporting a family member/friend (Change Foundation 2016b).

Caregivers struggle to find service information under stressful circumstances, often not knowing where to start. Caregivers in the Manitoba consultations said they wanted clear information about the services and resources available for older adults and how to access them. They reported barriers such as confusing application forms, unreturned phone calls, bureaucratic hurdles, inflexible criteria or policies and uncoordinated processes and services. One caregiver expressed her frustration and stress as follows: “I as a caregiver would not need support if I wasn’t constantly needing to: make phone calls, spend inordinate amounts of time documenting, arranging and attending meetings, write letters in order to access necessary services for my mother” (Funk 2012, 14). Some caregivers complained they needed to “prompt” the system and persistently advocate to access services. They resented having to convince others that help was needed or “beg, threaten, fight for necessary services” (Funk 2012, 15).

Caregivers can feel unsupported or disrespected in these situations. Some perceive formal systems as “impersonal and even hostile” (Schubart, Kinzie and Farace 2008, 67).

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[2] See, for instance, Canadian research by Cain, MacLean and Sellick (2004), Dalmer (forthcoming), Funk, Dansereau and Novek (2019), Funk, Stajduhar and Outcalt (2015), Hainstock, Cloutier and Penning (2017), Neufeld et al. (2002), Ploeg et al. (2017), Rosenthal, Martin-Matthews and Keefe (2007) and Sims-Gould and Martin-Matthews (2010).

Box 1. Caregiver Stories about Navigation Challenges

There are many examples of caregivers articulating their struggle to navigate the system. These examples come from an unpublished study of system navigation funded by Research Manitoba.

Example 1: A daughter caring for her mother who lived with dementia in a long-term residential care facility (referred to in Manitoba as a personal care home) described trying to learn about adaptive clothing:

> *And one night a health care aide trainee said to me, "Why don't you get your mom some of those pyjamas that zip up the back?" And I said, "I've never heard of that." And she said, "Well, I don't know where you get them, but I've seen them." So I thought, "This is great." I went to the nursing station and I said, "What do you know about these?" "Oh, we don't know anything about that. We've never heard about that." So I started on a hunt and it turns out that…there's adaptive clothing. It's called dementia clothing or anti-stripping clothing…We tried two different types to see what would handle in the laundry. And the one was great 'cause she couldn't get out of them. And the second thing that I thought…"What if I could get underwear that was like a onesie that she couldn't take off? Then she could wear her nice, normal clothes during the day." And after much searching, I found there's an incontinence product company in Winnipeg that actually has these. So my question was, "Why wouldn't a personal care home know that?"*

Example 2: A coresident daughter caregiver recounted the challenges of navigating timely access to specialists, recalling a time when...her father needed to meet with his urologist, who was on holiday:

> *Dad's file was given to another urologist who's a surgeon, who said he couldn't do anything for us. So it was sent back to the original urologist and [laughs] I can't even tell you how frustrating that was. We're talking maybe three months at this point. Because it all happened during the summer and the surgeon urologist didn't want to do anything because the original urologist hadn't sent a formal referral letter. From where I was sitting, it was political logistics within the clinic and somebody hadn't been approached the proper way and so they weren't going to do anything. But then this urologist was on holiday for three weeks and so nobody else could take the file.*

Example 3: A coresident caregiver for her mother described her attempt to access the provincial family-managed home care program:

> *I e-mailed them and they sent back an auto-reply saying, "Thank you for this and it takes seven days before we even look at your request." Finally somebody gets back to me and they said, "Oh, the application has to come from your home care case coordinator, and according to our system your [mother's] file is open with the home care case coordinator…." It turns out my home care case coordinator was on maternity leave and they hadn't filled the position….So I waited basically two months before they assigned [my mother a home care case coordinator]. So all I'm basically asking is for the application form [for family-managed care]. Just send me an application form for the thing. And then, of course, because it had been six months, whatever, and [the case coordinator] was new..., they'd have to come and do a reassessment. Okay, fair enough….So basically they did that. Then they have to meet with their team manager and meet with their team and do that; get a letter of support from the doctor. Okay, fine, so I have to do that, blah, blah, blah. I have to get her into day hospital; okay, I do that, blah, blah, blah….So then they sent out the application process and the application was nine typewritten pages, budget-wise, this, that and the other thing. So I'd say it probably took me, and I know the system, 10 to 12 hours to complete the application; send it away. They send me back, "Thank you, it'll be 8 to 12 weeks before you hear from us. Don't call us. We'll call you."*

Problems navigating access to care resources may also exacerbate their sense of isolation. And when they are unsuccessful, caregivers may grapple with the feeling that they failed their family member. On this topic, one explained:

> *I wasted a lot of time thinking that the problem was my failure to understand the system. I wasted a tremendous amount of time berating myself for not getting*

> *it and thinking like you're losing your touch, like how can you not figure this out? Until I finally had a moment when I thought maybe you can't figure it out because it doesn't make sense…(*Funk and Hounslow forthcoming).

Even when they are successful, navigation hurdles can contribute to caregivers' exhaustion. Some become discouraged and give up. In this way, "an individual caregiver's success or failure at navigation shapes the care pathways of older adults, which in turn has [further] implications for caregiver burden" (Funk, Dansereau and Novek 2019, 432).

Qualitative research and interviews with a range of patients, including older adults, and their caregivers have broadened policy-makers' understanding of the scope of navigational responsibilities. The stories that these individuals share speak to the issues many face in accessing care (see box 1 on page 7 for additional examples).

Navigation tasks contribute to the cost of care and caregivers' burden

Older adults and their families work in invisible, largely unrecognized ways across institutional and community care settings. They act as managers, record keepers, pseudo-paramedics and advocates (Bookman and Harrington 2007). The economic value of unpaid care provided by family caregivers in Canada — which includes additional daily tasks such as shopping, yardwork and personal care as a result of having an ill family member — was estimated to be over $25 billion per year in 2009 (Hollander, Liu and Chappell 2009). A decade later, their contribution is much higher: preliminary estimates by Dr. Janet Fast suggest it may be as high as $67 billion, and the Change Foundation (2018) estimates it at between $26 billion and $72 billion. And these estimates do not as a rule isolate, or likely even include, the costs associated with time spent navigating services.

Navigation work adds to the stress, isolation and economic hardship experienced by many patients and their caregivers. Short- and long-term impacts of family caregiving can include detrimental effects on health, labour force participation, and social relationships and networks (Eldh and Carlsson 2011; Singh et al. 2015). Statistics Canada found that 34 percent of spousal caregivers self-reported depression in 2012 (Turcotte 2013); rates of caregiver distress rose by 25 percent between 2012 and 2018 in Ontario (Health Quality Ontario 2018). Navigation struggles may be an important contributor to the problem, as they are known to result in emotional distress and reduced quality of life (Thorne and Truant 2010; Williams et al. 2018; Rosenthal, Martin-Matthews and Keefe 2007).

According to one study, coordinating and orchestrating care and other services on behalf of an older relative tends to generate stress in women, whereas it is the financial and bureaucratic aspects of managing care that are associated with stress in men (Rosenthal, Martin-Matthews and Keefe 2007). Coordinating care was also associated with self-reported job and personal opportunity costs for both sexes. Although most research on caregivers' burden focuses on the impact of tasks and interactions with the older adult (Purkis and Ceci 2015), “a substantial and increasing proportion of caregiver stress, and thus [structural] burden, arises from managing and negotiating services for recipients within [formal health and social care] systems” (Taylor and Quesnel-Vallée 2017, 20).

The root causes of navigation problems

Navigation challenges essentially stem from poorly functioning systems, a lack of compassion among system gatekeepers and inappropriate or unnecessary bureaucratic processes (Funk, Dansereau and Novek 2019). Health and social care reforms over the last several decades have exacerbated these problems for patients and their caregivers. Subtle policy shifts have placed increased demands on families to support the functioning of formal care institutions and medical systems (Bookman and Harrington 2007). For instance, the expansion of self-managed home care programs, which provide resources to directly pay for and manage home support services, entails more administrative and managerial work for clients and their families.

Yet few caregivers would likely characterize navigation work as something they should be doing. Many families reach out to others for help: the market for private advocates and navigators has expanded in recent years. Wealthier families often hire private consultants and case managers for this purpose. Governments, as well as some disease-specific charities, have also responded with their own navigator programs.

THE RISE OF THE NAVIGATOR

Patient or system navigators are typically formally organized, government-funded and government-initiated support services provided for a particular time, often during a specific phase of illness or a location-of-care transition (Paskett, Harrop and Wells 2011; Manderson et al. 2012). Although some navigation support is offered by other providers and professionals working within health and social care systems — case managers, social workers, physicians, voluntary organizations — it is navigators’ primary role to help identify and address barriers to accessing defined services.

During the last decade in Canada, the number of publicly funded patient navigation programs has grown, especially in cancer care, in response to patients’ concerns. In the US, cancer patient navigation programs tend to explicitly address service and health disparities among racial or ethnic minority populations. In some regions, there is an accreditation requirement for health care organizations to have patient navigation supports in place (Krok-Schoen, Oliveri and Paskett 2016; Lorhan et al. 2012; Ramsey et al. 2009).

In health care settings, patient navigation programs have focused on reducing the time it takes patients to obtain specific medical screenings or treatments. However, older adults often need social services as well, which involve a variety of providers and other government departments.

Over time, patient navigation services are expanding to cover chronically ill older adults (Manderson et al. 2012; Paskett, Harrop and Wells 2011). For example, a volunteer navigator program (Nav-CARE) for older adults with life-limiting conditions living in rural communities is being implemented by several hospice agencies across Canada (Pesut et al. 2018). The Winnipeg Regional Health Authority has introduced navigation services for older adults transitioning from hospitals to nursing homes. And in 2018, in its call for proposals, the federally funded Healthy Seniors Pilot Project in New Brunswick welcomed applications for projects to evaluate navigators who assist seniors and their families in accessing information and services.

In general, as formal navigation programs have spread across Canada, the emphasis has been on helping people with specific health conditions, such as high-risk groups of frail or disabled persons, or during care-setting transitions (Manderson et al. 2012). However, navigation programs are becoming more diversified as navigator roles vary widely among programs and across regions. Some of this variation may reflect organizations' attempt to adapt programs to local circumstances, the needs of specific target populations or particular policy priorities.

How effective are navigators?

Though the initial evidence on the effects of both professional and volunteer navigation programs is promising,[3] research on the efficiency and equity of different policy approaches is still in its early stages (Ferrante, Chen and Kim 2008; Manderson et al. 2012; Paskett, Harrop and Wells 2011). And although researchers have begun to examine the effects of navigators on caregivers, most studies focus on patient outcomes.

Large-scale syntheses of patient navigation program evaluations, relying heavily on US research focusing on disadvantaged cancer patients, suggest positive effects on patients' timely access to screening and treatment, as well as improved quality of life and satisfaction, diminished perceptions of barriers, better health and reduced disparities (e.g., Corrigan et al. 2014; Krok-Schoen, Oliveri and Paskett, 2016; McKenney, Martinez and Yee 2018). Similar positive outcomes of navigation interventions for more general patient populations have also been reported in a few evaluation studies (Bradford, Coleman and Cunningham 2007; Freund et al. 2014; Guadagnolo et al. 2011).

Evaluation of navigation supports for primary care clients, including those providing linkages with community-based social services (Valaitis et al. 2017; Carter et al. 2018), also suggests such supports can improve access to care, self-management skills, patient satisfaction and wellness (and, to a lesser extent, reduce institutional service use). However, some researchers, especially in the US, have emphasized that navigation programs may be most effective at improving outcomes for disadvantaged groups (Freund et al. 2014).

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[3] Concerns about the cost of training specialist navigators have generated interest in potentially less costly models, such as community volunteers, or former caregivers or patients who likely work for less pay than professionals (Rocque et al. 2016; Vargas et al. 2008).

According to some studies, older adults perceived navigators as helpful (for example, Pieters et al. 2011; Rocque et al. 2016; Pesut et al. 2018). One review of navigation programs for older adults with chronic diseases concludes that there is "some evidence that integrated and coordinated care guided by a navigator, using a variety of interventions such as care plans and treatment goals, is beneficial for chronically ill older adults transitioning across care settings" (Manderson et al. 2012, 113). The benefits included positive economic outcomes, patient satisfaction and better quality of life.[4]

Evidence also suggests that nonprofit or volunteer navigators can provide more objective service information than health care system insiders, who may feel pressure to protect (and not overwhelm) limited service capacities. As one nonprofit agency representative explained:

> *What we can do is say: "really, you can have up to 55 hours [of home care] if you're an employed person caring for someone. Be aware that even if they say you can [only] have 10 or 15 hours of assistance that the parameters are such that you can go to this level"…we can have very factually just put it on the table and say: "it's there – feel good about asking."* (Funk and Hounslow 2019, 5)

Nonprofit navigators are able to focus primarily on the goals of the patient or family, whereas publicly funded navigators may be torn between patient and organizational objectives. Some programs appear more oriented to patient- or caregiver-identified needs; goals and preferences (e.g., direct, tangible assistance with completing applications; advocacy) and others to the needs of organizations, such as facilitating patient flow and controlling service use (Black et al., 2010; Fillion et al. 2012; Parker and Lemak 2011; Wenzel et al., 2012). Although these objectives can coincide, navigators may sometimes feel conflicted between them (Funk and Hounslow 2019; Yosha et al. 2011).

Volunteer and nonprofit navigation programs may also be more familiar with the community, its resources, its culture and its language, and there is some evidence supporting this (Corrigan et al. 2014; Doolan-Noble et al. 2013; Lorhan et al. 2012). However, both volunteer and nonprofit navigation models can be strained by turnover, time and resource constraints, and poorly integrated care services (Dohan and Schrag 2005; Pesut et al. 2017). A nonprofit representative expresses the challenges of time constraints in supporting families trying to access services:

> *If we did the same [advocacy] for everyone we wouldn't have enough to go around. So we have to be very careful on and very diligent on picking and choosing who we're really going to "go to war" for, because we can't possibly do it for everybody.* (Funk and Hounslow 2019, 14)

Moreover, nonprofits are usually limited in scope, serving specific geographic areas and population groups, which restricts their reach and potential effectiveness on a

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[4] The two Canadian studies that found little to no improvement from navigator intervention focused more on information provision rather than on direct hands-on support or advocacy (Gagnon et al., 1999; Mayo et al. 2008).

larger scale. The complexity of systems may also demand professional navigation expertise (Egan, Anderson and McTaggart 2010).

Beyond evaluating broad goals, such as addressing barriers to accessing care, improving case management, building relationships, facilitating care and providing support, few evaluation studies explain which specific navigation interventions have led to the evaluated outcomes. Navigation programs often include multiple activities (e.g., education, outreach, instrumental help, care coordination, emotional support) designed to meet multiple goals. This makes it difficult to know which activities are most consistently associated with the outcomes reported in research.

What effect do navigators have on caregivers?

Although patients and caregivers have common needs (such as accessing public services), caregivers must manage a range of care-related tasks as well as their own work and family obligations. Navigation programs are not normally designed to address or evaluate caregivers' needs. That said, some preliminary evidence suggests navigators serving older adults may also be helpful to family caregivers (Brookman et al. 2011). One nurse-led navigation program reported reduced depression and strain among caregivers (Wolff et al. 2009). Another community navigation program for stroke survivors, however, was found to have no effect on family caregivers (Egan, Anderson and McTaggart 2010). Ultimately, the effects on caregivers are normally not an intended part of program design and may be more indirect, as illustrated by the following statement from one caregiver in the Manitoba consultations: "The most important way to care for caregivers is to provide care services for the person who needs [them]" (Funk 2012, 16).

Because service providers often have difficulty assessing the needs of older adults and their caregivers, patient- and family-centred navigation approaches have the potential to help improve service-user satisfaction. Patient- and family-centred system navigation goes beyond professional assessments of the barriers to care or teaching clients how to overcome the barriers on their own. It also means focusing on the goals and activities that are most meaningful for patients and their families, and representing their interests when serving as mediators between them and service providers.

In some studies, however, even health care providers and formal navigators reported feeling unable to effectively support patients and their families because of the sheer complexity of formal systems, time constraints and scope-of-practice limitations (Change Foundation 2016b; Funk and Hounslow 2019; Carter et al. 2017). Addressing these issues when developing navigation supports could increase their effectiveness in alleviating caregivers' burden.

Weighing the benefits and costs of navigators

In addition to the limited evidence on how to appropriately design navigation programs, there are concerns about the financial viability of public system navigators due to the costs of training and paying them to carry out this work. However, the benefits they can provide should be recognized as well. Navigation support can generate public savings,[5] by reducing emergency room visits and hospitalizations, broadening access to preventive forms of care and enabling earlier diagnoses (Valaitis et al. 2017; Carter et al. 2018). Facilitating access to social and health care resources may enable older adults to remain in their homes and their communities longer if they want to. It may also prevent or delay caregiver burnout by reducing emotional distress and frustration, and allow them to focus on other aspects of care provision. Indeed, advocacy-based navigation models, like effective case management, can be cost-effective or at least cost-neutral (Oeseburg et al. 2009).

Some decision-makers will ask whether it is more appropriate and cost-effective in the long term to increase the capacity of health or social services professionals (or teams) to provide navigational support as part of their role[6] or to restructure services and systems to ensure better integration and coordination of care for all. I would argue that, even if services were to be better integrated, providing targeted navigation support should be part of a multipronged strategy, as should improving service information.

POLICY OPTIONS FOR IMPROVING SYSTEM NAVIGATION

Making navigation a public concern

When older adults and family caregivers are expected to navigate public health and social systems on their own, it generates service-access inequities and makes private individuals bear the costs of coordinating care. By acknowledging that the shortcomings of the public system create major hurdles in accessing care services and supports, we can begin to shift the responsibility for overcoming these obstacles away from patients and their caregivers and start to alleviate the navigation burden.

There are a number of options policy-makers should consider to respond to Canadians' struggles with system navigation, including improving service information, expanding public navigation programs and addressing the bigger issue of service integration. In doing so, they must also grapple with complex issues concerning leadership, authority and costs.

Improving service information

From a policy-maker's perspective, the least costly and most politically feasible option to reduce navigation problems is to enhance the quality, quantity and reach of information

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[5] It remains difficult to evaluate navigators' cost-effectiveness, however, because of "the heterogeneity of navigation programs, the sometimes distant relationship between navigation programs and outcome of interest (e.g., improving access to prompt diagnostic resolution and life years gained) and accounting for factors in underserved populations that may influence both access to services and outcomes" (Ramsey et al. 2009, 5494).

[6] For instance, some have argued that navigation work is best undertaken within the scope of existing professional roles, such as community health workers, social workers, nurses, case managers or family doctors (Thorne and Truant 2010; Miller, Allen and Mor 2008; Wenzel et al. 2012). Yet few of these professionals are connected to their clients for extended periods of time or across care settings. This may limit their potential to have a significant impact in addressing older adults' needs for services, which evolve over time.

provided to older adults and their families about available health and social care services. Although providing better service-access information should be straightforward with modern technology, only limited steps have been taken in this direction. For instance, some provincial governments (such as Manitoba and Ontario), local governments and nonprofit agencies have produced resource guides in print and online. Other governments have provided dedicated telephone lines (Nova Scotia, New Brunswick, Northwest Territories and Manitoba). Some nonprofit caregiver support agencies and workplaces also offer navigational workshops that combine information about services and specific diseases with other forms of group-based support.

There is much room for improvement. Caregivers favour centralized information hubs or "one-stop shops" for service information (Miller, Allen and Mor 2008; Ogilvie and Eggleton, 2016) and interactions with a real person who can directly address navigational needs (Funk 2012).[7] Moreover, information should be provided prior to crises and be tailored to caregivers' knowledge and understanding of how systems work (Giosa et al. 2014; Meyer 2017).[8]

There are several reasons why there has been limited progress on improving service information. Some public service providers may be reluctant to "advertise" their programs or provide explicit information about eligibility and assessment processes, especially if resources are limited. Governments also may be unable to publicize private or for-profit service options because of conflicts of interest, neutrality policies and the need to avoid political risks.

The effectiveness of improving service information is still unclear. Some studies indicate that better information leads to better patient outcomes, such as enhanced quality of life and reduced neuropsychiatric symptoms in persons with dementia,[9] yet it may be of limited benefit to caregivers (Corbett et al. 2012). Additional information may actually increase caregivers' burden due to the work required to sift and process new information, especially in the absence of other assistance (Dalmer, forthcoming). As well, internet and automated phone options can generate more work because they are often not user-friendly or responsive to individual needs (Bookman and Harrington 2007; Dalmer, forthcoming). Disseminating information on its own is clearly not sufficient. Navigational challenges extend far beyond obtaining information. They include filling out applications and reimbursement forms, advocating with professionals about the suitability of particular levels or types of service and dealing with adverse care circumstances.

Despite its appeal as an inexpensive solution, improving service information may only marginally reduce navigational needs and costs. Although it is part of a comprehensive

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[7] The Alzheimer Society's First Link® program is a positive step, involving telephone follow-up with persons with dementia and their caregivers, who are referred by health professionals soon after diagnosis, to provide information about community resources.

[8] The federally funded Huddol initiative, for instance, is an online tool that can help caregivers access information and services: https://www.huddol.com/

[9] Although delivering different types of support and services in group settings may be helpful, it also makes it difficult for researchers to pinpoint which aspects of navigation support services produce observable benefits.

solution, it should not be viewed as the silver bullet, especially among disadvantaged populations. Direct navigational support, such as advocating for families in interactions with service providers or filling out application forms, may be more empowering (Funk and Hounslow 2019).

Expanding public navigation programs

Encouraging greater use of privately hired advocates would not support equity, and poorly funded nonprofit agencies may have limited capacity to provide adequate navigational support on an ongoing basis. Public navigators can compensate for these weaknesses, but system navigation must be their primary mandate, and they must be able to take an active role in care coordination and liaison with professionals.[10] They can also help reduce inequities and mitigate the effects of socio-economic factors on access to care services by, for instance, helping their clients complete application forms for tax credits, arranging accessible transportation services or referring them to a social worker.

For public navigators to be effective, policy-makers need to ensure that they have the necessary time and authority to organize services on a patient's behalf and that they are adequately compensated for this work. Navigation programs must be publicly financed, delivered through public health and social care systems, and designed to avoid service fragmentation. One drawback of this approach, however, is that public navigators may believe they need to prioritize organizational goals over maintaining a more patient/family-centred approach where these goals conflict. Keeping the interests and perspectives of older adults and their caregivers at the forefront when developing supports for navigating systems of care is critical to reducing navigation burden.

Public responsibility for resolving the navigation problems of older adult populations with complex needs extends beyond the jurisdiction of any one government department. Some provinces might choose to address this issue by devolving some responsibility for navigational supports either to community agencies or to primary care groups. This option would require strong government leadership as well as additional financing and cooperation. But there are examples of success: provinces and cancer care associations have worked together to help provide more integrated cancer care services, using navigators for particular patients at risk of receiving fragmented care. Complications tend to emerge when the services involved cut across provincial government ministries: for example, some individuals may require home care services and income and housing supports, which would require the involvement of both health and social services agencies. Improving navigation therefore needs to be viewed as an overarching political priority among cabinet members.

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[10] Schulz and McDonald (2014) define care coordination as "the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities" (19).

Integrating care services: The key to patient- and caregiver-friendly systems

Some stakeholders argue that introducing patient navigators fails to address the root causes of navigation problems such as system complexity, fragmentation, gatekeeping and the downloading of administrative and coordination tasks to families (Change Foundation 2013; Thorne and Truant 2010). One navigator herself remarked: “I think that’s a reason why we need navigators, is we’ve just made it so that it tends to be that you need to speak with a few people in order to get things in place” (Funk and Hounslow 2019, 16). A comprehensive approach to alleviating navigational burden should seek to address these core issues.

One step in this direction would be to encourage interdisciplinary health care teams to work in more collaborative, proactive and patient-centred ways (Thorne and Truant 2010), making the entire team responsible for facilitating system navigation for older adults and their families. Indeed, early patient navigation approaches envisioned “navigation [as] a system, as opposed to a person, comprised primarily of navigators and directors that work together to remove barriers and facilitate access” (Vargas et al. 2008, 426). There may, however, be some resistance among professionals who do not consider navigation work or addressing family caregivers’ needs as being part of their roles or responsibilities. A mix of government leadership, clearly defined responsibilities, mandates and authority to organize services and proper compensation for that work could promote the necessary culture shift.

More broadly, adopting integrated care models to reduce system complexity would lessen the navigational burden on families. System leaders, board members and health care consultants should actively champion the evidence-based integration, streamlining and simplification of procedures and make it easier for all concerned to access needed care services. Though substantial, changes like these would align with broader movements toward integrated models of health and social care for older adults. Integrated care systems usually entail a single administrative structure (a single point of entry) and a single funding envelope covering a range of services across care settings, along with appropriate system-level case management and the engagement of multidisciplinary teams (Johri, Béland and Bergman 2003; MacAdam et al., 2009).

Implementing an integrated, patient-centric care system would also require better incorporating family caregivers’ needs. This might involve amending legislation or regulations to broaden the mandates of health and continuing care systems to serve both patients and caregivers. Precedent for such an approach can be found in some palliative care systems (such as that in Quebec), which recognize both dying persons and their family members as needing support. Another example is the *Caregiver Recognition Act* in Manitoba, which aims to guide the development of a framework for caregiver recognition and supports. There are also resources that policy-makers and health organizations can use, such as the Caregiver Policy Lens (part of the Caregiver Toolkit), to help them systematically consider the effects of particular programs and policies on family caregivers (MacCourt and Krawczyk 2012).

Weighing the three policy options

The time and effort required to navigate the health care and social services systems and the risks posed for well-being are currently borne mainly by those individuals who regularly use and interact with these systems. Better-integrated care has the greatest potential to reduce the navigational burden, but progress to date on this front has been limited.

Advocating for governments to do more to address navigation problems by providing additional formal navigation supports — among other initiatives — may further the impetus for better service integration. In the short term, expanding public navigation programs can help reduce navigational burden and inequities in access to care. Public navigators serving older adults are currently available only in some regions and usually focus on patients with specific diseases or transitioning between locations of care.

Although available evidence suggests that providing formal navigation services may improve patient outcomes and reduce society-wide costs, researchers and policy-makers need to learn more about the specific benefits as they relate to older adult populations in terms of improving health and well-being, alleviating caregivers' burden and reducing care access inequities. To do so would require that navigation support initiatives and programs for older adults across Canada be evaluated.

Governments must also encourage the spread of successful innovations. Evidence gathered through pilot projects could help policy-makers improve on policy design and learn about the best ways to reduce navigational burden:[11] results from pilots can be shared both within and across provinces to determine what are the elements — be they administrative, organizational or financial — of successful navigation programs. Best practices can then be promoted and measures put in place to encourage their broader adoption.

CONCLUSION

Growing numbers of older Canadians with chronic illness, disability, frailty and cognitive impairment are regularly discouraged by the efforts required to access and coordinate fragmented health and social care services. These challenges are often most profound for those who cannot rely on help from family members or friends. The navigational struggles encountered by older persons and their caregivers suggest that more support is key not only for improving their well-being, but also for preventing exhaustion among caregivers and reducing inequities in service access. If older persons continue to be viewed as a drag on health care costs and if caregivers continue to

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[11] Concretely, governments could monitor overall progress and outcomes through regular patient and caregiver satisfaction surveys, which can include broad measures of navigational experiences. Analyses of administrative data can also track which older adults, with the support of a navigator, are more or less likely to access a service and how fast they do so. Process and quality evaluations should provide essential information about how navigational needs and barriers are assessed and identified, as well as which approaches are most effective in reducing navigational burden.

be viewed only as sources of unpaid labour to keep family members out of hospitals, then there will be little interest within systems or among care professionals in easing navigation hurdles or facilitating access to care. Given growing public concern and awareness of the distress and costs imposed on older patients and their family caregivers due to these problems, policy-makers should take action.

A multipronged strategy is the responsible way forward. Because navigation challenges stem from fragmented, complex and uncoordinated service systems, improving information and providing more integrated care are essential to alleviate the problem. However, more substantial and timely progress would be made if the provinces also commited additional resources and public funding for formal system navigation programs and their evaluation.

Existing navigation supports, whether provided by nonprofit organizations or by local government agencies, are often specific to particular services or care-setting transitions, such as from hospital to home, or to people with particular health conditions, such as cancer or dementia. Availability also varies across regions and locations of care. A dedicated, comprehensive policy strategy could significantly reduce the navigation burden for broader patient and caregiver populations. Critically, such a strategy also requires boosting efforts to expand the evidence base upon which these policies are designed and evaluated. Hence, the meaningful involvement of researchers, providers, service users and caregivers in measuring and evaluating different policy approaches is essential if we are to tackle the problem effectively.

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