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# Healthcare system navigation difficulties among informal caregivers of older adults: a logistic regression analysis of social capital, caregiving support and utilization factors

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## Abstract

**Background** Informal caregivers of older adults play a vital role in improving the degree to which older adults access community and healthcare services in a seamless and timely manner. They are fulfilling important navigation and support roles for their older care recipients. However, there is still little knowledge of the most significant facilitators and barriers to effective and efficient system navigation among caregivers. This paper aims to fill these knowledge gaps through investigation of the key factors (i.e., social capital/cohesion, caregiving supports, and utilization factors) affecting navigation difficulties faced by informal caregivers of older adults.

**Methods** The Behavioural-Ecological Framework of Healthcare Access and Navigation (BEAN) model is used to frame the study. Using the General Social Survey on Caregiving and Care Receiving 2018, we analyzed 2,733 informal caregivers whose primary care recipients were aged 65 or older. Hierarchical logistic regression was conducted to identify the relationship between system navigation difficulties among informal caregivers and four sequentially ordered blocks of predictors: (1) sociodemographic (2), social capital/cohesion (3), caregiving supports, and (4) healthcare demand.

**Results** The fully adjusted model showed that the probability of reporting navigation difficulties was lower for caregivers with social capital/cohesion compared to those without social capital/cohesion. In comparison, the probability of reporting navigation difficulties was higher among caregivers with caregiving support and among caregivers whose care receivers use a higher amount of health service use. Several sociodemographic covariates were also identified.

**Conclusion** Our findings support certain aspects of the BEAN model. This study extends our understanding of potential facilitators and barriers that informal caregivers of older adults face while navigating complex community and health systems. There is a need to implement coordinated schemes and health policies especially for older adults with mental/neurological issues to address the challenges of their caregivers given the specific vulnerability identified

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in this study. The need for further research using different approaches to examine the disproportionate impact of COVID-19 on caregivers' system navigation experience is crucial.

**Keywords** System navigation, Informal caregivers, Older adults, Care coordination, Community and health system access

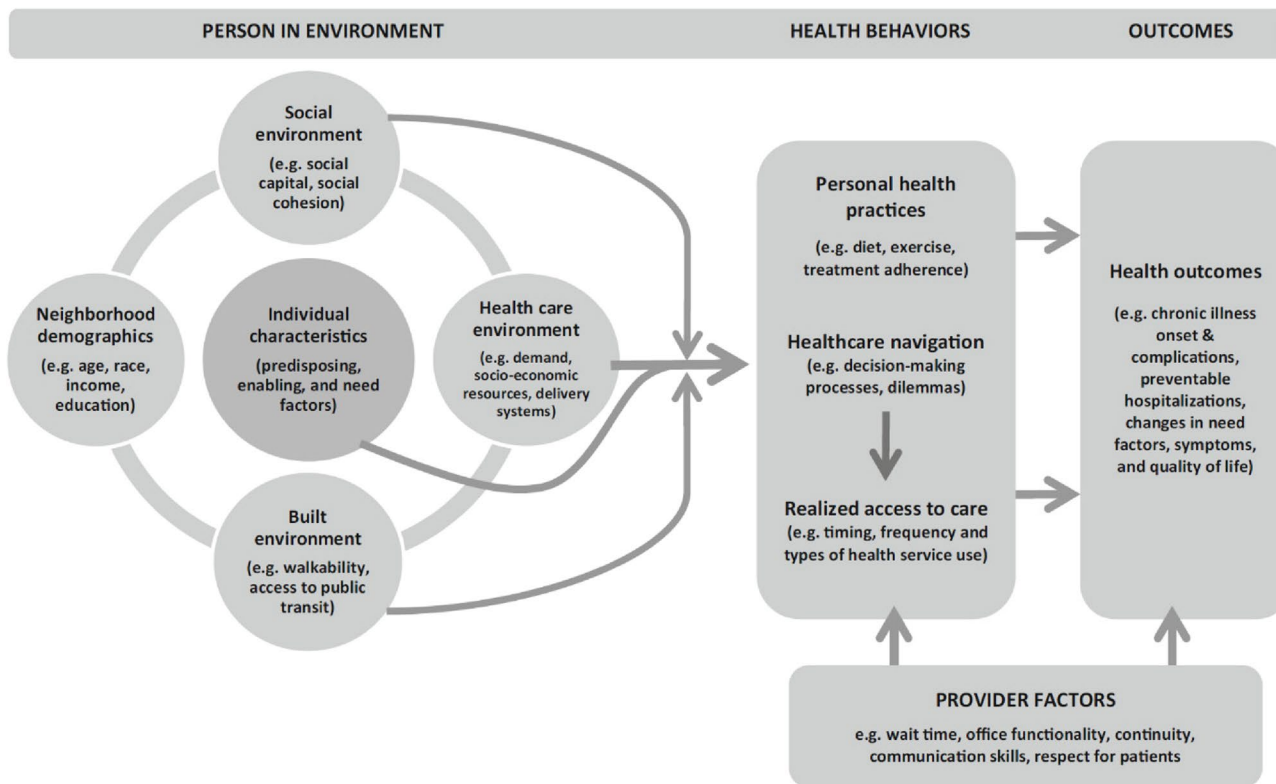
## Background

Healthcare system navigation (SN) can be defined as the process by which older adults and/or their health caregivers transition through the healthcare system in order to access and use services to maximize positive health outcomes [1]. Thus, navigation is a set of dynamic processes through which individuals respond to healthcare needs, pursue opportunities, and manage constraints [2]. As older adults experience an increase in the likelihood of chronic diseases, including physical/mental health problems and multimorbidity [3–7], they tend to require greater use of a variety of care providers while they are navigating community and healthcare systems to fulfill their complex health needs. Existing healthcare systems, however, are poorly suited to address older adults' complex, wide-ranging and changing needs due to siloed system-level organizational structures, thereby posing significant challenges to older adult users and their caregivers [8, 9]. Specifically, the challenges include a lack of awareness of available services in care settings among health professionals and caregivers [10, 11] and an incomplete transfer of information among stakeholders due to miscommunications [12]. Thus, older adults and their caregivers often fall through the cracks due to a lack of information on care service options and fragmented medical information. This may prevent them from accessing various types of services in community and healthcare settings. Community care includes respite care, adult day services, and activity programs provided in home and communities, whereas healthcare services cover GPs/specialists service from hospitals, pharmaceutical, and ancillary services. Navigating and accessing necessary services in complex systems with such issues may present significant challenges in managing and coordinating care delivery to ensure optimal outcomes for older adults [13, 14]. Against this backdrop, informal caregivers, who have been recognized as the backbone of the healthcare system [15–17], often play a vital role in improving the degree to which older adults access community and healthcare services in a more seamless and timely manner. Informal caregivers are fulfilling important navigation and support roles for older care recipients given that they are providing unpaid adult care to about 35% of care receivers in Canada [16, 18–20]. This pattern is intensified by rapid population aging, whereby 19% of the population in 2021 was aged 65 and over, with an estimated 1 in 4 Canadians in this age category by 2041 [21, 22]. Yet, there is still little knowledge on

the most significant facilitators and barriers to effective and efficient SN among caregivers, which is fundamental to reducing disparities in community and healthcare access for this focused group. This paper aims to fill these knowledge gaps through an investigation of the key factors affecting navigation difficulties faced by informal caregivers when accessing and navigating services for their older adult care-receivers.

We frame this research using the Behavioural-Ecological Framework of Healthcare Access and Navigation (BEAN) developed by Ryvicker (2018) to understand and explore the factors that support and hinder SN [2]. The model integrates two models found in gerontology—namely, the Behavioural Model of Health Service Use [23] and the Ecological Model of Aging [24]. The model (Fig. 1) includes the basic structure of the Behavioural Model of Health Service Use while highlighting important environmental domains of influence, such as social and healthcare environment. Building on the Behavioural Model of Health Service Use, the BEAN posits that the complex interactions among an individual's predisposing, enabling, and need characteristics influence a person's health behaviour, which includes health practices (e.g., diet, exercise), SN processes and accessibility to care. Building on the ecological model of aging [24, 25], the BEAN focuses on three categories of environmental characteristics in which the individual is embedded: the social environment (e.g., social capital/cohesion), the healthcare environment (e.g., health service demand), and the built environment (e.g., walkability). This model helps to identify, organize and interpret the key factors affecting SN difficulties among informal caregivers of older adults. This paper proposes to investigate the association between navigation difficulties and the social capital of informal caregivers along with other factors (i.e., caregiving support and utilization factors). This aspect of SN specifies the significance of informal caregivers in the BEAN model. The model notes that informal caregivers should be involved in the navigation process stating that “informal caregiver support has been identified as important factors in navigation” (Ryvicker, 2018: page 228). Recognizing that informal caregivers provide instrumental (e.g., locating services, driving), informational (health knowledge and literacy), and emotional support in SN of older adults, it is critical to identify factors affecting related challenges among informal caregivers.

Studies have highlighted the advantage of social capital underlying caregiving access and navigation of the



**Fig. 1** Behavioral-ecological framework of healthcare access and navigation. Source: Ryvicker (2018)

healthcare system [26, 27]. One case study found that the community-based organization supports socio-economically vulnerable people by providing various social capital resources (using a measure of mobilizing accessibility resources through informal relationships with friends and neighbours), which was found to be key in enabling navigation of healthcare during the COVID-19 pandemic [27]. Volunteers of the organization connected individuals to health services in various ways, relying on informal personal contacts within public services. This study demonstrated that linking social capital/cohesion and caregiving supports can foster more effective navigation practices. Another study [26] identified that system knowledge can be operationalized through social networks of trust and privilege (i.e., social capital). Researchers conducted in-depth, semi-structured interviews to explore the perspectives of participants pertaining to navigating the healthcare system and the knowledge that they used to make choices. They found that system knowledge requires social capital that can provide an advantage in utilizing the healthcare system. One of the participants of the study, for example, described how they sought information from their networks to ‘check the reputation’ of medical specialists. They noted that they were able to find suitable service providers effectively through their reliable social networks. The study illustrates that having trustworthy/reliable people (i.e., social

capital) and/or caregiving support when having problems can facilitate the navigation of complex community and healthcare systems. Other studies have also noted that social support positively affects the SN [28–30], although many of these studies have focused on younger people or refugees of any age rather than older adults or caregivers.

Conversely, some research has found that the effects of social support on SN might not always be straightforward, and in fact, can enable or hinder SN in some instances [2]. For instance, a cohesive social support system can be an obstacle to effective SN in an environment in which distrust of health professionals can occur, due to past experiences and cultural differences [2, 31, 32]. Thus, the role of social capital and/or caregiving supports in SN is under-researched and findings remain equivocal, suggesting the need for further study.

Healthcare navigation for caregivers is also likely linked to the care demands of older care recipients, since their health context can affect the amount of healthcare needed. Many studies have shown that functional limitations are associated with health service utilization [33–37]. For instance, Rhee and colleagues (2020) found that multimorbidity (i.e., more than one concurrent chronic condition) was associated with higher healthcare among older adults. Specifically, they found that older adults with more severe functional limitations (disability) use a higher amount of health services to fulfill their complex

health needs than those with less functional limitations, and concluded that this raises the risk for navigation challenges [34].

Other individual characteristics such as education level, health literacy, communication skills, and degree of self-efficacy have been identified as important factors in SN [1, 31, 32, 38–40]. A higher level of education is associated with enhanced health literacy and confidence in communicating with health professionals [39, 40], which may positively facilitate one's SN process. In addition, psycho-social factors that have been associated with higher use of services (such as health-related self-efficacy and depression) can either improve SN or hinder effective SN, respectively, as has been shown for self-management of chronic conditions [38].

In summary, while several studies have been conducted to examine the potential factors of difficulties in SN among older adults, there is a dearth of empirical studies that fully explore facilitators and/or barriers to SN among informal caregivers. This study will specifically identify the social capital, caregiving support and utilization factors that can facilitate or act as a barrier to the effective use of community and healthcare services among informal caregivers of older adults. It examines a specific aspect of the BEAN model focusing on the social environment and individual characteristics among informal caregivers as potential facilitators and/or barriers to SN.

The hypotheses of this study are as follows:

- 1) Higher levels of social capital/cohesion among informal caregivers will be associated with less difficulties in SN.
- 2) Higher levels of caregiving support among informal caregivers will be associated with less difficulties in SN.
- 3) Greater amounts of health service utilization among older care receivers will be associated with more difficulties in SN among informal caregivers.

## Methods

### Design and sample

This study employs the General Social Survey (GSS) on Caregiving and Care Receiving 2018 (Cycle 32) (hereafter: GSS 32). This survey collected information between April 3rd to December 28th, 2018 on Canadians who received help or care because of a long-term health condition, a disability or problems related to aging, and those who provide help or care to family members or friends with these types of conditions. The target population includes all persons 15 years of age and older in Canada, excluding (1) residents of the Yukon, Northwest Territories, and Nunavut; (2) full-time residents of institutions. The final sample size for GSS 32 was 20,258.

The definition of informal caregivers for this study entails: (1) a person who has helped or cared for someone with a long-term health condition or a physical/mental disability or problems related to aging, (2) a person who provided care at least 1 h per week, (3) whose primary care receiver had received help from professionals, that is paid workers or organizations, and (4) whose primary care receiver are aged 65 or older. Based on the criteria, the final sample size of this study is 2,733.

## Measures

### Outcome variable

The primary outcome variable used to measure community and healthcare navigation problems is a binary response (yes, no) to a question asking: "what specifically did you find stressful about caregiving: Finding services for your care receiver(s)." The majority of the sample (81%) reported having no difficulties while 19% reported in the affirmative (see Table 1).

### Predictor variables

The independent variables used for the analysis encompass four domains: (1) sociodemographic variables (caregivers/care receivers), (2) social capital/cohesion variables, and (3) caregiving supports variables, and (4) healthcare demand variables (see Fig. 2).

### Sociodemographic variables-caregivers

Predisposing factors (e.g., sex, age, visible minority status), enabling factors (e.g., marital status, income, employment, emotional health and well-being), and need factors (e.g., self-rated health, self-rated mental health, long-term health condition/disability) were used as socio-demographic individual characteristics of caregivers. Sex is a dichotomous variable coded with males as the reference category. Age is a categorical variable grouping informal caregivers into three groups (under 45/45 to 64/ over 65). The education level variable was measured with the following dummy coded categories: "below high school," (reference) "high school or equivalent," "college diploma/certificate," and "university degrees or above." Personal annual income was also dummy coded using the available categories in the dataset as possible responses: "less than \$40,000," (reference) "\$40,000 to \$80,000," "\$80,000 and over." Marital status and employment status were dichotomized as "not married," (reference) "married or common-law" in the case of the former variable, "no" (reference) and "yes," for the latter variable. Emotional health and well-being was also dichotomized as "unhappy," (reference) "happy". Self-rated health and self-rated mental health were recoded from the original scale to "poor/fair" (reference) and "good/excellent, while self-rated stress was recoded to "not stressful" (reference) and "stressful." Variables measuring their long-term health

**Table 1** Characteristics of informal caregivers and their care receivers, weighted

<b>Dependent Variable</b>	<b>Percentage (%)</b>			
Navigation difficulties				
No	81.01			
Yes	18.99			
<b>Independent variables</b>	<b>Percentage (%)</b>			
	<b>Entire Study population</b>	<b>Having Navigation difficulties</b>	<b>Not Having Navigation difficulties</b>	<b>Chi-square (df)</b>
<i>Informal Caregiver Variables</i>	60.37	68.59	58.45	18.10
Sex	39.63	31.41	41.55	(1) ***
Female				
Male				
Age	17.09	13.68	17.89	18.38
Under 45 years old	51.48	59.92	49.50	(2) ***
45 to 64 years old	31.43	26.40	32.61	
65 years and older				
Education	7.74	2.94	8.88	25.01
Below high school	32.20	30.00	32.73	(3) ***
High school or equivalent	28.24	30.98	27.58	
College diploma/certificate	31.82	36.08	30.81	
University degrees or above				
Personal annual income	43.51	43.16	43.59	0.08 (2)
Less than \$40,000	34.39	34.30	34.42	
\$40,000 to \$80,000	22.10	22.54	22.00	
More than \$80,000				
Marital status	36.22	34.30	36.68	1.03 (1)
Not married	63.78	65.70	63.32	
Married or common law				
Employment	50.05	53.37	49.14	3.01 (1)
No	49.95	46.63	50.86	
Yes				
Emotional health and well-being	8.71	10.98	8.18	4.17
Unhappy	91.29	89.02	91.82	(1) *
Happy				
Self-rated health	84.64	78.36	86.11	19.20
Good/Excellent	15.36	21.64	13.89	(1) ***
Poor/Fair				
Self-rated mental health	86.68	80.86	88.05	18.58
Good/Excellent	13.32	19.14	11.95	(1) ***
Poor/Fair				
Self-rated stress	31.46	16.73	34.94	63.94
Not stressful	68.54	83.27	65.06	(1) ***
Stressful				
Long-term health condition/disability	78.18	75.44	78.82	2.77 (1)
No	21.82	24.56	21.18	
Yes				
Visible minority	92.67	92.20	92.78	0.21 (1)
No	7.33	7.80	7.22	
Yes				
Primary caregiver	58.43	43.55	61.92	58.47
No	41.57	56.45	38.08	(1) ***
Yes				
Relationship with care receiver	14.34	15.41	14.09	40.60
Spouse	57.85	64.16	55.92	(3) ***
Immediate family	12.73	14.07	12.42	
Family in-law	15.44	6.36	17.57	
Others				

**Table 1** (continued)

Social capital/cohesion	13.56	20.51	11.91	44.57
No	26.64	31.84	25.41	(2) ***
More or less	59.80	47.66	62.68	
Yes				
Caregiving supports	72.83	63.94	74.93	24.78
No	27.17	36.06	25.07	(1) ***
Yes				
Healthcare demand	21.81	17.53	22.81	70.94
(formal health service use)	25.21	25.43	25.16	(5) ***
Less than 1 h	10.65	10.98	10.57	
1 h to less than 3 h	9.29	13.29	8.36	
3 h to less than 5 h	15.66	23.89	13.73	
5 h to less than 10 h	17.38	8.86	19.38	
10 h or more				
Not stated				
<i>Care Receiver Variables</i>	64.50	66.80	63.96	1.47 (1)
Sex	35.50	33.20	36.04	
Female				
Male				
Age	24.19	20.59	24.96	17.05
65 to 74 years	36.35	30.88	37.52	(2) ***
75 to 84 years	39.46	48.53	37.52	
85 years and older				
Employment status receivers	95.15	95.38	95.09	0.07 (1)
No	4.85	4.62	4.91	
Yes				
Living arrangement	22.70	26.11	21.91	4.23
Living in the same household	77.30	73.89	78.09	(1) *
Not living together				
Main Health Condition	42.96	44.12	42.69	17.24
Chronic issues and/or disability	14.52	19.46	13.35	(3) ***
Mental and neurological issues	27.02	22.16	28.16	
Aging and frailty	15.51	14.26	15.80	
Others				

condition, visible minority status, and whether being a primary caregiver or not were used as it is in the original scale. Relationship with the (primary) care receiver was recoded from the original scale to “spouse,” “immediate family,” “family-in-law,” and the reference category “others.”

#### **Sociodemographic variables-primary care receivers**

Sex at birth was a dichotomous variable measured by “female” and “male,” with males being used as the reference category. Age is measured using three groups (65 to 74/75 to 84/ over 85), which were subsequently re-coded with the lowest age as the reference category. Employment status was dichotomized as “no” (reference) and “yes.” Living arrangement was dichotomous variable with “not living together” (reference) and “living in the same household.” Main health condition was measured with the following dummy coded categories: “aging and frailty,” (reference) “chronic issues and/or disability,” “mental and neurological issues,” and “others.”

#### **Social capital/cohesion variable**

For social capital/cohesion, the original scale “there are plenty of people I can rely on when I have problems” was used, of which the measure was “no,” (reference) “more or less,” and “yes.”

#### **Caregiving supports variable**

In terms of caregiving supports, the answer category “your close friends or neighbours provided him/her with help” was utilized to indicate the caregiving supports given to informal caregivers while navigating the systems for their older care receivers, which was asked by the original question “to accommodate your caregiving duties, has any of the following support been provided to you?”. It was measured as a dichotomous variable with “no” (reference) and “yes.”

#### **Healthcare demand variable**

The number of hours of help from health professionals that the primary care receiver received was used as an indicator, which was measured with the following answer categories: “less than 1 hour,” (reference) “1 hour to less

Independent Vars		Dependent Var	
I . Sociodemographic Characteristics	II . Social Capital/Cohesion	Difficulties in Navigation	
<p><u>Caregivers</u></p> <ul style="list-style-type: none"> <li>• Predisposing factors</li> <li>- Sex, age, visible minority status, etc.</li> <li>• Enabling factors</li> <li>- Income, employment, emotional health and well-being, etc.</li> <li>• Need factors</li> <li>- Self-rated health, self-rated mental health, self-rated daily stress</li> <li>- Long-term health condition/disability, etc.</li> </ul> <p><u>Care receivers</u></p> <ul style="list-style-type: none"> <li>• Predisposing factors</li> <li>- Sex, age</li> <li>• Enabling factors</li> <li>- Employment status, living arrangement</li> <li>• Need factors</li> <li>- Main health condition</li> </ul>	<ul style="list-style-type: none"> <li>• Question: there are plenty of people I can rely on when I have problems</li> <li>• Answer categories: yes, more or less, no</li> </ul>		
	III . Caregiving Supports		<ul style="list-style-type: none"> <li>• Question: your close friends or neighbours provided help to your primary care receiver</li> <li>• Answer categories: yes, no</li> </ul>
	IV . Health Care Demand		<ul style="list-style-type: none"> <li>• Question: In an average week, how many hours of help has your primary care receiver received from professionals?</li> <li>• Answer categories: less than 1 hour, 1 hour to less than 3 hours, 3 hour to less than 5 hours, 5 hour to less than 10 hours, 10 hours or more</li> </ul>

Fig. 2 Variables

than 3 hours,” “3 hour to less than 5 hours,” “5 hour to less than 10 hours,” and “10 hours or more.”

**Data analysis**

Descriptive analyses were performed to summarize the characteristics of older adults and their informal caregivers. Additionally, hierarchical logistic regression was conducted to identify the relationship between SN difficulties among informal caregivers (outcome variable) and four sequentially ordered blocks of predictors: [1] sociodemographic [2], social capital/cohesion [3], caregiving supports, and [4] healthcare demand [41]. Hierarchical logistic regression is appropriate for modelling binary dependent variables such as ours [42]. Model 1 consisted of sociodemographic variables. Model 2 included the social capital/cohesion variable in addition to all variables in Model 1. Model 3 comprised all variables in Model 2 adding the caregiving supports variable. The final Model 4 constituted all variables in previous models in addition to healthcare demand variable. Each chi-square value of the model was presented to show the change across the four models. All analyses were conducted with STATA version 18.0.

**Results**

**Descriptive statistics**

**Characteristics of informal caregivers and their older care receivers**

Table 1 shows the characteristics of informal caregivers and their older care receivers. For the caregivers, 60.37% were female. Close to half (51.48%) were 45 to 64 years old. About 28% had a college diploma/certificate and over 40% had an income of less than \$40,000. In addition, 36.22% were not married and almost half of respondents (49.95%) were employed. Most (91.29%) reported that they were happy with their emotional health. About 85% perceived their health or mental health to be good/excellent (84.64% and 86.68%, respectively), whereas almost 69% felt stressed. Also, 21.82% had a long-term health condition/disability. A small percentage (7.33%) were a visible minority. A significant proportion (41.57%) were primary caregivers and over half of the respondents (57.85%) were immediate family members of their older care receivers. We found that 13.56% had social capital/cohesion and 27.17% had caregiving supports while navigating the community and healthcare system. About a quarter of respondents’ care receivers used 1 h to less than 3 h of formal health service use. In the case of older care receivers, 64.50% were female and almost 40% were 85 years and older. The majority of care receivers were

not employed (95.15%). Also, 22.70% lived with their caregivers. Over 42% had chronic issues and/or disability.

### **Navigation difficulties among Informal caregivers of older adults**

Table 1 also presents the proportion of informal caregivers who had navigation difficulties. Almost 19% of caregivers (18.99%) faced challenges while navigating the community and healthcare system for their older care receivers, while about 81% (81.01%) did not have navigation difficulties.

### **Factors associated with navigation difficulties among informal caregivers**

Table 2 shows the results on factors associated with navigation difficulties among informal caregivers of older adults. All four models were significant ( $p < .001$ ) and the chi-square of each model was presented (Model 1: 252.21, Model 2: 266.55, Model 3: 283.62, and Model 4: 320.64). Only results in the final model (Model 4) are presented for each section below, although all hierarchical models are displayed in the tables. SN difficulties (yes/no) was significantly associated with 11 variables. Only statistically significant associations are reported below.

#### **Socio-demographic variables**

The likelihood of reporting navigation difficulties (compared to not reporting) was higher for female caregivers than for male caregivers (OR=1.42,  $p < .05$ , CI 1.08–1.87). The probability of having navigation problems was also associated with higher education levels for the following contrasts: “high school or equivalent,” (OR=3.93,  $p < .001$ , CI 1.79–8.65) “college diploma/certificate,” (OR=4.91,  $p < .001$ , CI 2.23–10.83) and “university degrees or above,” (OR=5.96,  $p < .001$ , CI 2.68–13.22) compared to “below high school.” Better self-rated health was associated with a lower likelihood of having navigation difficulties: “good/excellent,” (OR=0.66,  $p < .05$ , CI 0.46–0.95) compared to “poor/fair.” A higher likelihood of reporting navigation problems was found for reporting feeling “stressful,” (OR=2.24,  $p < .001$ , CI 1.61–3.13) compared to “not stressful”; and for being a primary caregiver: “yes” (OR=2.37,  $p < .001$ , CI 1.77–3.16) compared to “no.” For the relationship with the primary care receiver, the higher likelihood of having navigation difficulties was reported for being “immediate family,” (OR=2.61,  $p < .001$ , CI 1.57–4.35) “family-in-law” (OR=3.18,  $p < .001$ , CI 1.73–5.82) compared to “others”.

For the care receivers-related variables, both age and main health condition showed significant positive relationships with navigation difficulties among caregivers. The likelihood of navigation problems was higher among informal caregivers whose primary care receivers were “85 years and older” compared to “65 to 74 years”

(OR=1.67,  $p < .01$ , CI 1.14–2.44). Also, the probability of reporting higher navigation difficulties was found for reporting having “mental and neurological issues” compared to “aging and frailty” (OR=2.09,  $p < .05$ , CI 1.11–3.95).

#### **Social capital/cohesion variables**

The likelihood of navigation problems was lower among informal caregivers reporting more social capital/cohesion compared to those without social capital/cohesion. Specifically, the probability of reporting navigation difficulties was lower for caregivers who have comparatively higher level of social capital/cohesion (those who answered “more or less” or “yes”) (OR=0.78,  $p < .001$ , CI 0.54–0.95; OR=0.45,  $p < .001$ , CI 0.32–0.65, respectively) compared to those answering “no”.

#### **Caregiving supports variables**

The probability of reporting navigation difficulties was higher among caregivers with caregiving support compared to caregivers without caregiving support (OR=1.90,  $p < .001$ , CI 1.44–2.50).

#### **Healthcare demand variables**

Healthcare demand was significantly associated with difficulties in SN. That is, the likelihood of reporting navigation difficulties was higher for caregivers whose care receivers use a comparatively higher amount of formal health service use: “5 hours to less than 10 hours,” (OR=2.23,  $p < .001$ , CI 1.42–3.50) “10 hours or more” (OR=2.86,  $p < .001$ , CI 1.93–4.24) compared to “less than 1 hour.”

## **Discussion**

The importance of community and healthcare system navigation (SN) among informal caregivers is vital to meeting the care needs of a growing older population, which is in its most rapid phase primarily due to the aging of the baby boomers and rising life expectancy [43, 44]. This paper extends our understanding of potential facilitators and barriers that informal caregivers of older adults face while navigating complex community and health systems. We specifically test several hypotheses pertaining to the importance of social capital/cohesion, caregiving supports, and healthcare demand, as well as examine several socio-demographic covariates.

In support of Hypothesis 1, our study revealed that informal caregivers with higher levels of social capital/cohesion reduces the likelihood of navigation difficulties, adjusting for all covariates. This finding is indicative of the potential benefits of social capital, such as providing reliable information and other forms of social support that may mitigate the problems associated with negotiating potentially challenging community and health



**Table 2** Hierarchical logistic regression of navigation difficulties among informal caregivers of older adults (n = 2,733)

	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>	<b>Model 4</b>
	<b>Odds Ratio</b>	<b>Odds Ratio</b>	<b>Odds Ratio</b>	<b>Odds Ratio</b>
	<b>(95% C.I.)</b>	<b>(95% C.I.)</b>	<b>(95% C.I.)</b>	<b>(95% C.I.)</b>
<b>1) Sociodemographic model</b>				
<b>Caregivers</b>				
<b>Sex</b> (male—ref)	1.41**	1.42**	1.44**	1.42*
Female	[1.09 to 1.82]	[1.10 to 1.85]	[1.10 to 1.88]	[1.08 to 1.87]
<b>Age</b> (Under 45 years—ref)	1.42	1.35	1.38	1.39
45 to 64 years	[0.96 to 2.09]	[0.91 to 2.01]	[0.92 to 2.05]	[0.92 to 2.09]
65 years and older	1.44	1.39	1.54	1.54
	[0.87 to 2.34]	[0.85 to 2.27]	[0.94 to 2.54]	[0.93 to 2.55]
<b>Education level</b> (below high school—ref)				
high school or equivalent	4.39***	4.11***	4.04***	3.93***
	[2.03 to 9.51]	[1.89 to 8.96]	[1.85 to 8.85]	[1.79 to 8.65]
college diploma/certificate	5.25***	4.89***	4.91***	4.91***
	[2.42 to 11.41]	[2.24 to 10.68]	[2.24 to 10.76]	[2.23 to 10.83]
university degrees or above	7.32***	6.67***	6.31***	5.96***
	[3.35 to 16.02]	[3.35 to 14.67]	[2.86 to 13.93]	[2.68 to 13.22]
<b>Personal annual income</b> (less than \$40,000—ref)				
\$40,000 to \$80,000	0.84	0.85	0.87	0.91
	[0.63 to 1.11]	[0.64 to 1.13]	[0.65 to 1.17]	[0.68 to 1.23]
\$80,000 and over	0.78	0.82	0.89	0.95
	[0.56 to 1.10]	[0.58 to 1.15]	[0.62 to 1.26]	[0.67 to 1.36]
<b>Marital status</b> (not married—ref)	1.10	1.14	1.20	1.20
Married or common-law	[0.83 to 1.46]	[0.86 to 1.51]	[0.90 to 1.61]	[0.89 to 1.61]
<b>Employment status</b> (No—ref)				
Yes	1.17	1.18	1.19	1.17
	[0.88 to 1.55]	[0.89 to 1.56]	[0.89 to 1.59]	[0.87 to 1.57]
<b>Emotional health and well-being</b> (unhappy—ref)	1.06	1.09	1.06	1.10
Happy	[0.67 to 1.67]	[0.68 to 1.76]	[0.65 to 1.74]	[0.66 to 1.82]
<b>Self-rated health</b> (poor/fair—ref)	0.62**	0.65*	0.66*	0.66*
Good/Excellent	[0.44 to 0.88]	[0.46 to 0.93]	[0.46 to 0.94]	[0.46 to 0.95]
<b>Self-rated mental health</b> (poor/fair—ref)	0.79	0.87	0.90	0.90
Good/Excellent	[0.54 to 1.16]	[0.59 to 1.29]	[0.60 to 1.36]	[0.60 to 1.36]
<b>Self-rated stress</b> (not stressful—ref)	2.51***	2.35***	2.26***	2.24***
Stressful	[1.83 to 3.44]	[1.71 to 3.23]	[1.63 to 3.14]	[1.61 to 3.13]
<b>Long-term health condition</b> (no—ref)	1.05	1.02	1.04	0.91
Yes	[0.79 to 1.40]	[0.76 to 1.35]	[0.78 to 1.40]	[0.68 to 1.23]
<b>Visible minority status</b> (visible minority—ref)	0.96	1.04	1.13	1.09
Not a visible minority	[0.62 to 1.48]	[0.67 to 1.61]	[0.71 to 1.79]	[0.81 to 1.47]
<b>Primary caregiver</b> (no—ref)	2.40***	2.39***	2.34***	2.37***
Yes	[1.82 to 3.16]	[1.81 to 3.15]	[1.77 to 3.11]	[1.77 to 3.16]
<b>Relationship with the Care receiver</b> (others—ref)	1.53	1.54	1.46	1.44
Spouse	[0.75 to 3.10]	[0.75 to 3.15]	[0.70 to 3.05]	[0.69 to 3.04]
Immediate family	2.49***	2.53***	2.69***	2.61***
Family in-law	[1.54 to 4.02]	[1.55 to 4.12]	[1.63 to 4.45]	[1.57 to 4.35]
	3.27***	3.33***	3.36***	3.18***
	[1.86 to 5.75]	[1.87 to 5.92]	[1.86 to 6.08]	[1.73 to 5.82]
<b>Primary care receivers</b>				
<b>Sex</b> (male—ref)	1.15	1.16	1.09	1.73
Female	[0.88 to 1.50]	[0.88 to 1.51]	[0.83 to 1.43]	[0.81 to 1.41]
<b>Age of Care receivers</b> (65 to 74 years—ref)	0.94	0.94	0.95	0.92
75 to 84 years	[0.66 to 1.33]	[0.66 to 1.39]	[0.66 to 1.36]	[0.64 to 1.34]
85 years and older	1.54**	1.74**	1.87***	1.67**
	[1.21 to 2.47]	[1.22 to 2.50]	[1.29 to 2.72]	[1.14 to 2.44]
<b>Employment status of Care receivers</b> (no—ref)	0.99	0.98	0.98	1.08
Yes	[0.53 to 1.83]	[0.53 to 1.82]	[0.52 to 1.84]	[0.58 to 2.03]
<b>Living arrangement of Care receivers</b> (not living together—ref)	1.07	1.04	1.03	1.05
Living in the same household	[0.72 to 1.59]	[0.70 to 1.56]	[0.68 to 1.56]	[0.69 to 1.60]

**Table 2** (continued)

	<b>Model 1</b>	<b>Model 2</b>	<b>Model 3</b>	<b>Model 4</b>
	<b>Odds Ratio (95% C.I.)</b>	<b>Odds Ratio (95% C.I.)</b>	<b>Odds Ratio (95% C.I.)</b>	<b>Odds Ratio (95% C.I.)</b>
<b>Main health condition</b> (aging and frailty—ref)	1.61*	1.55	1.54	1.56
Chronic issues and/or disability	[1.01 to 2.59]	[0.95 to 2.51]	[0.93 to 2.56]	[0.92 to 2.65]
Mental and neurological issues	2.21***	2.30***	2.41***	2.09*
Others	[1.24 to 3.93]	[1.30 to 4.05]	[1.33 to 4.34]	[1.11 to 3.95]
	1.70	1.67	1.76	1.82
	[0.94 to 3.11]	[0.92 to 3.03]	[0.97 to 3.21]	[0.99 to 3.35]
<b>2) Social capital/cohesion model</b>				
<b>Having reliable people when having problems</b> (no—ref)				
More or less		0.82***	0.76***	0.78***
Yes		[0.58 to 0.96]	[0.54 to 0.97]	[0.54 to 0.95]
		0.55***	0.47***	0.45***
		[0.39 to 0.78]	[0.33 to 0.67]	[0.32 to 0.65]
<b>3) Caregiving supports model</b>				
<b>Close friends/neighbours provide help</b> (no—ref)				
Yes			1.92***	1.90***
			[1.46 to 2.53]	[1.44 to 2.50]
<b>4) Healthcare demand model</b>				
<b>Formal health service use</b> (less than 1 h—ref)				
1 h to less than 3 h				1.31
3 h to less than 5 h				[0.92 to 1.89]
5 h to less than 10 h				1.40
10 h or more				[0.87 to 2.25]
Not stated				2.23***
				[1.42 to 3.50]
				2.86***
				[1.93 to 4.24]
				1.03
				[0.63 to 1.68]
<b>Model Chi-Square (df)</b>	252.21*** (28)	266.55*** (30)	283.62*** (31)	320.64*** (36)

Model 1=Sociodemographic variables; Model 2=All variables in Model 1 plus social capital/cohesion variable; Model 3=All variables in Model 2 plus caregiving supports variable; Model 4=All variables in Model 3 plus healthcare demand var

Ref:reference category, CI confidence interval

\*p<.05, \*\*p<.01, \*\*\*p<.001

systems. Indeed, researchers have noted that navigation challenges and caregiver burden can be compounded by vague or conflicting information on how to access public resources [9, 45]. Caregivers with stronger cohesion have also been found to be more likely to request timely, user-friendly guidance and information [8, 46, 47].

However, we also found that caregivers who received more help from their close friends/neighbours were more likely to face difficulties in SN, contrary to Hypothesis 2. This finding is consistent with the literature on this topic that has shown mixed results or even a possible “downside” of community/neighbourhood resources [2]. For example, a previous study found that higher levels of community social trust were associated with better self-rated health [48]; yet, this effect differed greatly depending on a person’s level of social trust, an indicator of social capital [2, 48]. For this study, it is possible to assume that reverse causation occurred. That is, informal caregivers dealing with navigation challenges might seek more

support from their close friends/neighbours. Similar findings have been reported in other research examining the association between caregiving demands and community peer support use. Researchers of the study found that those with greater caregiving demands (measured by caregiving burden, time spent caregiving, total number of activities with which caregiver assists care receivers) were more likely to need peer support [49]. Our study uses the BEAN model and prior research in terms of our interpretation. Also, given that a substantial amount of literature stresses the importance of the roles of friends and neighbours in supporting older adults [49–54], it is assumed that the current variable to measure caregiving support is appropriate to verify hypothesis 2. Additionally, we contend that a significant reliance on informal social networks rather than on professional sources may disturb caregivers in obtaining proactive and timely information which is one of their significant information needs during the help-seeking process [55–57]. This is particularly

relevant in our study, since the primary care receiver had to have received professional help. Yet, other sources and/or forms of social support not included in this study may actually reduce navigation problems.

In support of Hypothesis 3, our study found that higher healthcare demand of care receivers increased the navigation difficulties of their informal caregivers. Older care receivers who are using higher amounts of health services may have more complex social and health needs to be fulfilled. To address their complex needs, their informal caregivers often need to contact numerous community and health institutions and various professional care providers, which may cause significantly more challenges in the help-seeking process. While this finding is intuitive, it nonetheless emphasizes the importance of focusing on high-demand older adults with respect to healthcare navigation and integration.

Several sociodemographic indicators were also consistently associated with difficulties in SN. It is well established that female caregivers tend to be the most affected by caregiving [58–62]. Previous studies demonstrate that, particularly for women, entering a caregiving role reduces labour force participation [63, 64] as well as increases the probability of being retired [65]. Another recent study found a statistically significant positive association between transitioning into a caregiving role and increased network size among male caregivers, while female caregivers reported the opposite effect [62]. This may suggest that female caregivers are more likely to face greater challenges in SN, in part, due to the greater caregiving load and types of care, while having a smaller social network compared to male caregivers [66–68].

The positive relationship between caregivers' education level and navigation difficulties differs from previous research in which education is a facilitator for more effective system use [39, 40]. Although speculative, the opposite association found in our study may be indicative of a higher level of health literacy and understanding of community and healthcare systems, which may raise expectations and increase perceptions of utilization problems, perhaps heightened due to higher rates of users. However, the role of education in SN should be investigated further. For caregivers with worse self-rated stress, and who are a primary caregiver may have more difficulties in SN due to their relatively vulnerable psychosocial and caregiving outcomes, while better self-rated health decreased navigation challenges among caregivers [69–71].

It was notable that the relationship with the care receiver had a significant association with navigation difficulties of caregivers. It is well established that taking care of family members causes a significant burden to caregivers compared to those who are taking care of others such as friends, neighbours or co-workers [51,

72–75]. Many studies have also demonstrated that caregivers who provide care to a chronically ill family member are at risk for caregiver burden and declining physical and mental health, factors that may constrain effective system use [73, 74, 76–80].

Our study also found that informal caregivers are likely to have higher navigation difficulties for taking care of the oldest old (85 years and older) compared to those providing care for the young-old (65 to 74 years). A significant number of studies have shown that older age is associated with a higher prevalence of multimorbidity, which can be a barrier to a negotiating community and health systems [81–84]. Accordingly, it is assumed that navigation difficulties among informal caregivers whose primary care receivers are the oldest-old may be higher, given that caregivers need to contact more community and healthcare institutions and stakeholders to address the complex needs of their care receivers.

It was also observed that informal caregivers whose care receivers have mental and neurological issues have greater difficulties than those whose care receivers have aging and frailty issues. Previous literature has found that older adults, and especially those living with dementia, can experience barriers in accessing and navigating fragmented service systems [10, 85–87]. In the case of older adults experiencing mental or neurological disease, their caregivers may misinterpret symptoms and declines in function as normal aging or grief [88]. In addition, Dawson and colleagues (2017) noted that delays in services were often experienced by caregivers in the face of mental health problems of their care receivers, since specialist services take more time. As such, individual-level problems stemming from the characteristics of mental/neurological disease significantly affect the SN. Furthermore, system-level factors such as continuity of care, wait time, and communication skills across the sectors are also critical to navigation experiences among informal caregivers and realized access to care [88].

Given the significance of the social capital and utilization factors, as well as several key covariates as predictors of navigation difficulties among informal caregivers, our findings support certain aspects of the BEAN model by Ryvicker (2018)—used to frame this study. That is, social capital/cohesion and health service use are identified as factors affecting healthcare navigation. Also, our study confirmed that some individual characteristics such as sex, education level, and self-rated stress affect the way in which caregivers navigate healthcare systems along with their care receivers' characteristics (i.e., age, main health condition), which is aligned with the assumptions of the BEAN model. Indeed, the BEAN model is valuable for further understanding the effects of social capital/cohesion, healthcare demand, and several socio-demographic

factors on accessing and navigating the community and healthcare system.

### Implications

In order to address the challenges and to fill the care gaps on SN among informal caregivers, there is a need to implement coordinated schemes and health policies for older adults and their caregivers, enabling user-friendly integrated care in community and healthcare systems. Potential strategies can focus on comprehensive personal and environmental assessment, care coordination matched to the level of client needs, and referral to additional service providers, etc. [89–91], thereby improving the navigation experience of informal caregivers as well. In doing so, there is also a need to pay more attention to older adults with mental/neurological issues to address the challenges of their caregivers given the specific vulnerability during the help-seeking process. Additionally, the COVID-19 pandemic has significantly affected not only the lives of older adults but also those of informal caregivers by increasing their level of stress, anxiety, and depression in care provision due to decreased support from both formal and informal sources [85, 92, 93]. Such adversity may negatively affect the experience of navigating the complex community and health systems among informal caregivers. Future research needs to further investigate these disproportionate impacts on caregivers. For example, qualitative studies can more deeply explore the SN challenges and/or experiences among informal caregivers during and after the COVID-19 pandemic.

### Limitations

This study has several limitations. First, the cross-sectional design of the GSS 32 does not provide information on causal relationships. Thus, it may measure the existence and associations of relationships between independent variables and outcome variables that are present in the data collection environment. Still, this study fills the knowledge gap between the previous studies by focusing on navigation difficulties among informal caregivers, albeit in a cross-sectional design. Second, while the GSS 32 contains a wide variety of measures on caregiving and care receiving, the measure available for the outcome variable of the current study—navigation difficulties of informal caregivers—needs further development and specification. Third, not all of the components of the BEAN model were utilized. However, this study still contributes to aspects of the BEAN model by focusing on the social environment and individual characteristics of caregivers as potential facilitators/barriers to SN. Understanding the key predictors of navigation difficulties among informal caregivers can also be enhanced by including additional indicators of environmental areas (e.g., built environment), given our conceptual model [2].

Finally, SN problems are affected by the type and organization of health systems, as well as insurance, thereby necessitating research to be extended to other countries.

### Conclusions

Informal caregivers are fulfilling a pivotal navigator role for their older care receivers, thereby filling care gaps within often fragmented and complex community and healthcare systems. Our findings highlight that there are several key factors that are associated with navigation difficulties among caregivers in both social and healthcare environments. In particular, our study clearly demonstrates that coordinated initiatives and health policy should be developed to fully support informal caregivers and their older care receivers, especially those with greater and more complex health needs, to foster improved navigation experiences, such as seamless integrated care. This study serves as a stepping stone for research investigating the understanding and development of integrated care and comprehensive health policy strategies to reduce the navigation challenges among informal caregivers and older care receivers.

### Abbreviations

SN	System Navigation
BEAN model	the Behavioural-Ecological Framework of Healthcare Access and Navigation model
GSS	General Social Survey

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### Authors' contributions

All authors have contributed to the manuscript. BK led the writing and development of the manuscript with substantial contributions from AW, BM, LL and LK. BK analyzed the data with the support of AW and LL. All authors contributed to the discussion, review, and final approval of the manuscript.

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### Availability of data and materials

All data generated or analysed during this study are included in this published article.

### Declarations

#### Ethics approval and consent to participate

This study is not an experiment involving human participants, but rather a secondary data analysis using a public dataset (General social survey). Thus, it has been exempted from the research ethics board of SFU (Simon Fraser University, Canada) (REB #30001758).

#### Consent for publication

Not applicable.

#### Competing interests

The authors declare no competing interests.

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## References

- Sofaer S. Navigating poorly charted territory. *Med Care Res Rev.* 2009;66(1 suppl):S75–93.
- Ryvicker M. A conceptual framework for examining healthcare access and navigation: a behavioral-ecological perspective. *Social Theory Health.* 2018;16:224–40.
- Ashbourne J, Boscart V, Meyer S, Tong CE, Stolee P. Health care transitions for persons living with dementia and their caregivers. *BMC Geriatr.* 2021;21(1):285.
- Charles L, Brémault-Phillips S, Parmar J, Johnson M, Sacrey L-A. Understanding how to support family caregivers of seniors with complex needs. *Can Geriatr J.* 2017;20(2):75.
- Marengoni A, Rizzuto D, Wang HX, Winblad B, Fratiglioni L. Patterns of chronic multimorbidity in the elderly population. *J Am Geriatr Soc.* 2009;57(2):225–30.
- Ploeg J, Yous M-L, Fraser K, Dufour S, Baird LG, Kaasalainen S, et al. Healthcare providers' experiences in supporting community-living older adults to manage multiple chronic conditions: a qualitative study. *BMC Geriatr.* 2019;19(1):316.
- Wister AV, Coatta KL, Schuurman N, Lear SA, Rosin M, MacKey D. A lifecourse model of multimorbidity resilience: theoretical and research developments. *Int J Aging Hum Dev.* 2016;82(4):290–313.
- Bookman A, Harrington M. Family caregivers: a shadow workforce in the geriatric health care system? *J Health Polit Policy Law.* 2007;32(6):1005–41.
- Funk LM. Relieving the burden of navigating health and social services for older adults and caregivers. Institute for Research on Public Policy Montreal, QC, Canada; 2019.
- Di Gregorio D, Ferguson S, Wiersma E. From beginning to end: perspectives of the dementia journey in northern Ontario. *Can J Aging/La Revue Canadienne Du Vieillessement.* 2015;34(1):100–12.
- Hansen E, Robinson A, Mudge P, Crack G. Barriers to the provision of care for people with dementia and their carers in a rural community. *Aust J Prim Health.* 2005;11(1):72–9.
- Kripalani S, LeFevre F, Phillips CO, Williams MV, Basaviah P, Baker DW. Deficits in communication and information transfer between hospital-based and primary care physicians: implications for patient safety and continuity of care. *JAMA.* 2007;297(8):831–41.
- Golden AG, Tewary S, Dang S, Roos BA. Care management's challenges and opportunities to reduce the rapid rehospitalization of frail community-dwelling older adults. *Gerontologist.* 2010;50(4):451–8.
- Manderson B, McMurray J, Piraino E, Stolee P. Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature. *Health Soc Care Commun.* 2012;20(2):113–27.
- Bremault-Phillips S, Parmar J, Johnson M, Huhn A, Mann A, Tian V, et al. The voices of family caregivers of seniors with chronic conditions: a window into their experience using a qualitative design. *Springerplus.* 2016;5:620.
- Sinha M. Portrait of caregivers, 2012. Statistics Canada = Statistique Canada; 2013.
- Van Houtven CH, Voils CI, Weinberger M. An organizing framework for informal caregiver interventions: detailing caregiving activities and caregiver and care recipient outcomes to optimize evaluation efforts. *BMC Geriatr.* 2011;11:1–18.
- Kim B, Wister A, O'dea E, Mitchell BA, Li L, Kadowaki L. Roles and experiences of informal caregivers of older adults in community and healthcare system navigation: a scoping review. *BMJ open.* 2023;13(12):e077641.
- Sinha M, Bleakney A. Receiving care at home. Statistics Canada = Statistique Canada; 2014.
- Statistics Canada. Study: sandwiched between multiple unpaid caregiving responsibilities. Statistics Canada; 2024.
- Wister A, Kim B, Qiu S. Fact Book on Aging in British Columbia and Canada. Gerontology Research Centre, Simon Fraser University; 2023.
- Statistics Canada. Tables 17-10-0005-01 Population estimates on July 1, by age and gender [Internet]. Ottawa: Statistics Canada; 2024 [cited 2024 Sep 3]. Available from: <https://doi.org/10.25318/171000501-eng>
- Andersen R. A behavioral model of families' use of health services. *Behav model families' use health Serv.* 1968(25).
- Lawton MP. *Environment and aging.* Albany, NY: Center for the Study of Aging; 1986.
- Satariano W. *Epidemiology of aging: an ecological approach.* Jones & Bartlett Learning; 2006.
- Willis K, Collyer F, Lewis S, Gabe J, Flaherty I, Calnan M. Knowledge matters: producing and using knowledge to navigate healthcare systems. *Health Sociol Rev.* 2016;25(2):202–16.
- Zanni F. How social capital enabled healthcare access and navigation by vulnerable people during Covid-19. *Eur J Pub Health.* 2022;32(Supplement3):ckac131.
- Gage-Bouchard EA. Social support, flexible resources, and health care navigation. *Soc Sci Med.* 2017;190:111–8.
- Varda DM, Talmi A. Social connectedness in family social support networks: strengthening systems of care for children with special health care needs. *EGEMs.* 2018;6(1).
- Yun K, Paul P, Subedi P, Kuikel L, Nguyen GT, Barg FK. Help-seeking behavior and health care navigation by Bhutanese refugees. *J Community Health.* 2016;41:526–34.
- Ganter C, Chuang E, Aftosmes-Tobio A, Blaine RE, Giannetti M, Land T, et al. Community stakeholders' perceptions of barriers to childhood obesity prevention in low-income families, Massachusetts 2012–2013. *Prev Chronic Dis.* 2015;12(3):E42.
- Musa D, Schulz R, Harris R, Silverman M, Thomas SB. Trust in the health care system and the use of preventive health services by older black and white adults. *Am J Public Health.* 2009;99(7):1293–9.
- Fredman L, Droge JA, Rabin DL. Functional limitations among home health care users in the National Health Interview Survey supplement on aging. *Gerontologist.* 1992;32(5):641–6.
- Rhee TG, Marottoli RA, Cooney LM Jr, Fortinsky RH. Associations of social and behavioral determinants of health index with self-rated health, functional limitations, and health services use in older adults. *J Am Geriatr Soc.* 2020;68(8):1731–8.
- Silva AMM, Mambrini JMV, Peixoto SV, Malta DC, Lima-Costa MF. Use of health services by Brazilian older adults with and without functional limitation. *Rev Saúde Pública.* 2017;51:55.
- Wang J, Kong D, Sun BC, Dong X. Health services utilization among Chinese American older adults: moderation of social support with functional limitation. *J Appl Gerontol.* 2020;39(5):481–9.
- Zhao D, Li J, Gao T, Sun J, Wang Y, Wang Q, et al. Do older adults with multimorbidity prefer institutional care than those without multimorbidity? The role of functional limitation. *BMC Geriatr.* 2022;22(1):126.
- Bayliss EA, Ellis JL, Steiner JF. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. *Annals Family Med.* 2007;5(5):395–402.
- Gwynn KB, Winter MR, Cabral HJ, Wolf MS, Hanchate AD, Henault L, et al. Racial disparities in patient activation: evaluating the mediating role of health literacy with path analyses. *Patient Educ Couns.* 2016;99(6):1033–7.
- Paasche-Orlow M. Caring for patients with limited health literacy: a 76-year-old man with multiple medical problems. *JAMA.* 2011;306(10):1122–9.
- Lewis M. Stepwise versus Hierarchical Regression: Pros and Cons. Online Submission. 2007.
- Wong GY, Mason WM. The hierarchical logistic regression model for multi-level analysis. *J Am Stat Assoc.* 1985;80(391):513–24.
- Tomioka K, Kurumatani N, Hosoi H. Positive and negative influences of social participation on physical and mental health among community-dwelling elderly aged 65–70 years: a cross-sectional study in Japan. *BMC Geriatr.* 2017;17:1–13.
- Wister AV. *Baby boomer health dynamics: how are we aging?* University of Toronto; 2005.
- Funk LM, Dansereau L, Novek S. Carers as system navigators: exploring sources, processes and outcomes of structural burden. *Gerontologist.* 2019;59(3):426–35.
- Brookman C, Holyoke P, Toscan J, Bender D, Tapping E. A guide to the promising practices and indicators for caregiver education and support programs. Markham, Ontario: Saint Elizabeth Health Care; 2011.
- Meyer K. Carers' experiences accessing information on supports and services: learning the social care dance. *Qualitative Social Work.* 2018;17(6):832–48.

48. Subramanian SV, Kim DJ, Kawachi I. Social trust and self-rated health in US communities: a multilevel analysis. *J Urb Health*. 2002;79:521–34.
49. Friedman EM, Trail TE, Vaughan CA, Tanielian T. Online peer support groups for family caregivers: are they reaching the caregivers with the greatest needs? *J Am Med Inform Assoc*. 2018;25(9):1130–6.
50. Donnellan WJ, Bennett KM, Soulsby LK. Family close but friends closer: exploring social support and resilience in older spousal dementia carers. *Aging Ment Health*. 2017;21(11):1222–8.
51. Lopez Hartmann M, De Almeida Mello J, Antheriens S, Declercq A, Van Durme T, Cès S, et al. Caring for a frail older person: the association between informal caregiver burden and being unsatisfied with support from family and friends. *Age Ageing*. 2019;48(5):658–64.
52. Sanders S. Experiences of rural male caregivers of older adults with their informal support networks. *J Gerontol Soc Work*. 2007;49(4):97–115.
53. Shiba K, Kondo N, Kondo K. Informal and formal social support and caregiver burden: the AGES caregiver survey. *J Epidemiol*. 2016;26(12):622–8.
54. Verbakel E, Metzelthin SF, Kempen GI. Caregiving to older adults: determinants of informal caregivers' subjective well-being and formal and informal support as alleviating conditions. *Journals Gerontology: Ser B*. 2018;73(6):1099–111.
55. Hargreaves S, Sbaifi L, Ford N. Information seeking amongst informal caregivers of people with dementia: a qualitative study. *J Doc*. 2023;79(2):281–300.
56. Peterson K, Hahn H, Lee AJ, Madison CA, Atri A. The Information Age, do dementia caregivers get the information they need? Semi-structured interviews to determine informal caregivers' education needs, barriers, and preferences. *BMC Geriatr*. 2016;16:1–13.
57. Washington KT, Meadows SE, Elliott SG, Koopman RJ. Information needs of informal caregivers of older adults with chronic health conditions. *Patient Educ Couns*. 2011;83(1):37–44.
58. Bauer JM, Sousa-Poza A. Impacts of informal caregiving on caregiver employment, health, and family. *J Popul Ageing*. 2015;8:113–45.
59. Penning MJ, Wu Z. Caregiver stress and mental health: impact of caregiving relationship and gender. *Gerontologist*. 2016;56(6):1102–13.
60. Rosenthal CJ, Martin-Matthews A, Keefe JM. Care management and care provision for older relatives amongst employed informal care-givers. *Ageing Soc*. 2007;27(5):755–78.
61. Zahed S, Emami M, Eslami AA, Barekatain M, Hassanzadeh A, Zamani-Alavijeh F. Stress as a challenge in promoting mental health among dementia caregivers. *J Educ Health Promotion*. 2020;9(1):65.
62. Zwar L, König H-H, Hajek A. Psychosocial consequences of transitioning into informal caregiving in male and female caregivers: findings from a population-based panel study. *Soc Sci Med*. 2020;264:113281.
63. Spiess CK, Schneider AU. Interactions between care-giving and paid work hours among European midlife women, 1994 to 1996. *Ageing Soc*. 2003;23(1):41–68.
64. Wakabayashi C, Donato KM. The consequences of caregiving: effects on women's employment and earnings. *Popul Res Policy Rev*. 2005;24:467–88.
65. Van Houtven CH, Coe NB, Skira MM. The effect of informal care on work and wages. *J Health Econ*. 2013;32(1):240–52.
66. Lee H, Vogel RI, LeRoy B, Zierhut HA. Adult adoptees and their use of direct-to-consumer genetic testing: searching for family, searching for health. *J Genet Couns*. 2021;30(1):144–57.
67. Swinkels J, Tilburg Tv, Verbakel E, Broese van Groenou M. Explaining the gender gap in the caregiving burden of partner caregivers. *Journals Gerontology: Ser B*. 2019;74(2):309–17.
68. Xiong C, Biscardi M, Astell A, Nalder E, Cameron JJ, Mihailidis A, et al. Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: a systematic review. *PLoS ONE*. 2020;15(4):e0231848.
69. Werner S, Shulman C. Subjective well-being among family caregivers of individuals with developmental disabilities: the role of affiliate stigma and psychosocial moderating variables. *Res Dev Disabil*. 2013;34(11):4103–14.
70. Unsar S, Erol O, Ozdemir O. Caregiving burden, depression, and anxiety in family caregivers of patients with cancer. *Eur J Oncol Nurs*. 2021;50:101882.
71. Xu L, Liu Y, He H, Fields NL, Ivey DL, Kan C. Caregiving intensity and caregiver burden among caregivers of people with dementia: the moderating roles of social support. *Arch Gerontol Geriatr*. 2021;94:104334.
72. Beach SR, Schulz R, Yee JL, Jackson S. Negative and positive health effects of caring for a disabled spouse: longitudinal findings from the caregiver health effects study. *Psychol Aging*. 2000;15(2):259.
73. Chang H-Y, Chiou C-J, Chen N-S. Impact of mental health and caregiver burden on family caregivers' physical health. *Arch Gerontol Geriatr*. 2010;50(3):267–71.
74. Ge L, Mordiffi SZ. Factors associated with higher caregiver burden among family caregivers of elderly cancer patients: a systematic review. *Cancer Nurs*. 2017;40(6):471–8.
75. Okabayashi H, Sugisawa H, Takanashi K, Nakatani Y, Sugihara Y, Hougham GW. A longitudinal study of coping and burnout among Japanese family caregivers of frail elders. *Aging Mental Health*. 2008;12(4):434–43.
76. Bull MJ, Bowers JE, Kirschling JM, Neufeld A. Factors influencing family caregiver burden and health. *West J Nurs Res*. 1990;12(6):758–76.
77. Charles L, Bremault-Phillips S, Parmar J, Johnson M, Sacrey LA. Understanding how to support family caregivers of seniors with Complex needs. *Can Geriatr J*. 2017;20(2):75–84.
78. Marriott A, Donaldson C, Tarrier N, Burns A. Effectiveness of cognitive-behavioural family intervention in reducing the burden of care in carers of patients with Alzheimer's disease. *Br J Psychiatry*. 2000;176(6):557–62.
79. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health effects Study. *JAMA*. 1999;282(23):2215–9.
80. Young KE, Young SE, Mi KY. Caregiver burden and health-related quality of life among stroke caregivers. *J Korean Public Health Nurs*. 2004;18(1):5–13.
81. Marengoni A, Angleman S, Melis R, Mangialasche F, Karp A, Garmen A, et al. Aging with multimorbidity: a systematic review of the literature. *Ageing Res Rev*. 2011;10(4):430–9.
82. Walker AE. Multiple chronic diseases and quality of life: patterns emerging from a large national sample, Australia. *Chronic Illn*. 2007;3(3):202–18.
83. Schäfer I, Hansen H, Schön G, Höfels S, Altiner A, Dahlhaus A, et al. The influence of age, gender and socio-economic status on multimorbidity patterns in primary care. First results from the multicare cohort study. *BMC Health Serv Res*. 2012;12:1–15.
84. Uijen AA, van de Lisdonk EH. Multimorbidity in primary care: prevalence and trend over the last 20 years. *Eur J Gen Pract*. 2008;14(sup1):28–32.
85. Hazzan AA, Dauenhauer J, Follansbee P, Hazzan JO, Allen K, Omobepade I. Family caregiver quality of life and the care provided to older people living with dementia: qualitative analyses of caregiver interviews. *BMC Geriatr*. 2022;22(1):86.
86. Morgan DG, Walls-Ingram S, Cammer A, O'Connell ME, Crossley M, Dal Bello-Haas V, et al. Informal caregivers' hopes and expectations of a referral to a memory clinic. *Soc Sci Med*. 2014;102:111–8.
87. Peel E, Harding R. It's a huge maze, the system, it's a terrible maze': Dementia carers' constructions of navigating health and social care services. *Dementia*. 2014;13(5):642–61.
88. Dawson S, Gerace A, Muir-Cochrane E, O'Kane D, Henderson J, Lawn S, et al. Carers' experiences of accessing and navigating mental health care for older people in a rural area in Australia. *Aging Ment Health*. 2017;21(2):216–23.
89. Kodner DL. All together now: a conceptual exploration of integrated care. *Healthc Q (Toronto Ont)*. 2009;13:6–15.
90. Montenegro H, Holder R, Ramagem C, Urrutia S, Fabrega R, Tasca R, et al. Combating health care fragmentation through integrated health service delivery networks in the Americas: lessons learned. *J Integr Care*. 2011;19(5):5–16.
91. Scharlach AE, Graham CL, Berridge C. An integrated model of co-ordinated community-based care. *Gerontologist*. 2015;55(4):677–87.
92. Wister A, Li L, Mitchell B, Wolfson C, McMillan J, Griffith LE, et al. Levels of depression and anxiety among informal caregivers during the COVID-19 pandemic: a study based on the Canadian longitudinal study on aging. *Journals Gerontology: Ser B*. 2022;77(9):1740–57.
93. Wister A, Li L, Whitmore C, Ferris J, Klasa K, Linkov I. Multimorbidity resilience and health behaviors among older adults: a longitudinal study using the Canadian longitudinal study on aging. *Front Public Health*. 2022;10:896312.

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