Original Research Article

Predictors of Decision Regret among Caregivers of Older Canadians Receiving Home Care: A Cross-Sectional Online Survey

Tania Lognon, Amédé Gogovor⑩, Karine V. Plourde⑩, Paul Holyoke, Claudia Lai, Emmanuelle Aubin, Kathy Kastner, Carolyn Canfield, Ron Beleno, Dawn Stacey⑩, Louis-Paul Rivest, and France Légaré⑩

Abstract

Background. In Canada, caregivers of older adults receiving home care face difficult decisions that may lead to decision regret. We assessed difficult decisions and decision regret among caregivers of older adults receiving home care services and factors associated with decision regret. **Methods.** From March 13 to 30, 2020, at the outbreak of the COVID-19 pandemic, we conducted an online survey with caregivers of older adults receiving home care in the 10 Canadian provinces. We distributed a self-administered questionnaire through Canada's largest and most representative private online panel. We identified types of difficult health-related decisions faced in the past year and their frequency and evaluated decision regret using the Decision Regret Scale (DRS), scored from 0 to 100. We performed descriptive statistics as well as bivariable and multivariable linear regression to identify factors predicting decision regret. **Results.** Among 932 participants, the mean age was 42.2 y (SD = 15.6 y), and 58.4% were male. The most frequently reported difficult decisions were regarding housing and safety (75.1%). The mean DRS score was 28.8/ 100 (SD = 8.6). Factors associated with less decision regret included higher caregiver age, involvement of other family members in the decision-making process, wanting to receive information about the options, and considering organizations interested in the decision topic and health care professionals as trustworthy sources of information (all $P < 0.001$). Factors associated with more decision regret included mismatch between the caregiver's preferred option and the decision made, the involvement of spouses in the decision-making process, higher decisional conflict, and higher burden of care (all $P < 0.001$). **Discussion.** Decisions about housing and safety were the difficult decisions most frequently encountered by caregivers of older adults in this survey. Our results will inform future decision support interventions.

Corresponding Author

France Légaré, VITAM – Centre de recherche en santé durable, 2480, Chemin de la Canardière, Quebec, QC, G1J 2G1, Canada;
france.legare@fmed.ulaval.ca.

Highlights

- This is one of the first studies to assess decision regret among caregivers of older adults receiving home and community care services and to identify their most frequent difficult decisions.
- Difficult decisions were most frequently about housing and safety. Most caregivers of older adults in all 10 provinces of Canada experienced decision regret.
- Factors associated with less decision regret included higher caregiver age, the involvement of other family members in the decision-making process, wanting to receive information about the options, considering organizations interested in the decision topic, and health care professionals as trustworthy sources of information. Factors associated with more decision regret included mismatch between the caregiver's preferred option and the decision made, the involvement of spouses in the decision-making process, higher decisional conflict, and higher burden of care.

VITAM – Centre de recherche en santé durable, Quebec, QC, Canada (TL, AG, KVP, FL); Tier 1 Canada Research Chair in Shared Decision Making and Knowledge Translation, Université Laval, Quebec, QC, Canada (TL, AG, KVP, CL, FL); Research Center CHU de Québec, Université Laval, Quebec, QC, Canada (TL, AG, KVP, FL); Health and Social Services Systems, Knowledge Translation and Implementation component of the Quebec SPOR-SUPPORT Unit, Quebec, QC, Canada (AG); SE Research Centre, SE Health, Markham, ON, Canada (PH); Caregiver Partner, Canada (EA, KK, CC, RB); Faculty of Health Sciences, School of Nursing, University of Ottawa, Ottawa, ON, Canada (DS); Ottawa Hospital Research Institute, Patient Decision Aids Research Group, Clinical Epidemiology Program, Ottawa, ON, Canada (DS); Tier 1 Canada Research Chair in Statistical Sampling and Data Analysis, Université Laval, Quebec, QC, Canada (LPR); Faculty of Sciences and Engineering, Department of Mathematics and Statistics, Université Laval, Quebec, QC, Canada (LPR); Department of Family Medicine and Emergency Medicine, Université Laval, Quebec, QC, Canada (FL). The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article. The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Financial support for this study was provided entirely by a Foundation Grant (No. FDN-159937) from the Canadian Institutes of Health Research (CIHR). The funding agreement ensured the authors' independence in designing the study, interpreting the data, writing, and publishing the report. FL holds a Tier 1 Canada Research Chair in Shared Decision Making and Knowledge Translation. LPR holds a Tier 1 Canada Research Chair in Statistical Sampling and Data Analysis. AG is funded by a CIHR Patient-Oriented Research fellowship. The funders are not involved in the project.

Background

In Canada, people aged 65 y or older (older adults) have outnumbered children younger than 14 y since 2016.[1,2] The need for health services and independence support services provided at home will thus increase significantly because of the burden of chronic conditions and loss of personal autonomy. The current trend in Canadian health services is to promote aging at home for as long as possible and especially since 2020–2021, when long-term care facilities were disproportionately affected by COVID-19. Canada had the highest proportion of deaths in long-term care of all Organisation for Economic Co-operation and Development countries.[3–6]

Aging at home will require improving home and community care services (henceforth referred to as "home care") for older adults. Home care services are public and private services delivered in people's homes (including in seniors' private residences) by regulated health and social care professionals (e.g., nurses, dietitians, social workers) and nonregulated workers (e.g., personal support workers).[7] The goal is to help people stay at or return home and receive needed treatment, rehabilitation, or palliative care.

However, even in households already receiving home care services, informal caregivers provide much of the

care. In 2018, 25% of Canadians aged 15 y and older defined themselves as caregivers, and 40% of people receiving home care services were older adults. Nearly 9 of 10 care recipients received care from family or friends.[1,8,9] Caregivers provide practical help in daily living activities and also help with complex medical and nursing tasks that elsewhere are performed by trained professionals.[9] Caregivers may thus be involved in difficult decisions, with or on behalf of a dependent older adult, related to their health and social care.[10] We have little information about the proportion of caregivers who are routinely involved in decisions, but in a systematic review on caregivers of older adults, the caregivers indicated that there are gaps in the support they receive for making informed decisions and that these gaps lead to negative emotions, including decision regret.[10]

Decision regret is a negative emotion experienced when one realizes or imagines that the current situation would have been better if a decision made in the past had been different.[11,12] A study evaluating regret compared with other emotions (e.g., love, shame, guilt, fear) concluded that people put much more emphasis on regret than on other negative emotions.[13] Indeed, one study found that regret was the most common emotion in daily life.[14] Inadequate decision-making processes often precipitate expressions of regret,[15,16] and regret, in turn, may translate into negative outcomes such as lower satisfaction with treatment, complaints, and a reduced quality of life.[17–19] Some studies show links between decision regret among caregivers and decision-making processes such as being clear about values, playing the role desired in the decision making, sharing decision making, and feeling informed and supported.[20,21] Other factors associated with regret were caregiver characteristics (e.g., age, civil status, level of education), decisional conflict, burden of care, and caregiver role.[18,22] Regarding the kind of decisions caregivers may regret, numerous studies show caregiver regret as associated with end-of-life decisions[23–27] and decisions about housing.[20,28] However, none of these studies focused exclusively on caregivers of older people receiving home care services.

In the context of home care, identifying decisions caregivers consider most difficult and measuring decision regret and the factors that influence regret could help determine whether existing programs meet decision-making needs, establish priorities, and develop new programs.[29]

For home care clients and their caregivers, the most difficult decisions can change, not only because of changing health status but also external circumstances. During the COVID-19 pandemic, caregivers faced unprecedented challenges when they found they were no longer able to provide care for their loved one at home.[9,30,31] In planning a decision to move them into a seniors' residence, they had to consider that residents were dying or were confined to their rooms and allowed no visitors. In fact, many caregivers moved their loved ones back into their own homes if they were able to.[9,32,33]

Informed by an adapted conceptual framework (Figure 1) and the literature on predictors of regret, we hypothesized that higher decisional conflict, higher burden of care, unfavorable socioeconomic characteristics, and lower caregiver age would be associated with more decision regret.[15,18,22]

Therefore, we aimed to identify the most frequent difficult decision caregivers had to make for older adults receiving home care services, measure decision regret, and identify factors associated with decision regret.

Methods

Study Design

We conducted a cross-sectional online survey across the 10 Canadian provinces of adults who identified themselves as caregivers of older adults who had received home care services in the past year.

We report the results according to the Checklist for Reporting Results of Internet E-Surveys (CHERRIES).[34] This project is part of the initial phase of a 7-y program, funded by a Canadian Institutes for Health Research peer-reviewed grant, whose overarching goal is to ensure that more Canadian older adults receiving care at home and their caregivers become fully engaged as partners in their care.[35]

Participants and Recruitment

We used a pan-Canadian Web panel (Leger Marketing) to conduct our survey. With 400,000 individuals from the 10 provinces (the 3 territories are excluded from the sampling frame), the Leger Marketing panel is the largest Canadian online panel representative of the Canadian population.[36] To ensure the quality of the panel, Leger Marketing uses several internal control measures such as a double-consent process and regular update of panelist profiles every 6 mo. For this voluntary survey, a nonprobability sampling method was used to invite 97,568 panelists aged 18 y and older (that year) to participate. Eligible participants were caregivers of older adults receiving or having received home care services over the past year. Ethical approval was obtained from the Research Ethics Board of the Integrated University Health and Social
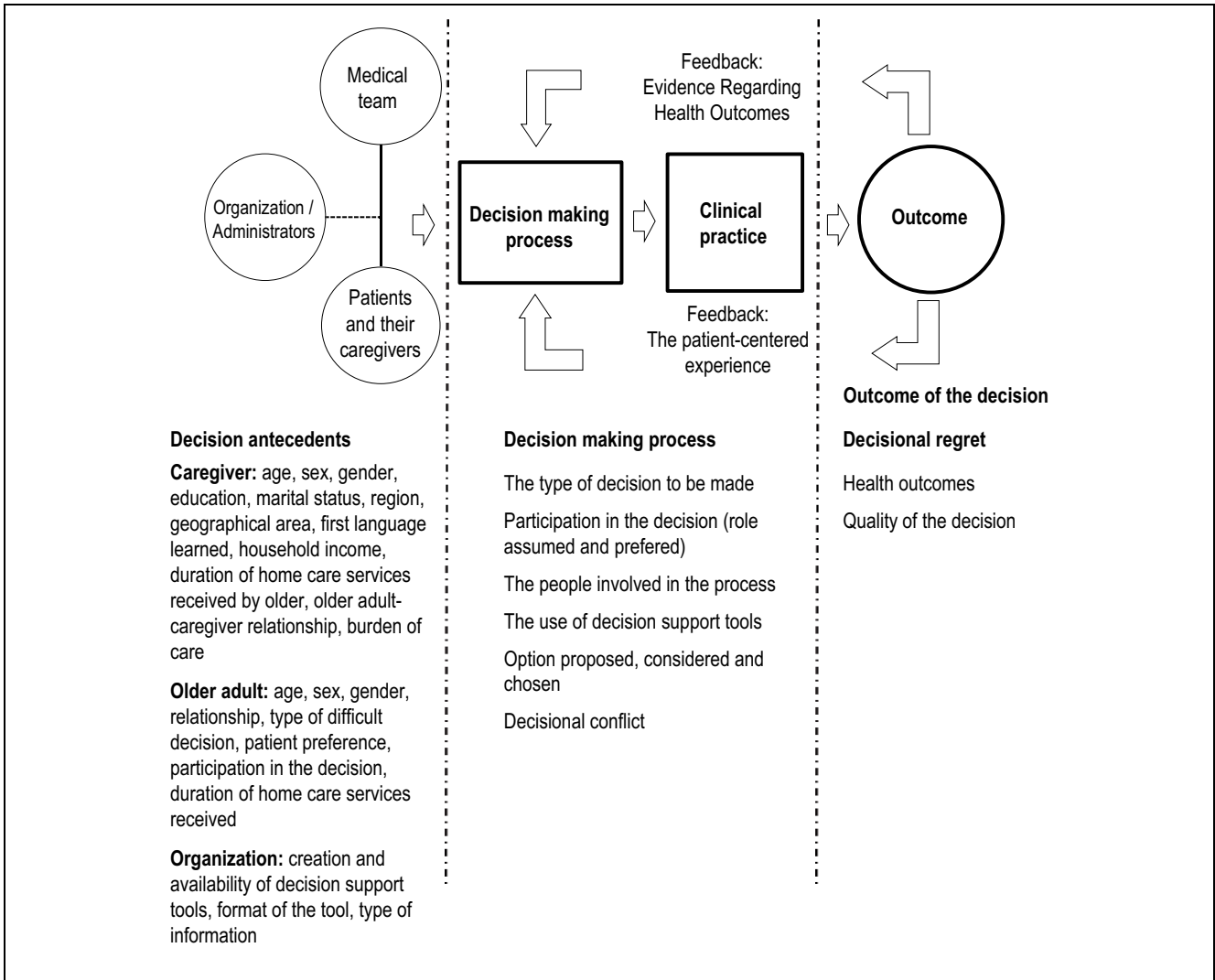
Figure 1 Conceptual framework of shared decision making with caregivers of older adults receiving home care, adapted from Sepucha and Mulley.[15]

Services Center of the Capitale-Nationale, Quebec, Canada. Consent to participate in the study was indicated by answering the question at the beginning of the survey. All information collected in this survey remains confidential, anonymous, and will be used only for scientific purposes. Data are stored on secure servers.

Measures

We adapted a self-administered questionnaire to identify the most difficult decision and the decision regret of caregivers of older adults receiving home care as well as other characteristics of the decision-making process

(Figure 1) potentially associated with regret such as information format and trusted sources of information (see Appendix 1, Questionnaire). The questionnaire also included 4 validated scales for measuring regret, decisional conflict, burden of care, and preferred decision-making role.[17,37–40] The questionnaire was based on the Ottawa Decision Support Framework,[41] the Decisional Needs Assessment in Populations Workbook,[29] and a conceptual framework for shared decision making adapted from a framework by Sepucha and Mulley.[15] The latter framework presents 3 phases of decision making: decision antecedents, decision-making processes, and decision outcomes. We adapted the framework by

applying these phases to the theoretical relationship between health care professionals, older adults, and caregivers during the process of shared decision making in the context of home care (Figure 1). We also used the framework to formulate hypotheses about factors that might be associated with decision regret among family caregivers of older adults receiving home care.

We considered as decision antecedents the sociodemographic characteristics of caregivers that could influence the decision-making process and their choices when faced with difficult decisions. The study questionnaire included 11 sociodemographic variables.

To identify difficult decisions for caregivers of older adults, we consulted a preliminary study conducted with older adults and caregivers within a large Canadian home and community care organization as well as expert opinion.[42] Based on these data, we proposed a list of 15 potentially difficult decisions faced by older adults and their caregivers over the past year. From these, caregivers were asked to select the most difficult decision they had made regarding their relative during the past year, such as, "Should my relative stay at home or move?" (e.g., nursing home, family member's home, private senior's residence) or "Should my relative get surgery or not?" (see Appendix 1, Questionnaire).

Decision regret was measured using the validated Decision Regret Scale (DRS).[19] This scale consists of 5 items, each with a Likert-type response scale ranging from 1 = *strongly agree* to 5 = *strongly disagree*.[17,19] The respondent must indicate agreement or disagreement with the following statements by choosing what best corresponds to their opinion as a result of a decision made: 1) It was the right decision, 2) I regret the choice that was made, 3) I would go for the same choice if I had to do it over again, 4) The choice did me a lot of harm, and 5) This decision was a wise one. To obtain a score, scores from items 2 and 4 are reversed, all items are summed, and the total is divided by 5. To ease interpretation, the global score is converted to a 0 to 100 scale (0 = no regret to 100 = high regret) by subtracting 1 from each item and multiplying by 25. The items are summed and the mean calculated. Scores thus ranged from 0 (no regret) to 100 (high regret). The literature suggests that a DRS score of 1 to 25 is mild, and a score of greater than 26 is moderate to strong.[18,43–45] However, there is currently no consensus on cutoff points for the scale and no guideline to indicate what scores should be considered clinically significant.[18,44] DRS has good internal psychometric properties (Cronbach α = 0.76) and correlates with decision satisfaction, decision conflict, and the overall quality of life.[17,19]

In accordance with our conceptual framework, we assessed other variables with 3 other scales and items (Appendices 1 and 2):

1. Decisional conflict: uncertainty about what to do when choosing among options. Items relate to discomfort with the decision to be made, questioning personal life values, uncertainty, feeling uninformed, feeling unclear about personal values, and feeling unsupported in decision making. Decisional conflict was measured using the multidimensional validated Decision Conflict Scale (DCS), 16 items rated on a 5-point scale (*strongly agree*, *agree*, *neither agree nor disagree*, *disagree*, and *strongly disagree*). The DCS score ranges from 0 to 100. Scores lower than 25 are associated with implementing decisions, and scores exceeding 37.5 are associated with decision delay or feeling unsure about implementation.

2. Burden of care among caregivers: caregiver's perception of activities performed for the older adult and emotions connected with these tasks. It is measured using the validated 22-item Zarit Burden Interview scale (ZBI). Questions are evaluated using 5 statements with 4 possible responses (0 = *never*, 1 = *rarely*, 2 = *sometimes*, 3 = *quite often*, 4 = *almost always*). For each question, respondents are asked how often they feel this way. The total score represents the sum of the scores obtained for all 22 items, ranging from 0 to 88. A score ≤ 20 indicates little or no burden, a score between 21 and 40 indicates a light burden, a score between 41 and 60 indicates a moderate burden, and a score >60 indicates a severe burden. In addition, the multidimensional ZBI reveals 3 dimensions of the burden on caregivers: the direct impact of caregiving on the lives of caregivers and feelings of guilt and frustration (or embarrassment).[46,47]

3. Participation in the decision: the people involved in the decision, the caregiver's preferred decision-making role, and the role they assumed in the decision making was measured using the validated Preference Control Scale (a 5-point response scale).[48,49]

Questionnaire Administration

The final questionnaire (available on request) was pretested with a random sample of 13 eligible panelists before data collection began. From March 13 to 30, 2020, we conducted a cross-sectional survey (coinciding with the beginning of a COVID-19 lockdown in most of

the country). A unique URL link to the closed survey was sent by email to participants, allowing them to access the survey in English or French. Respondents logged in using their panel member account, which allows only 1 validation per member to prevent duplication. The questions appeared in the same order for all participants: there was no randomization of questions or alternations. Participants had to answer all the questions on one page to move to the next one and had to click on the "Finish" button on the last page to validate their answers. Each page included a "Back" button to change the answer and a button with a list of older adult helplines for each province. There was no summary of participants' responses asking if they wished to correct them. The survey was voluntary, and $1 compensation was offered to participants.

Sample Size

Web surveys typically have a response rate that varies from 10% to 20%, depending on the respondents' occupations.[50–53] The average response rate among the active Leger panelists was around 20%, and ours was approximately 52%. The sample size was estimated using the central limit theorem formula $n = \left(\frac{z^{\alpha}/_{2} \cdot \sigma}{margin\ error}\right)^{2}$.[54] We based our sample size on calculations for a similar study by our group measuring the same outcome, decision regret, among caregivers.[16] A median decision regret score of 10 on a 100-point scale with a standard deviation of 19.5 was determined. To be able to detect a target margin of error of 1.25 with z-score of 1.96 and an alpha threshold of 5%, a minimum of 935 participants was required for the survey. The estimated power of our analysis was 95%. The survey was closed when the target sample of eligible participants with completed questionnaires was reached.

Data Analysis

First, the variables of age, decisional conflict, and burden of care were analyzed as continuous variables. The other independent variables were analyzed as categorical variables. After discussion, authors chose to organize the difficult decisions into 3 categories for statistical analysis with the DRS: housing and safety, management of health conditions, and end-of-life. Housing and safety were grouped together, as housing decisions are often provoked by safety concerns at home, the need for supervision in case of falls, or the older person's inability to take care of himself or herself in the judgment of their families

or home care staff.[55–57] We also grouped them together as they are not necessarily medical decisions, unlike decisions about medication or pain management, for example. We used descriptive statistics to summarize the variables. For the DRS, DCS, and ZBI, we verified internal consistency by calculating Cronbach alphas. We performed the Kolmogorov–Smirnov test to evaluate the distribution of DRS scores and other variables and verify the postulate of normality.[58] The DRS was analyzed as a continuous variable using general linear models. This is common in studies whose principal outcome is evaluating decisional regret.[18] A continuous scale allows a better understanding of the event, and the statistical treatment of the continuous variable is respected.

Regression modeling included only participants with complete data on all potential factors. The "prefer not to answer" choice for the variables was considered as missing data for simple and multiple regression analyses. Simple linear regressions with decisional regret as outcomes were performed for each independent variable. Variables estimated as significant (i.e., $P < 0.20$) in the bivariable linear regression models were entered in the multivariable linear regression model.[59,60] Factors associated with decision regret were identified using a stepwise selection[61] based on Schwarz's Bayesian information criterion.[62] Correlations were performed between the variables. All analyses were performed using SAS.[63]

Results

Characteristics of Participants

A total of 932 participants completed the survey (Figure 2). The view rate (ratio of unique survey visitors/ unique receiver of survey invitation) was 13.6%, the participation rate (ratio of users who agreed to participate/ unique survey visitors) was 8.6%, and the completion rate (ratio of users who completed the survey/users who agreed to participate) was 82.2% (Figure 2). The mean time to complete the questionnaire was 15:13 min, and the median time was 10:17 min. No data were missing, as the Web-based questionnaire did not accept unanswered items.

Most participants were male (58.4%), and their mean (SD) age was 42.2 (15.6) y (Table 1). Most were Caucasian (68.1%), university educated (59.9%), legally married (48.3%), and lived in central Canada (65.5%). The most common relationship of caregivers to the older adults in their care was child–mother (34%). Most caregivers had assumed an active role in the decision-making process ($n = 858$, 92.1%) and preferred to play an active role in the future ($n = 865$, 92.8%; Table 2). Also, 389
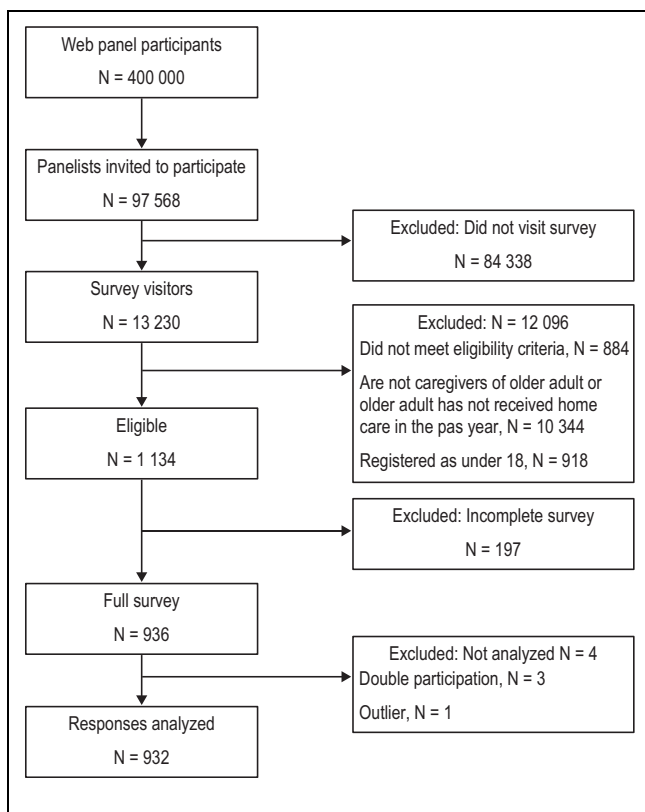
Figure 2 Flow chart of participant recruitment.

participants (41.8%) felt a moderate to severe burden of care when taking care of their relative (Table 2).

Of the 198 eligible participants who did not complete the questionnaire, only 45 gave their consent and answered the sociodemographic questions. Of the 45 withdrawn participants, 73.2% were women, with an average (SD) age of 47.7 (15.9) y. Their sociodemographic characteristics were similar to those of the participants: mostly Caucasian, university educated, English as the first language learned, coming from central Canada, and caring for their mother. Most participants who did not complete the questionnaire or dropped out of the study without giving their consent were women and people with a low level of education.

Difficult Decisions

The 3 most frequently reported difficult decisions over the past year were "should my relative stay at home or move?" (*n* = 326, 35.0%), "what is the best option for my relative for staying safe at home?" (*n* = 142, 15.2%),

and "what is the best option for my relative for preventing falls?" (*n* = 97, 10.4%; Table 3). All 3 related to the category of housing and safety. The frequencies of the most difficult decisions reported per category were 75.1% relating to housing and safety, 13.2% relating to management of health conditions, and 9.4% relating to end of life. "Other" decisions (2.3%) related to a variety of themes (data available on request).

Decision Regret

The DRS showed a Cronbach's coefficient of 0.76. DRS scores ranged from 0 to 100. The mean (SD) DRS score was 28.8 of 100 (18.6), and the median was 30.0 (Table 2). Of the 932 caregivers, 134 (14.4%) reported no decision regret (DRS scores of 0), whereas 798 (85.6%) reported some level of decision regret. More than half of participants (*n* = 503, 54.0%) experienced moderate to strong regret, with DRS scores greater than 25. Among the 3 categories, decisions relating to end of life had the highest mean (SD) decisional regret score (30.2 [18.1]), followed by those relating to housing and safety (28.7 [18.6]) and to the management of health conditions (28.3 [17.5]). Among all 3 categories, the decision with the highest mean decision regret score was "what is the best option for advance care planning?" (31.7 [14.2]; Table 3). Those identified as "other" difficult decisions had a higher mean decision regret score (32.4 [24.1]).

Factors Associated with Decision Regret

Factors significantly associated with decision regret when examined individually in bivariable linear regression with the statistical significance threshold of $P > 0.20$ are shown in Appendix 3. Analyses showed no collinearity between decision regret and other variables. Factors associated with less decision regret included higher caregiver age ($P < 0.001$), the involvement of other family members in the decision-making process ($P = 0.005$), wanting to receive information about the options ($P < 0.001$), considering organizations interested in the decision topic ($P = 0.001$), and health care professionals as trustworthy sources of information ($P < 0.001$). Factors associated with more decision regret included mismatch between the caregiver's preferred option and the decision made ($P < 0.001$), the involvement of spouses in the decision-making process ($P = 0.001$), higher decisional conflict ($P < 0.001$), and higher burden of care ($P < 0.001$; Table 4). Contrary to one of our hypotheses, lower socioeconomic status was not associated with more decision regret.

Table 1 Caregivers' Sociodemographic Characteristics ($N = 932$)

Sociodemographics Characteristics[a]		n (%)[b]
Age, y	Mean (SD)	42.2 (15.6)
	Median (IQR)	40.0 (25)
Sex	Male	544 (58.4)
	Female	385 (41.3)
	Prefer not to say	3 (0.3)
Gender	Male	527 (56.5)
	Female	397 (42.6)
	Another gender	4 (0.4)
	Prefer not to say	4 (0.4)
Level of education	Less than a high school diploma	23 (2.5)
	High school	129 (13.8)
	College	220 (23.6)
	University	558 (59.9)
	Prefer not to say	2 (0.2)
Ethnicity	Caucasian	635 (68.1)
	Non-Caucasian	252 (27.0)
	North American Indigenous	23 (2.5)
	Prefer not to say	22 (2.4)
First language learned	English	633 (67.9)
	French	167 (17.9)
	An Indigenous language	3 (0.3)
	Other language	129 (13.8)
Region	Western Canada	281 (30.2)
	Central Canada	610 (65.5)
	Atlantic region	41 (4.4)
Geographical area	Rural	73 (7.8)
	Urban	859 (92.2)
Household size	Average (SD)	3 (1.4)
	Median (IQR)	3.00 (2)
Marital status	Never legally married	282 (30.3)
	Legally married	450 (48.3)
	Separated, but still legally married	20 (2.1)
	Divorced	50 (5.4)
	Widowed	19 (2.0)
	Living common law	95 (10.2)
	Prefer not to say	16 (1.7)
Household income ($CAD)	<50,000	217 (23.3)
	50,000–59,999	110 (11.8)
	60,000–79,999	167 (17.9)
	80,000–99,999	149 (16.0)
	≥100,000	232 (24.9)
	Prefer not to say	57 (6.1)
Older adult–caregiver relationship	Wife/husband or common-law partner	107 (11.5)
	Mother	317 (34.0)
	Father	182 (19.5)
	Another member of your family	252 (27.0)
	Friend	50 (5.4)
	Other	24 (2.6)
Duration of home care services received by older adult	Short term (a few days or weeks)	522 (56.0)
	Long term (≥6 mo)	410 (44.0)

[a]Values are reported as mean (SD) for continuous variables and number (%) for categorical variables.
[b]Due to rounding errors, percentages in the row may not add up to 100%.

Table 2 Distribution of Decision Regret Scores and Characteristics of the Process of Shared Decision Making ($N = 932$)

Process of Shared Decision Making[a]		*n* (%)[b,c]
Decision regret, scale range 0–100	Mean (SD)	28.8 (18.6)
	Median (IQR)	30.0 (30.0)
Decision regret in 3 categories	0: No regret	134 (14.4)
	1 to 25: Mild regret	295 (31.7)
	≥25: Moderate to strong regret	503 (54.0)
Difficult decision	Housing and safety	700 (75.1)
	Management of conditions	123 (13.2)
	End-of-life	88 (9.4)
	Other	21 (2.3)
Decision made matches caregiver's preferred option	Yes	739 (79.3)
People involved in decision making		
Husband/wife	Yes	386 (41.4)
Child	Yes	189 (20.3)
Other family member	Yes	273 (29.3)
Friends	Yes	84 (9.0)
Alone	Yes	171 (18.3)
Other	Yes	28 (3.0)
Caregiver's assumed role in the decision-making process	My relative and I made the decision alone	309 (33.2)
	My relative and I made the decision alone but considered the opinion of the health care providers	333 (35.7)
	The health care providers, my relative, and I decided together, equally	216 (23.2)
	The health care providers made the decision but considered our (my relative's and mine) opinion	51 (5.5)
	The health care providers made the decision alone	23 (2.5)
Caregiver's assumed role	Active	858 (92.1)
	Passive	74 (7.9)
Caregiver's preferred role in the decision-making process	My relative and I would make the decision alone	304 (32.6)
	My relative and I would make the decision alone but considered the opinion of the health care providers	310 (33.3)
	The health care providers, my relative, and I would decide together, equally	251 (26.9)
	The health care providers would make the decision but consider our (my relative's and mine) opinion	44 (4.7)
	The health care providers would make the decision alone	23 (2.5)
Caregiver's preferred role	Active	865 (92.8)
	Passive	67 (7.2)
Match between decision-making role assumed and preferred	Preferred = assumed	855 (91.7)
	Assumed passive-active preferred	42 (4.5)
	Assumed active-passive preferred	35 (3.8)

(continued)

Table 2 (continued)

Process of Shared Decision Making[a]		n (%)[b,c]
Decisional Conflict Scale, range 0–100	Mean (SD)	27.0 (16.4)
	Median (IQR)	25 (23.4)
Burden of care scale, range 0–88	Mean (SD)	35.7 (16.8)
	Median (IQR)	37 (22.5)
	Little or no burden	179 (19.2)
	Light burden	364 (39.1)
	Moderate burden	323 (34.7)
	Severe burden	66 (7.1)
Formal home care support received by older adults		
Personal care	Yes	445 (47.7)
Medical treatments	Yes	398 (42.7)
Scheduling or coordinating care-related tasks	Yes	203 (21.8)
Food preparation, washing up, cleaning, laundry, or sewing	Yes	260 (27.9)
Maintenance of the house or exterior work	Yes	218 (23.4)
Transport to go shopping or to medical appointments or social events	Yes	193 (20.7)
Physiotherapy	Yes	193 (20.7)
Training and adaptation	Yes	84 (9.0)
None	Yes	78 (8.4)
Other	Yes	19 (2.0)
Information desired for future decisions		
The difficult decision	Yes	385 (41.3)
Options of the decision	Yes	542 (58.2)
The best available data on the decision	Yes	317 (34.0)
What others think or recommend about the decision	Yes	211 (22.6)
Information about the decision that relates to your values	Yes	195 (20.9)
Other information	Yes	22 (2.4)
Preferred format of information	Paper-based documents (booklets or pamphlets, newspapers, magazines)	169 (18.1)
	Personal communication with healthcare provider or relatives	304 (32.6)
	Multimedia (videos/DVDs, internet, television, radio)	392 (42.1)
	Discussion groups (with other persons including online discussions and social networks, information sessions in your community)	55 (5.9)
	Other	12 (1.3)
Information sources considered trustworthy		
Organizations interested in the decision topic	Yes	352 (37.8)
Health care professionals	Yes	673 (72.2)
Government agencies	Yes	361 (38.7)
Health care insurance companies	Yes	127 (13.6)
Consumer or patient associations	Yes	188 (20.2)
Nonprofit companies	Yes	164 (17.6)
Other	Yes	11 (1.2)

[a]Values are reported as mean (SD) for continuous variables and number (%) for categorical variables.
[b]Due to rounding errors, percentages in the row may not add up to 100%.
[c]All participants who did not reply with "yes" as displayed replied with "no." "No" answers are not displayed.

Table 3 Descriptive Statistics of Decision Points (*N* = 932)

	Difficult Decision	***n* (%)**	**Regret Mean (SD)**
Housing and safety *n* = 700 (75.1) Regret mean (SD) = 28.7 (8.6)	Should my relative stay at home or move? (e.g., nursing home, family member's home, private senior's residence)	326 (35.0)	29.5 (18.8)
	What is the best option for my relative to stay safe at home? (e.g., adapt or retrofit his home, use an assistive device, get extra help at home)	142 (15.2)	29.0 (18.7)
	What is the best option for my relative to prevent falls? (e.g., wheelchair, walker, chair lift, portable potty)	97 (10.4)	29.6 (17.2)
	What is the best option for my relative to seek immediate care? (e.g., call ambulance, go to the emergency room, call his doctor)	50 (5.4)	27.8 (20.8)
	Should my relative seek assistance with day-to-day activities or not?	43 (4.6)	26.3 (19.3)
	Should my relative stop driving his/her car or not?	42 (4.5)	22.0 (16.9)
Management of health conditions *n* = 123 (13.2) Regret mean (SD) = 28.3 (17.5)	Should my relative get surgery or not?	39 (4.2)	30.9 (18.1)
	What is the best option for my relative to manage his/her health condition(s)? (e.g., accept supplement treatments, change his level of care, accept to be hospitalized, go for tests)	39 (4.2)	27.3 (16.0)
	What is the best option for his/her pain management? (e.g., analgesics, marijuana, physiotherapy)	26 (2.8)	27.5 (19.8)
	Should my relative take medication or not?	19 (2.0)	25.8 (16.3)
End of life *n* = 88 (9.4) Regret mean (SD) = 30.2 (18.1)	What is the best option for my relative's advance care planning? (e.g., discuss with the doctor, discuss with the family and relatives)	23 (2.5)	31.7 (14.2)
	Should my relative be resuscitated/intubated or not?	22 (2.4)	29.5 (18.5)
	Should my relative choose a palliative approach to care or not?	17 (1.8)	29.7 (17.6)
	What is the best option for my relative's location of death (e.g., hospital, at home, palliative care residence)?	14 (1.5)	31.1 (24.4)
	Should my relative choose medical assistance in dying or not?	12 (1.3)	27.9 (19.4)
Other *n* = 21 (2.3) Regret mean = 32.4 (24.1)	Other (data available on request)	21 (2.3)	32.4 (24.1)

Discussion

We identified difficult decisions, measured decision regret, and identified factors associated with decision regret among caregivers who had made decisions for older adults receiving home care in all 10 provinces of Canada. Housing and safety decisions were the most frequently reported as most difficult. More than half of participants reported moderate to strong regret, with end-of-life decisions showing the highest level of regret. The factors associated with most regret were mismatch between the caregiver's preferred option and the decision made, the involvement of spouses in the decision-making process, higher decisional conflict, and higher burden of care. The factors associated with the least regret were higher caregiver age, the involvement of other family members, wanting to receive information about the

Table 4 Multivariable Factors Associated with Decision Regret among Caregivers of Older Adults Receiving Home Care Based on Stepwise Selection with Schwarz's Bayesian Information Criterion ($N = 932$)[a]

Selected Variable	β	Standard Error	95% CI	$P > F$
Age	−0.23	0.03	(−0.29; −0.17)	<0.001
Decisional conflict	0.40	0.03	(0.34; 0.46)	<0.001
Burden of care	0.20	0.02	(0.14; 0.26)	<0.001
Decision made matches preferred option				<0.001
No	8.90	1.16	(6.63;11.17)	<0.001
Yes	Ref			
People involved in decision making				
Other family member				0.005
Yes	−3.07	1.10	(−5.22; −0.92)	0.005
No	Ref			
Husband/wife				0.001
Yes	3.20	0.98	(1.27; 5.13)	0.001
No	Ref			
Information desired for future decisions				
Information about options of the decision				<0.001
Yes	−3.40	0.95	(−5.27; −1.53)	<0.001
No	Ref			
Information sources considered reliable				
Organizations interested in this kind of difficult decision				0.001
Yes	−3.15	0.96	(−5.04; −1.26)	0.001
No	Ref			
Health professionals				< 0.001
Yes	−5.81	1.09	(−7.94; −3.67)	< 0.001
No	Ref			

[a]The estimates β for each covariate and its 95% CI are presented. β = mean difference; CI = confidence interval. Adjusted R^2 = 43.44%.

options, and considering organizations interested in the decision topic and health care professionals as reliable information sources. These results led us to make the following observations.

First, to the best of our knowledge, this is among the first studies focusing exclusively on caregivers of older adults receiving care at home to identify which decisions they most frequently experience as difficult. Under the category of housing and safety, decisions about moving, home safety, and fall prevention were most frequently reported. Decisions about social determinants of health such as those associated with housing and safety clearly superseded more biomedical decisions such as those about drugs and tests. Having to leave one's home can be a highly distressing experience of loss and displacement.[16,64–68] A systematic review found that the experience of falls and feelings of insecurity or fear were among the factors influencing housing decisions among frail older adults.[57] It is worth noting that as this survey was rolled out at the end of March 2020, it is likely that our results were affected by the COVID-19 pandemic. In Canada, the difficulty in making decisions about housing and safety was compounded by the fact that in 2020, more than half of all COVID-19–related deaths were nursing home residents.[3,4] During the pandemic, 2 decision aids designed to support families making decisions about moving their relative were downloaded more than 10,000 times in 3 wk, indicating the urgent need for effective decision support in this area.[69] As the COVID-19 experience may propel an increase in preference for aging at home rather than in nursing homes or private senior residences, decisions about safety at home will only increase in importance.[56] Caregivers should be kept up to date on new options to help older adults stay safe.[56] This would allow them to better address the issue of safety and make informed decisions.[55,56]

Second, in our study, the average score of caregiver decision regret (28.8) was slightly higher than in other studies on decision regret among caregivers (12.5).[20,22] Previous studies focused on different populations such as future mothers, caregivers of children, caregivers of adults, and older adults with a loss of autonomy. Also, other studies have mostly only dealt with one decision at a time, while our analysis made it possible to measure decision regret for several types of decision. Nevertheless, some of our results do confirm these individual-decision

studies. For example, in our study, the highest levels of decision regret were in relation to end-of-life decisions, a finding consistent with results of other studies conducted in the end-of-life context.[18,22,24,70]

Third, as we expected, we found that caregiver's higher age was associated with less decision regret. Age of relatives can be found as predictors elsewhere in the literature on decision regret.[18,22,24,71] As caregivers age, they have more experience of dealing with the restrictions of old age, and they may have acquired health experiences that reduce their anxiety.

While other studies showed the presence of spouses or common-law partners as reducing decision regret, our results showed that their involvement in the decision-making process increased decision regret among caregivers.[20,22] This may be because, as spouses, they are closer witnesses to the distress felt by the older person. However, our research indicated that having another family member involved in the decision-making process reduced decision regret, suggesting that if caregivers have additional family support, their regret may be relieved.[16] A 2018 survey found that children, spouses, extended family, friends, and the community represent the most common sources of support received by caregivers. Being a caregiver of an older adult is a common role among extended family members.[72,73] The more other people are involved in caring for the older person, the more the caregiver can share the responsibilities and the burden of care and thus ultimately experience less decision regret.

Fourth, contrary to our expectations, we found no association between decision regret and unfavorable socioeconomic characteristics, such as having no more than a primary education. In the literature, higher regret is often observed in people with lower educational attainment.[20,44] People with lower educational attainment or low health literacy may experience difficulty understanding the information necessary for making informed decisions.[74] This finding may be attributable to the fact that only 2.5% of our sample had less than a high school diploma and were therefore underrepresented in our sample.

Fifth, as expected, our study indicated that higher decisional conflict and higher burden of care increased decision regret. The literature confirms that these 2 factors are strongly associated with decision regret.[17,20,75] Burden of care is associated with depression and anxiety, and anxiety breeds regret and dwelling on missed opportunities.[20] However, unlike sociodemographic factors such as age or education levels, decisional conflict and burden of care are factors that can be modified by the implementation of decision support interventions[76,77] as well as by providing mental and financial resources for caregivers.[78–81] Also, our data support our hypothesis that a match between the preferred option and the decision made would decrease decision regret. This reinforces how important it is to invite caregivers to express themselves on their preferred options and needs to better include them in the decision process. It also indicates how important it is for clinicians to become more competent in assessing the values and preferences of patients and of caregivers and also in assessing what options are indeed feasible.[82] The match between choice preferred and decision made could have been out of the control of caregivers due to a lack of options. For example, if a clinician offers the choice to an elderly person to move out or stay home, but their caregiver is no longer able to support the person at home, that option no longer exists, whatever they would have preferred. However, a choice that is regretted can later turn out to be the best choice, and support for seeing and acknowledging this can alleviate the pain of regret. Nevertheless, a real lack of options for this population also needs to be addressed at a system level, such as by improving home care.

Finally, our data showed that people who wanted to receive information about the options for future decisions, as well as those who considered relevant organizations interested in the decision topic and health professionals as trustworthy sources of information, were statistically less likely to experience decision regret. These results are congruent with those of other studies that have shown the importance of formal decision support and the utility of decision support tools.[83] A recent systematic review on the experiences of families caring for older adults showed that negative experiences reflected lack of information, while positive experiences were linked to formal as well as well as informal support.[57] Our results can inform the design of tools and programs for supporting caregivers with loved ones aging at home and for health care professionals and organizations who need the interprofessional SDM skills to support difficult decisions. An interprofessional SDM approach is particularly appropriate for home care, in which care may be provided by health care teams as well as caregivers. With our results, for example, interprofessional teams can collaborate with caregivers to better assess the risks of decision regret in terms of the decision types faced, the age of decision makers and family involvement in decision making.[84,85]

Limitations

Our study has a few limitations. The results are based on recall of the health decisions participants made over the previous year, and therefore, our data may have been

subject to recall bias. Second, our sample may not be representative of all caregivers of older adults in Canada. For example, in Canada, more than half of caregivers are women, whereas 58.4% of our sample comprised men.[8,86] The Leger panel is made up of 48% men and 52% women. Men are more likely to be Internet users (proficient users and advanced users) than women are, and male caregivers spend fewer hours per week providing care.[1,87] Future recruitment strategies will create weighting that considers sociodemographic data such as sex and gender during sampling. In addition, 66% of participants were university educated, so people with limited literacy were underrepresented, and our sample frame did not include people from the 3 Canadian territories (more remote regions). Our results may therefore understate some of the decision-making difficulties specific to rural, female caregivers with less education. With online surveys, it is difficult to reach people with limited internet access, those with unfamiliarity with computers or mobile telephones (dexterity and literacy), and those who are living in remote areas.[88–90] The Leger web panel uses demographic characteristics to set quotas for the sample. However, web panels use nonprobability sampling and therefore suffer from self-selection bias. Although propensity score adjustment is often used to try to remove this bias, we did not use it, as evidence of its effectiveness is mixed.[91] However, with face-to-face contact limited during the COVID-19 pandemic, an online panel was a practical if temporary solution. Future studies should include the Canadian territories, where there are large populations of Indigenous peoples, and adopt a culturally safe and relevant research lens. Fourth, it was challenging to interpret our decision regret scores because no clinical threshold for the DRS has yet been established in the literature.[18,44] Thus, results on the frequency of decision regret identified as low, moderate, and high should be interpreted with caution. A consensus on the appropriate cutoff points for the DRS would better guide clinicians and researchers in using this important tool. Despite this drawback, a DRS version designed for caregivers, which better captures their subjective experiences, could be used for future studies.[92] Finally, this study began at the start of the COVID-19 lockdown in Canada, and the results may reflect the emotional state of caregivers of older adults in the context of a pandemic at its initial stage, rather than at all times before and after the pandemic.

Conclusion

We found that decision regret among caregivers of older adults receiving home care in Canada was high and that the difficult decisions made were most frequently about older adults' housing and safety. In the decision-making process, the presence of family or friends to support caregivers, the life experience of the caregiver, and support tools created by organizations and health professionals can reduce decision regret. Our results may serve as a guideline for the creation of targeted strategies to provide effective decision support, such as the creation and dissemination of decision aids, interactive counseling, and self-help groups for caregivers of older adults receiving care at home. Ultimately, this will improve caregivers' own health outcomes too and ensure Canada is at the forefront of ensuring caregivers' well-being, a cornerstone of caring for a healthy aging population.

ORCID iDs

Amédé Gogovor https://orcid.org/0000-0001-5988-0442
Karine V. Plourde https://orcid.org/0000-0001-8628-3950
Dawn Stacey https://orcid.org/0000-0002-2681-741X
France Légaré https://orcid.org/0000-0002-2296-6696

Supplemental Material

Supplementary material for this article is available on the *MDM Policy & Practice* website at https://journals.sagepub.com/home/mpp.

References

1. Statistics Canada. *General Social Survey: Caregiving and Care Receiving*. Ottawa: Statistics Canada; 2018.
2. Statistics Canada. *Canada's Population, July 1 2019*. Ottawa: Statistics Canada; 2019.
3. Comas-Herrera A, Zalakaín J, Lemmon E, et al. Mortality associated with COVID-19 in care homes: international evidence. 2020. Available from: https://ltccovid.org/2020/04/12/mortality-associated-with-covid-19-outbreaks-in-care-homes-early-international-evidence/

4. Canadian Institute for Health Information. *Pandemic Experience in the Long-Term Care Sector: How Does Canada Compare With Other Countries?* Ottawa: Canadian Institute for Health Information; 2020.

5. Stall NM, Johnstone J, McGeer AJ, et al. Finding the right balance: an evidence-informed guidance document to support the re-opening of Canadian nursing homes to family caregivers and visitors during the coronavirus disease 2019 pandemic. *J Am Med Dir Assoc*. 2020;21(10):1365–70e7.

6. Canadian Institute for Health Information. *The Impact of COVID-19 on Long-Term Care in Canada: Focus on the First 6 Months*. Ottawa: Canadian Institute for Health Information; 2021.

7. Government of Canada. Home and community health care 2016. Updated April, 13, 2016. Available from: https://www.canada.ca/en/health-canada/services/home-continuing-care/home-community-care.html. Accessed January 27, 2022.

8. Hango D.Support received by caregivers in Canada. In: Statistics Canada, ed. *Insights on Canadian Society*. Ottawa: Statistics Canada; 2020.

9. Dang S, Penney LS, Trivedi R, et al. Caring for caregivers during COVID-19. *J Am Geriatr Soc*. 2020;68(10):2197–201.

10. Garvelink MM, Ngangue PA, Adekpedjou R, et al. A synthesis of knowledge about caregiver decision making finds gaps in support for those who care for aging loved ones. *Health Aff (Millwood)*. 2016;35(4):619–26.

11. Zeelenberg M, Pieters R. A theory of regret regulation 1.0. *J Consum Psychol*. 2007;17(1):3–18.

12. Joseph-Williams N, Edwards A, Elwyn G. The importance and complexity of regret in the measurement of 'good' decisions: a systematic review and a content analysis of existing assessment instruments. *Health Expect*. 2011;14(1):59–83.

13. Saffrey C, Summerville A, Roese NJ. Praise for regret: people value regret above other negative emotions. *Motiv Emot*. 2008;32(1):46–54.

14. Shimanoff SB. Commonly named emotions in everyday conversations. *Perceptual Motor Skills*. 1984;58(2):514.

15. Sepucha K, Mulley AG Jr. A perspective on the patient's role in treatment decisions. *Med Care Res Rev*. 2009;66(1 suppl):53s–74s.

16. Adekpedjou R, Stacey D, Briere N, et al. "Please listen to me": a cross-sectional study of experiences of seniors and their caregivers making housing decisions. *PLoS One*. 2018;13(8):e0202975.

17. Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Med Decis Making*. 2003;23(4):281–92.

18. Becerra Perez MM, Menear M, Brehaut JC, et al. Extent and predictors of decision regret about health care decisions: a systematic review. *Med Decis Making*. 2016;36(6):777–90.

19. O'Connor AM. *User Manual—Decision Regret Scale*. Ottawa (Canada): Ottawa Hospital Research Institute; 1996.

20. Elidor H, Ben Charif A, Djade CD, et al. Decision regret among informal caregivers making housing decisions for older adults with cognitive impairment: a cross-sectional analysis. *Med Decis Making*. 2020;40:416–27.

21. Cohan JN, Orleans B, Brecha FS, et al. Factors associated with decision regret among patients with diverticulitis in the elective setting. *J Surg Res*. 2021;261:159–66.

22. Elidor H, Adekpedjou R, Zomahoun HTV, et al. Extent and predictors of decision regret among informal caregivers making decisions for a loved one: a systematic review. *Med Decis Making*. 2020;40(8):946–58.

23. Lichtenthal WG, Roberts KE, Catarozoli C, et al. Regret and unfinished business in parents bereaved by cancer: a mixed methods study. *Palliat Med*. 2020;34(3):367–77.

24. Smith-Howell ER, Hickman SE, Meghani SH, et al. End-of-life decision making and communication of bereaved family members of African Americans with serious illness. *J Palliat Med*. 2016;19(2):174–82.

25. Holland JM, Plant CP, Klingspon KL, et al. Bereavement-related regrets and unfinished business with the deceased. *Death Stud*. 2020;44(1):42–7.

26. Shiozaki M, Hirai K, Dohke R, et al. Measuring the regret of bereaved family members regarding the decision to admit cancer patients to palliative care units. *Psycho-Oncology*. 2008;17(9):926–31.

27. Holland JM, Thompson KL, Rozalski V, et al. Bereavement-related regret trajectories among widowed older adults. *J Gerontol Ser B Psychol Sci Soc Sci*. 2014;69(1):40–7.

28. Chang Y-P, Schneider JK, Sessanna L. Decisional conflict among Chinese family caregivers regarding nursing home placement of older adults with dementia. *J Aging Stud*. 2011;25(4):436–44.

29. Jaconsen MJ, O'connor AM, D. S. Decisional needs assessment in populations 1999. Available from: www.ohri.ca/decisionaid

30. Sugawara S, Nakamura J. Long-term care at home and female work during the COVID-19 pandemic. *Health Policy*. 2021;125(7):859–68.

31. Sun N, Wei L, Shi S, et al. A qualitative study on the psychological experience of caregivers of COVID-19 patients. *Am J Infect Control*. 2020;48(6):592–8.

32. Hado E, Friss Feinberg L. Amid the COVID-19 pandemic, meaningful communication between family caregivers and residents of long-term care facilities is imperative. *J Aging Soc Policy*. 2020;32(4–5):410–5.

33. Weeks LE, Nesto S, Hiebert B, et al. Health service experiences and preferences of frail home care clients and their family and friend caregivers during the COVID-19 pandemic. *BMC Res Notes*. 2021;14(1):271.

34. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *J Med Internet Res*. 2004;6(3):e34.

35. Legare F. Scaling up shared decision making for patient-centred care: Canadian Institutes of Health Research. 2017.

Available from: https://webapps.cihr-irsc.gc.ca/decisions/p/project_details.html?applId=369259&lang=en

36. Leger Opinion. Born from research panel book data collection 360. 2020. Available from: https://2g2ckk18vixp3ne olz4b6605-wpengine.netdna-ssl.com/wp-content/uploads/20 20/01/PANEL-BOOK-LEO-EN.pdf

37. O'Connor A. *User Manual-Decisional Conflict Scale*. 2010. Available from: https://decisionaid.ohri.ca/eval_dcs.html.

38. Zarit S, Orr NK, Zarit JM. *The Hidden Victims of Alzheimer's Disease: Families under Stress*. New York: NYU Press; 1985.

39. Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res Arch*. 1997;29(3):21–44.

40. Hébert R, Bravo G, Girouard D. Fidélité de la traduction française de trois instruments d'évaluation des aidants naturels de malades déments. *Can J Aging*. 1993;12(3):324–37.

41. O'Connor AM. Ottawa decision support framework to address decisional conflict. 2006. Available from: www.ohri .ca/decisionaid

42. Lai C, Holyoke P, Plourde KV, et al. What older adults and their caregivers need for making better health-related decisions at home: a participatory mixed methods protocol. *BMJ Open*. 2020;10(11):e039102.

43. Lorenzo AJ, Pippi Salle JL, Zlateska B, et al. Decisional regret after distal hypospadias repair: single institution prospective analysis of factors associated with subsequent parental remorse or distress. *J Urol*. 2014;191(5 suppl):1558–63.

44. Becerra-Perez MM, Menear M, Turcotte S, et al. More primary care patients regret health decisions if they experienced decisional conflict in the consultation: a secondary analysis of a multicenter descriptive study. *BMC Fam Pract*. 2016;17(1):156.

45. Wilding S, Downing A, Selby P, et al. Decision regret in men living with and beyond nonmetastatic prostate cancer in the United Kingdom: a population-based patient-reported outcome study. *Psycho-Oncology*. 2020;29(5):886–93.

46. Springate BA, Tremont G. Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables. *Am J Geriatr Psychiatry*. 2014;22(3):294–300.

47. Ankri J, Andrieu S, Beaufils B, et al. Beyond the global score of the Zarit Burden Interview: useful dimensions for clinicians. *Int J Geriatr Psychiatry*. 2005;20(3):254–60.

48. Degner LF, Sloan JA. Decision making during serious illness: what role do patients really want to play? *J Clin Epidemiol*. 1992;45(9):941–50.

49. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAMA*. 1984;252(21):2990–4.

50. Margevicius S, Daly B, Schluchter M, et al. Randomized trial of a web-based nurse education intervention to increase discussion of clinical trials. *Contemp Clin Trials Commun*. 2021;22:100789.

51. Aitken C, Power R, Dwyer R. A very low response rate in an on-line survey of medical practitioners. *Aust N Z J Public Health*. 2008;32(3):288–9.

52. Martinez RN, Gordon EJ, Tully S, et al. A mixed-methods study of Veterans Affairs providers' experiences communicating with patients about the Affordable Care Act. *Mil Med*. 2017;182(5):e1715–23.

53. Surdam J, Daly B, Fulton S, et al. Recruitment strategies for nurse enrollment in an online study. *Nurs Res*. 2020;69(1):69–73.

54. Kwak SG, Kim JH. Central limit theorem: the cornerstone of modern statistics. *Korean J Anesthesiol*. 2017;70(2):144–56.

55. Canadian Home Care Association CPSI. Am I safe ? Supporting conversations about patient safety in the home. Edmonton, AB: Canadian Home Care Association and the Canadian Patient Safety Institute; 2015.

56. Canadian Patient Safety Institute. Safety at home: a pan-Canadian home care safety study. Ottawa, ON: Canadian Patient Safety Institute; 2013.

57. Roy N, Dube R, Despres C, et al. Choosing between staying at home or moving: a systematic review of factors influencing housing decisions among frail older adults. *PLoS One*. 2018;13(1):e0189266.

58. Razali NM, Wah YB. Power comparisons of shapiro-wilk, kolmogorov-smirnov, lilliefors and anderson-darling tests. *J Stat Model Anal*. 2011;2(1):21–33.

59. Costanza MC, Afifi AA. Comparison of stopping rules in forward stepwise discriminant analysis. *J Am Stat Assoc*. 1979;74(368):777–85.

60. Lazraq A, Cléroux R. Un algorithme pas à pas de sélection de variables en régression linéaire multivariée. *Statistique et analyse des données*. 1988;13(1):39–58.

61. SAS Institute Inc. *SAS/STAT® 13.1 User's Guide*. Cary (NC): SAS Institute Inc; 2013.

62. Schwarz G. Estimating the dimension of a model. *Ann Stat*. 1978;6(2):461–4.

63. SAS Institute Inc. *Base SAS 9.4 Procedures Guide*. Cary (NC): SAS Institute Inc; 2015.

64. Legare F, Briere N, Stacey D, et al. Implementing shared decision-making in interprofessional home care teams (the IPSDM-SW study): protocol for a stepped wedge cluster randomised trial. *BMJ Open*. 2016;6(11):e014023.

65. Legare F, Stacey D, Briere N, et al. A conceptual framework for interprofessional shared decision making in home care: protocol for a feasibility study. *BMC Health Serv Res*. 2011;11:23.

66. Adekpedjou R, Stacey D, Briere N, et al. Engaging caregivers in health-related housing decisions for older adults with cognitive impairment: a cluster randomized trial. *Gerontologist*. 2020;60(5):947–57.

67. Adekpedjou R, Haesebaert J, Stacey D, et al. Variations in factors associated with healthcare providers' intention to engage in interprofessional shared decision making in home care: results of two cross-sectional surveys. *BMC Health Serv Res*. 2020;20(1):203.

68. Stones D, Gullifer J. 'At home it's just so much easier to be yourself': older adults' perceptions of ageing in place. *Ageing Soc*. 2016;36(3):449–81.

69. Stacey D, Ludwig C, Archambault P, et al. Feasibility of rapidly developing and widely disseminating patient decision aids to respond to urgent decisional needs due to the COVID-19 pandemic. *Med Decis Making*. 2021;41(2): 233–9.

70. Chiou CP, Chung YC. Effectiveness of multimedia interactive patient education on knowledge, uncertainty and decision-making in patients with end-stage renal disease. *J Clin Nurs*. 2012;21(9–10):1223–31.

71. Yun YH, Lee MK, Park S, et al. Use of a decision aid to help caregivers discuss terminal disease status with a family member with cancer: a randomized controlled trial. *J Clin Oncol*. 2011;29(36):4811–9.

72. Nichols LO, Martindale-Adams J, Burns R, et al. Typical and atypical dementia family caregivers: systematic and objective comparisons. *Int J Aging Hum Dev*. 2011;72(1): 27–43.

73. Rahayu S, Daulima NHC, Putri YSE. The experience of older people living in an elderly residential home (Panti Sosial Tresna Werdha): a phenomenology. *Enfermeria clinica*. 2018;28:79–82.

74. Paasche-Orlow MK, Parker RM, Gazmararian JA, et al. The prevalence of limited health literacy. *J Gen Intern Med*. 2005;20(2):175–84.

75. Boucher A, Haesebaert J, Freitas A, et al. Time to move? Factors associated with burden of care among informal caregivers of cognitively impaired older people facing housing decisions: secondary analysis of a cluster randomized trial. *BMC Geriatr*. 2019;19(1):249.

76. Hoffman AS, Bateman DR, Ganoe C, et al. Development and field testing of a long-term care decision aid website for older adults: engaging patients and caregivers in user-centered design. *Gerontologist*. 2020;60(5):935–46.

77. Davies N, Schiowitz B, Rait G, et al. Decision aids to support decision-making in dementia care: a systematic review. *Int Psychogeriatr*. 2019;31(10):1403–19.

78. Kontrimiene A, Sauseriene J, Blazeviciene A, et al. Qualitative research of informal caregivers' personal experiences caring for older adults with dementia in Lithuania. *Int J Ment Health Syst*. 2021;15(1):12.

79. Lauritzen J, Pedersen PU, Sorensen EE, et al. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: a systematic review. *JBI Database System Rev Implement Rep*. 2015; 13(6):373–433.

80. Slatyer S, Aoun SM, Hill KD, et al. Caregivers' experiences of a home support program after the hospital discharge of an older family member: a qualitative analysis. *BMC Health Serv Res*. 2019;19(1):220.

81. Lee Y, Bierman A, Penning M. Psychological well-being among informal caregivers in the Canadian longitudinal study on aging: why the location of care matters. *J Gerontol B Psychol Sci Soc Sci*. 2020;75(10):2207–18.

82. Mulley AG, Trimble C, Elwyn G. Stop the silent misdiagnosis: patients' preferences matter. *BMJ*. 2012;345:e6572.

83. Stacey D, Legare F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev*. 2017;4:CD001431.

84. Garvelink MM, Emond J, Menear M, et al. Development of a decision guide to support the elderly in decision making about location of care: an iterative, user-centered design. *Res Involv Engag*. 2016;2:26.

85. Légaré F, Stacey D, Brière N, et al. An interprofessional approach to shared decision making: an exploratory case study with family caregivers of one IP home care team. *BMC Geriatr*. 2014;14:83.

86. Statistics Canada. Care counts: caregivers in Canada, 2018. Available from: https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2020001-eng.htm

87. Wavrock D, Schellenberg G, Schimmele C. *Internet-Use Typology of Canadians: Online Activities and Digital Skills*. Ottawa: Statistics Canada; 2021.

88. Lindhjem H, Navrud S. Using internet in stated preference surveys: a review and comparison of survey modes. *Int Rev Environ Res Econ*. 2011;5:309–51.

89. Shin E, Johnson TP, Rao K. Survey mode effects on data quality: comparison of web and mail modes in a US national panel survey. *Soc Sci Comput Rev*. 2012;30(2): 212–28.

90. Bethlehem J, ed. Can we make official statistics with self-selection web surveys. In: *Proceedings of Statistics Canada Symposium*. Ottawa: Statistics Canada; 2008.

91. Copas A, Burkill S, Conrad F, et al. An evaluation of whether propensity score adjustment can remove the self-selection bias inherent to web panel surveys addressing sensitive health behaviours. *BMC Med Res Methodol*. 2020;20(1):251.

92. Haun MW, Schakowski A, Preibsch A, et al. Assessing decision regret in caregivers of deceased German people with cancer—a psychometric validation of the Decision Regret Scale for Caregivers. *Health Expect*. 2019;22(5): 1089–99.