

# Difficult Decisions for Older Canadians Receiving Home Care, and Why They Are So Difficult: A Web-Based Decisional Needs Assessment

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## Abstract

**Background.** Older adults receiving home care services often face decisions related to aging, illness, and loss of autonomy. To inform tailored shared decision making interventions, we assessed their decisional needs by asking about the most common difficult decisions, measured associated decisional conflict, and identified factors associated with it. **Methods.** In March 2020, we conducted a cross-sectional survey with a pan-Canadian Web-based panel of older adults ( $\geq 65$  y) receiving home care services. For a difficult decision they had faced in the past year, we evaluated clinically significant decisional conflict (CSDC) using the 16-item Decisional Conflict Scale (score 0–100) with a  $>37.5$  cutoff. To identify factors associated with CSDC, we performed descriptive, bivariable, and multivariable analyses using the stepwise selection method with an assumed entry and exit significance level of 0.15 and 0.20, respectively. Final model selection was based on the Bayesian information criterion. **Results.** Among 460 participants with an average age of 72.5 y, difficult decisions were, in order of frequency, about housing and safety (57.2%), managing health conditions (21.8%), and end-of-life care (8.3%). CSDC was experienced by 14.6% (95% confidence interval [CI]: 11.5%, 18.1%) of respondents on all decision points. Factors associated with CSDC included household size = 1 (OR [95% CI]: 1.81 [0.99, 3.33];  $P = 0.27$ ), household size = 3 (2.66 [0.78, 8.98];  $P = 0.83$ ), and household size = 4 (6.91 [2.23, 21.39];  $P = 0.014$ ); preferred option not matching the decision made (4.05 [2.05, 7.97];  $P < 0.001$ ); passive role in decision making (5.13 [1.78, 14.77];  $P = 0.002$ ); and lower quality of life (0.70 [0.57, 0.87];  $P < 0.001$ ). **Discussion.** Some older adults receiving home care services in Canada experience CSDC when facing difficult decisions. Shared decision-making interventions could mitigate associated factors.

## Highlights

- This is the first study in Canada to assess the decisional needs of older adults receiving care at home and to identify their most common difficult decisions.
- Difficult decisions most frequently made were about housing and safety. The most significant decisional conflict was experienced by people making decisions about palliative care.
- When their quality-of-life score was low, older adults experienced clinically significant decision conflict.

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## Keywords

aging, seniors, home care, community services, decisional needs, decisional conflict, shared decision making, clinically significant decisional conflict

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## Background

The proportion of older adults in almost every country in the world is growing, and Canada is no exception<sup>1</sup> Living longer has multiple age-related consequences,<sup>2</sup> and due to declining health and autonomy, many older adults need additional care but wish to receive it at home,<sup>3,4</sup> especially since the COVID-19 epidemic, which has caused more deaths in residential care than anywhere else.<sup>5</sup>

In Canada, home care services are a range of services provided in the home by trained staff, including nurses, physiotherapists, occupational therapists, nutritionists, social workers and personal support workers.<sup>6</sup> Home care is not covered by the Canada Health Act, which ensures federal funding transfers to provinces and territories for health care, funds that are administered by Canada's provinces and territories according to their own priorities. Thus, home care across Canada varies widely in scope of services, eligibility requirements, and funding arrangements (i.e., public/private, not-for-profit/for profit).<sup>7</sup>

Older adults have complex health care needs and face many health-related decisions, some more difficult than others.<sup>8</sup> A difficult decision is a situation in which there is a priori no evident best option among the choices. Older adults may also be overwhelmed or insecure about their ability to make decisions.

Decisional needs are defined as “deficits that can adversely affect the quality of a decision and require tailored decision support.”<sup>9</sup> When decisional needs are unmet, uncertainty and distress escalate, decision quality is reduced, and decision regret may follow.<sup>10</sup> These hamper effective decision making and timely follow through. Manifestations of decisional needs are lack of knowledge, unrealistic expectations, unclear values, inadequate support, complexity of decisions (including difficult decision types), personal and clinical needs, and, foremost of all, decisional conflict.<sup>9</sup> Decisional conflict is defined as ambiguity or oscillation between options, causing stress and difficulty in deciding.<sup>11</sup> Decisional conflict can be measured to identify factors associated with a person's most difficult decisions and to indicate other decisional needs.

An effective approach to reducing decisional conflict and meeting other decisional needs is shared decision making (SDM),<sup>12–17</sup> a collaborative process whereby health care teams support clients in making decisions informed by best evidence and by what matters most to them.<sup>18–20</sup> Key to patient-centered care,<sup>21–23</sup> SDM also respects patients through asking them about their goals and the role they desire to play in the decision-making process.<sup>24–27</sup> Although SDM has been promoted by several provincial governments,<sup>28–31</sup> it is still not widely practiced by health care professionals in Canada. Little is known about the extent to which SDM has been adopted specifically with older adults in home care, and indeed, troubling evidence shows that older Canadians receiving home care services have the least experience of SDM.<sup>32</sup>

While SDM is challenging with older adults, and their complex care needs,<sup>27,33–37</sup> it has been shown to improve their decision-making experiences.<sup>36,38</sup> During the SDM process, decision aids or coaching can be used to improve decision quality by addressing unresolved decisional

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needs.<sup>39,40</sup> To prepare the way for these SDM tools and custom design them to this population, a detailed portrait of their most difficult decisions and the variables that affect them is needed. However, no decisional needs assessment has yet been published regarding older adults or those receiving home care services specifically.<sup>39</sup>

Consequently, to provide SDM tailored to the context of older adults receiving home care services, we sought to assess the decisional needs of this population in Canada, including identifying the most difficult decisions they faced, and to measure clinically significant decisional conflict (CSDC) and factors associated with it.

## Methods

### *Study Design*

We conducted a cross-sectional survey across the 10 Canadian provinces and used the Checklist for Reporting Results of Internet E-Surveys to guide reporting of results.<sup>41</sup> This project is embedded in a 7y Canadian Institutes for Health Research–funded research program whose overarching goal is ensuring that more older Canadians and caregivers in home care become fully engaged as partners in their care.<sup>42</sup>

### *Study Participants and Recruitment*

Eligible participants were Canadians aged 65 y or older from the 10 provinces (excluding the territories) who were receiving home care services or had received such services in the past year and who were enrolled in Leger Marketing's pan-Canadian Web panel of a total of 400,000 individuals. Leger uses traditional and mobile telephone methodologies to recruit participants using the Leger call center (61%), partner programs (25%), recommendations from other panel members (5%), registration on the panel website and social media (5%), and offline recruitment (4%). Panelists fill out a detailed profiling questionnaire at registration to decrease multiple entries and fraudulent panelists. A quality control of the panel is also carried out continuously. Each time panelists complete a new survey, their answers to the sociodemographic questions are re-recorded and their profile is renewed. Thus, the panelists, already profiled by demographics, occupation, and chronic conditions, could be directly recruited based on our eligibility criteria. A non-probability sampling method was used to invite 29,628 panelist adults aged 65 or older to participate. Using the Leger random sampling software, the sample was balanced across age, sex, and region. A query was then entered into the panel software based on the screening

criteria to locate all eligible respondents, who were asked how old they were, whether they had received home care services during the last 12 mo, and to indicate if possible the exact date. Participants were not aware that they would be asked about decision-making needs or related issues before signing consent, which appeared after the eligibility filter questions.

### *Data Collection*

To our knowledge, no other study has reported on decisional needs for this population and context. We were inspired by the populational decisional needs assessment by O'Connor et al.<sup>43</sup> and by another decisional needs assessment in focus groups by Légaré et al.<sup>44</sup> Because of the lack of a standardized questionnaire, we developed our own using the Ottawa Decision Support Framework (a guide to the development of interventions to prepare patients and health care professionals for SDM),<sup>9</sup> the *Decisional Needs Assessment in Populations Workbook* (which includes outlines for establishing questions to assess decisional needs),<sup>45</sup> and the informed decision model, which refines the understanding of the decision node in SDM.<sup>46</sup> The questions were designed in February 2020 (before the COVID-19 outbreak reached Canada).

The survey first asked questions about the sociodemographic characteristics, including household size, and to indicate which of 15 potential decisions made in the home care setting in the past year the participant found the most difficult. In phase 1 of this research program, interviews with older adults and caregivers in a Canadian home and community care organization identified difficult decisions they had made.<sup>47</sup> We triangulated these results with decisions found in other published studies with older adults and caregivers<sup>48–50</sup> as well as with expert opinion (Table 1) to arrive at the 15 difficult decisions presented to our participants. If participants were unable to find 1 in the 15 that matched their personal experience, they were invited to add a new difficult decision in their own words. For the identified difficult decision, we measured decisional conflict using the validated 16-item Decisional Conflict Scale (DCS) with responses on a 5-point Likert-type scale.<sup>51</sup> We also measured components of their decision-making process using the validated 5-item Control Preferences Scale,<sup>52</sup> the validated 5-item Decision Regret Scale (DRS),<sup>53</sup> and the Kemp Quality of Life Scale.<sup>54</sup>

In total, the survey asked 25 questions including 3 open (age, options considered, and decision made) and 8 semi-open questions (decision points, ethnicity, first

language learned, people involved in decision making, information desired for future decisions, preferred format of information, information sources considered reliable, and professional home-care help received). The full questionnaire in both French and English was pilot tested for navigability and comprehensibility by a random sample of 30 eligible panelists before data collection. Questionnaire completion time was about 20 min.

Leger Marketing created a Web-based closed survey for our questionnaire. A unique URL link to the survey was emailed to participants. This allowed respondents who had interrupted the completion of the questionnaire to pick up again where they had stopped. Participants completed the survey in English or French. Respondents logged in using their panel member account, which allowed only 1 questionnaire validation per member to avoid duplicate entries. Questions appeared in the same order for all participants. Participants had to answer all questions on 1 page to move to the next and clicked on the Finish button on the last page to submit their responses. The survey was voluntary; as is Leger's practice, \$1.60 was offered to participants for completing the survey.

### *Sample Size and Data Analysis*

Our sample size was informed by previous work,<sup>26</sup> a cross-sectional study with a quantitative approach supplemented by a qualitative data arm reporting on older adults' and caregivers' experiences of housing decisions. We extracted the proportion of older adults who had CSDC associated with a housing decision at the threshold of 37.5 for sample size calculation. The computed sample size a priori was 460 participants, which ensured at least 80% power for the study. A nonprobability sample of this size would guarantee that if we estimated at least 26% of respondents would have CSDC at the threshold of 37.5, the 95% confidence interval would be  $\pm 4\%$  or narrower. First, after discussion, we chose to organize<sup>43,55</sup> the 15 difficult decisions into 3 categories for statistical analysis with CSDC: 1) decisions about housing and safety, which were grouped together because housing decisions are often provoked by safety concerns, such as falls, and are not necessarily medical decisions<sup>56</sup>; 2) decisions about management of health conditions; and 3) decisions about end-of-life care. To ease interpretation of decisional conflict scores, following the user manual, we calculated the average value of DCS items, subtracted 1, and multiplied it by 25 to standardize the total score from 0 (low decisional conflict) to 100 (high decisional conflict).<sup>51</sup> We defined older adults with CSDC as those

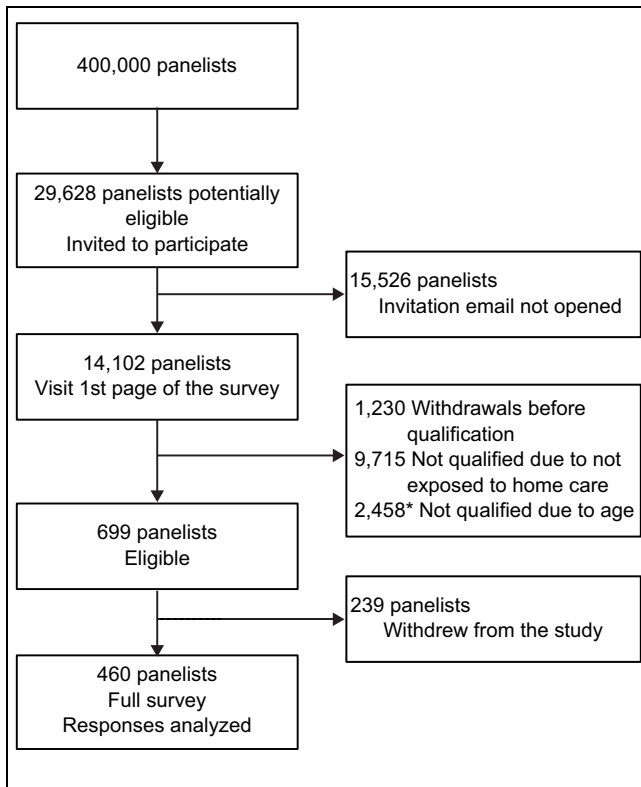
with DCS scores greater than 37.5,<sup>57</sup> a threshold associated with delayed decision making and uncertainty about following through with the decision.<sup>58</sup> We also converted decision regret scores by reverse-coding statements 2 and 4 of the DRS and subtracting 1 from each item, as mentioned in the DRS manual. We then multiplied the sum by 25 and divided it by 5 to obtain a score out of 100.

To identify the category of decisions for which the CSDC was most frequent, we calculated the proportion of respondents with DCS scores greater than 37.5 in each decision category in relation to the total for that decision category.

Third, we performed descriptive, bivariable analysis and multivariable analysis of CSDC for 46 independent variables (Supplemental material) using generalized linear models regression to determine factors associated with CSDC. To achieve the underlying assumption of multivariable analyses, the variables were checked for linearity and multicollinearity. We found no multicollinearity problem, and the linearity assumption was not violated. The 18 variables with  $P$  values of  $<0.20$  in the bivariate analysis were eligible for exploratory multivariable analysis. For the latter, we used the stepwise selection method to examine models with different combinations of variables that otherwise might be overlooked. The entry and exit significance levels were 0.15 and 0.20, respectively. An entry significance level of 0.15 indicated that a variable must have a  $P$  value  $<0.15$  to enter the model during stepwise selection. An exit significance level of 0.20 indicated that a variable must have a  $P$  value  $>0.20$  to leave the model during stepwise selection.<sup>59</sup> The regression modeling included only participants with complete data on all potential factors. A "preferred not to answer" response to sociodemographic questions was considered as missing data. Selection of the final model was based on the Bayesian information criterion. We also performed a sensitivity analysis at the 25/100 threshold for the CSDC, as scores below this cutoff are associated in the literature with implementing decisions.<sup>51</sup> Statistical analyses were performed using SAS 9.4 (SAS Institute Inc.).

### *Ethics Approval*

Ethics approval was obtained from the Research Ethics Board of the Integrated University Health and Social Services Center of the Capitale-Nationale, Quebec, Canada. Respondents gave their consent to participate in the study after being informed in a language that they understood of the drawbacks and risks of the project, the voluntary nature of their participation, that their



**Figure 1** Flow chart of participant recruitment.

\*Disqualified because they were 64 y old at the time they took the survey. The survey was sent to panelists 65 y of age or older. To maintain confidentiality, only a panelist's year of birth at the time of profiling was collected. To qualify for the survey, respondents were asked to provide their exact date of birth, and they had to be 65 y of age or older at the time they took the survey. Hence, panelists' ages were based on the year of birth and not the exact date of birth.

data would be used only for scientific purposes and treated in complete confidentiality. The data are stored on secure servers.

## Results

### Participants

Of 29,628 panelists invited to participate, 14,102 visited the first page of the survey (47.6%), about 30% more than the usual response rate for Leger panel members, showing a high interest in the topic. A total of 2458 panelists were disqualified because they were 64 on the date of the survey and not yet 65. Among the 699 who were eligible (4.96%), 239 withdrew and 460 completed the survey and were considered for our analysis (Figure 1). The average age of participants was 72.5 y, and 50.3% were female. Table 1 shows the detailed

characteristics of the participants. The prevalence of about 5% of panelists who were receiving home care services is a ratio similar to that observed in a previous study with Leger panelists (8%)<sup>32</sup> and in the Canadian population as a whole (4%).<sup>60</sup> Professional support services received by participants were mostly for medical treatments (37.6%), for home maintenance (31.1%), and for food preparation (25.7%).

Of the 239 participants who withdrew, 73.7% were from Ontario and Quebec, and the mean age was 73.4 y. The sociodemographic characteristics of the 81 withdrawn participants who provided them were similar to the characteristics of participants who completed the survey, except that 45.5% were female and 66.2% had English as their first language.

Data collection was performed from March 13 to 29, 2020. The World Health Organization declared COVID-19 a pandemic on March 11, and lockdown in Canada occurred on March 19. One-third of the included participants completed the survey before this date, and we observed no changes over the period of data collection, suggesting that COVID-19 had little impact on our results.

### Types of Difficult Decisions

Participants' decisional needs cover multiple aspects and difficult decisions were about housing and safety (53.5%), managing health conditions (24.4%), and end-of-life care (8%; Tables 2 and 3). Under the housing and safety category, decisions points related to home safety, moving, and fall prevention were most frequently reported (Table 3). Other than with their care team, participants reported they had made these decisions with a spouse (43.5%), alone (27%), or with their children (25.5%).

### CSDC and Its Associated Factors

Overall, 14.6% of respondents had experienced CSDC (DCS above the threshold of 37.5) when faced with their difficult decision (Table 4). In the house and safety category, the most difficult decision was whether to ask for help at home or not, whereas in the health care decisions, the most difficult decision was about pain management, and in the end-of-life decisions, the most difficult decision was about palliative care. CSDC was most frequent among those who chose end-of-life decisions; that is, of the total 460 respondents, 37 (8%) chose end-of-life decisions as the most difficult, and 6 of those 37 (16.2%) had DCS scores above the 37.5 threshold (Table 3). The final list of factors associated with CSDC included household

**Table 1** Characteristics of the participants ( $N = 460$ )

Sociodemographic Characteristic		No. of Respondents (%)
Age, $y, \bar{x} \pm s$		72. $\pm$ 6.2
Sex	Male	238 (51.7)
	Female	222 (48.3)
Level of education	University	201 (43.7)
	College	127 (27.6)
	High school	102 (22.2)
	Less than a high school diploma	26 (5.7)
	No answer	4 (0.9)
Ethnicity	White	444 (96.5)
	Non-White group:	14 (3.0)
	North American Indigenous (First Nations, Métis or Inuk) $n = 2$ ;	
	Black $n = 1$ ;	
	Latin American $n = 1$ ;	
	South Asian (East Indian, Pakistani, Sri Lankan) $n = 4$ ;	
	Chinese $n = 1$ ;	
	Other $n = 5$	
Marital status	No answer	2 (0.4)
	Never married	40 (8.7)
	Married	215 (46.7)
	In a common-law relationship	26 (5.7)
	Separated	17 (3.7)
	Divorced	83 (18.0)
	Widow/widower	76 (16.5)
	No answer	3 (0.7)
First language learned	French	260 (56.5)
	English	172 (37.4)
	Other	28 (6.1)
Family income, \$CAD <sup>a</sup>	< 50,000	233 (50.7)
	50,000–59,999	42 (9.1)
	60,000–79,999	65 (14.1)
	80,000–99,999	47 (10.2)
	$\geq 100,000$	42 (9.1)
	No answer	31 (6.7)
Region	Western Canada	69 (15.0)
	Central Canada	383 (83.3)
	Atlantic region	8 (1.7)
Geographical area	Urban	383 (83.3)
	Rural	77 (16.7)
Household size, $\bar{x} \pm s$	1 person	183 (39.8)
	2 persons	239 (52.0)
	3 persons	20 (4.3)
	More than 4 persons	18 (3.9)

Numbers may not total 460 in all cases because of approximations; the sum of the approximations may result in a difference of + 1 or -1 in the total.

<sup>a</sup>Canadian dollars.

size = 1 person (odds ratio [OR] [95% confidence interval {CI}]: (1.81 [0.99, 3.33];  $P = 0.27$ ), household size = 3 persons (2.66 [0.78, 8.98];  $P = 0.83$ ), and household size =  $\geq 4$  persons (6.91 [2.23, 21.39];  $P = 0.014$ ); preferred option not matching the decision made (4.05 [2.05, 7.97];  $P < 0.001$ ); passive role in decision making (5.13

[1.78, 14.77];  $P = 0.002$ ); and poor quality of life (0.70 [0.57, 0.87];  $P < 0.001$ ; Table 5).

The mean score for decision regret was 13.77 ( $s = 15.54$ ), and its association with decisional conflict was statistically significant (Spearman correlation coefficient = 0.56;  $P = 0.0001$ ).

**Table 2** Respondent Descriptions ( $N = 460$ )

Shared Decision Making and Decisional Needs		No. of Respondents (%)
People involved in decision making <sup>b</sup>	None (yes)	141 (30.7)
	Spouse (yes)	200 (43.5)
	Child (yes)	114 (24.8)
	Other family member (yes)	35 (7.6)
	Friends (yes)	43 (9.3)
	Other (yes)	49 (10.7)
Decision points	Decision about housing and safety	246 (53.5)
	Decisions about management of conditions	112 (24.3)
	Decisions about end-of-life care	37 (8.0)
	Other	65 (14.1)
Decision made matches preferred option	Yes	405 (88.0)
	No	55 (12.0)
Decision-making role assumed	I made the decision.	208 (45.2)
	I made the decision after seriously considering the opinion of health professionals.	161 (35.0)
	Health professionals and I shared the responsibility for making the decision.	71 (15.5)
	The health professionals made the decision after seriously considering my opinion.	14 (3.0)
	Health professionals made the decision.	6 (1.3)
Decision-making role preferred	I would make the decision alone.	187 (40.7)
	I would make the decision but considering my care team's option.	157 (34.1)
	My care team and I would decide together.	97 (21.1)
	My health care team would make the decision but considering my opinion.	13 (2.8)
	My health care team would make the decision alone.	6 (1.3)
Match between decision-making role assumed and preferred	Assumed active–preferred active or Assumed passive—preferred passive	439 (95.4)
	Assumed passive–preferred active	11 (2.4)
	Assumed active–preferred passive	10 (2.2)
Information desired for future decisions <sup>b</sup>	About the difficult decision (yes)	114 (24.8)
	About available options for the decision (yes)	251 (54.6)
	The best available data on the decision (yes)	157 (34.1)
	Perceptions or recommendations of others about the decision (yes)	72 (15.7)
	That relates to your values about the decision (yes)	175 (38.0)
	Other information (yes)	47 (10.2)
Preferred information format	Paper-based documents	86 (18.7)
	Personal communication with health care provider or relatives	233 (50.7)
	Multimedia (videos/DVDs, internet, television, radio)	100 (21.7)
	Discussion groups (with other persons including online discussions and social networks, information sessions in your community)	13 (2.8)
	Other	28 (6.1)
Information sources considered reliable <sup>b</sup>	Organizations interested in this kind of difficult decision (yes)	166 (36.1)
	Health care professionals (yes)	398 (86.5)
	Government agencies (yes)	110 (23.9)
	Health care insurance companies (yes)	14 (3.0)
	Consumer or patient associations (yes)	74 (16.1)
	Companies/nonprofit companies (yes)	64 (13.9)
	Other (yes)	28 (6.1)
Decision Regret Scale, median (IQR)		10 (0–25)
Quality-of-life score, $\bar{x} \pm s$		4.9 $\pm$ 1.3
Duration of home care services	Short term (a few days or weeks)	256 (55.7)
	Long term (6 mo or more)	204 (44.3)

(continued)

Table 2 (continued)

Shared Decision Making and Decisional Needs		No. of Respondents (%)
Professional help received <sup>b</sup>	Personal care (yes)	104 (22.6)
	Medical treatments (yes)	173 (37.6)
	Scheduling or coordinating care-related tasks (yes)	21 (4.6)
	Food preparation, washing up, cleaning, laundry, or sewing (yes)	118 (25.7)
	Maintenance of the house or exterior work (yes)	143 (31.1)
	Transport to go shopping or to medical appointments or social events (yes)	98 (21.3)
	Physiotherapy (yes)	113 (24.6)
	Training and adaptation (yes)	39 (8.5)
	None (yes)	69 (15.0)
	Other (yes)	41 (8.9)

Numbers may not total 460 in all cases because the process involves approximations; the sum of the approximations may result in a difference of + 1 or - 1 in the total.

<sup>b</sup>Questions with a choice of mutually nonexclusive answers.

Table 3 Descriptive Statistics of Decision Points (*N* = 460)

Decision Points		Total No. of Respondents (%)	CSDC, DCS >37.5, No. of Respondents (%)
Decision about housing and safety	What is the best option for me to stay safe at home?	69 (15.0)	5 (7.3)
	Should I choose to stay at home or move?	55 (12.0)	7 (12.7)
	What is the best option for me for preventing falls?	41 (8.9)	7 (17.1)
	Should I choose to receive assistance for my daily activities or not?	32 (7.0)	7 (21.9)
	What is the best option for me for getting immediate treatment?	35 (7.6)	5 (14.3)
	Should I stop driving my car or not?	14 (3.0)	3 (21.4)
Decision about management of conditions	Should I choose surgery or not?	40 (8.7)	4 (10.0)
	What is the best option for me for managing my pain?	32 (7.0)	5 (15.6)
	What is the best option for me for managing my health?	26 (5.7)	3 (11.5)
	Should I choose to take medication or not?	14 (3.0)	2 (14.3)
Decision about end-of-life care	What is the best option for advance care planning?	13 (2.8)	0 (0)
	What is the best option for me in terms of where I want to die?	9 (2.0)	2 (22.2)
	Should I choose to be resuscitated/intubated or not?	7 (1.5)	2 (28.6)
	Should I choose medical assistance to die or not?	6 (1.3)	1 (16.7)
	Should I choose palliative care or not?	2 (0.4)	1 (50.0)
Other		65 (14.1)	13 (20.0)

We calculated the percentages of clinically significant decisional conflict for each decision. The respective denominators correspond to the number of total participants for each decision.

## Discussion

This decisional needs assessment of older adults receiving home care informed us about their most difficult decisions, why they were difficult, and the level of CDSC associated with the decisions. Housing and safety decisions were the most frequently mentioned, while end-of-life decisions elicited the highest level of decisional

conflict. CSDC was experienced by 14.6% of participants. Household size, preferred option not matching the decision made, passive role in decision making, and poor quality of life were the factors associated with CSDC. Our results lead us to make the following observations.

First, the frequency of decisions related to home safety, moving decisions, and fall prevention is congruent with



**Table 4** Descriptive Statistics According to Decision Categories ( $N = 460$ )

Decision Themes	Total No. of Respondents (%)	CSDC, DCS >37.5, No. of Respondents (%)
All decisions points	460	67 (14.6)
Decision about housing and safety	246 (53.5)	34 (13.8)
Decision about management of conditions	112 (24.3)	14 (12.5)
Decision about end-of-life care	37 (8.0)	6 (16.2)
Other	65 (14.1)	13 (20.0)

Percentages of CSDC were calculated for each decision category. The respective denominators correspond to the number of participants for each decision category.

CSDC, clinically significant decisional conflict; DCS, Decisional Conflict Scale.

**Table 5** Factors Associated with CSDC, DCS >37.5 of 100 ( $n = 420$ )

Selected Variable		OR (95% CI)	P Value
Household size	2 persons	Ref	
	1 person	1.81 (0.99, 3.33)	0.27
	3 persons	2.66 (0.78, 8.98)	0.83
	More than 4 persons	6.91 (2.23, 21.39)	0.014
Preferred option matches decision made	Yes	Ref	
	No	4.05 (2.05, 7.97)	<0.001
Role assumed in decision-making	Active	Ref	
	Passive	5.13 (1.78, 14.77)	0.002
Quality of life		0.70 (0.57, 0.87)	inf 0.001

CI, confidence interval; CSDC, clinically significant decisional conflict; DCS, Decisional Conflict Scale; OR, odds ratio.

the evidence that prompted the Canadian Home Care Association's initiative "Am I Safe" to help people in home care reduce the likelihood of falls.<sup>61,62</sup> 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.<sup>56</sup> Our results highlight that health decisions faced by older adults in home care in Canada are far broader than medical decisions and include decisions about where to live and staying safe at home. In addition, by the end of the data collection period for our study, COVID-19 outbreaks were starting in nursing homes in Canada.<sup>63,64</sup> Early in the pandemic, 2 patient decision aids were developed in Canada to support the decision of whether or not to move older adults out of retirement or nursing homes. They were downloaded more than 10,000 times in 2 wk.<sup>64-66</sup> This high number of downloads together with our survey results stresses an urgent need for decision support felt by older adults in Canada for their decisions about home and safety.<sup>43,67</sup> It also suggests that well-supported decision making about home and safety could have reduced the harm experienced in long-term residential care.<sup>68</sup>

Second, almost 1 in 10 of our participants experienced CSDC. These older adults may delay decisions or feel unsure about following through.<sup>57</sup> They may also experience more decision regret and ultimately dissatisfaction with and loss of trust in the health care system in general.<sup>10,51,53</sup> Notably, older adults who identified end-of-life care decisions as the most difficult also showed the highest prevalence of CSDC. These results are particularly important in the context of the COVID-19 pandemic, where end-of-life decisions were often left to the last minute and made without support from caregivers. This is a key area to prioritize for decision support interventions targeting older adults receiving home services.

Third, we identified a number of factors associated with CSDC, some of which have been identified before. Taking into account that the category of reference was 2, we observed that the more the household size increases, the more CSDC increases and becomes significant at 4 people or more in the home (4 or more compared to a household of 2). The larger the family, the more opinions there are about what option to choose. The older adult must take them into account and evaluate the decision's

impact on each person. They may be handling more sources of pressure and have more difficulty playing the role they desire in the decision process. Indeed, they may not have control over the final decision<sup>69</sup>: our results show that when the decision made was not the preferred option, the odds of CSDC were 4 times higher than when they matched. In this case, the mismatch may not be due to lack of SDM; perhaps the decision was made by others or was made when certain options were no longer available. Whatever the reason, a mismatch is a clear signal of CSDC. Furthermore, the CSDC was 5 times higher when the older adult took a passive role in decision making. Indeed, the literature supports that playing (or preferring) an active role improves the decision-making process.<sup>26,43,70</sup> In addition, our study showed that, as supported by the literature, older adults with a higher quality of life were protected to some extent from experiencing CSDC.<sup>15,71,72</sup>

### Limitations and Strengths

Some of our results are based on decisions made as much as a year ago, which may have caused information bias (recall bias) leading to overestimation or underestimation of the measure of association. Second, our sample may not be representative of all older Canadians receiving home care services, such as those with no internet connection or computer skills, who could not participate in the survey. Also, as study participants were self-selected as home care recipients, it is possible that at least some of them did not actually receive home care. Third, some demographic categories (ethnicity, first language, province, information format) were grouped together, which could result in data loss. This may have been exacerbated by the snowball sampling used to build the panel. The survey likely excluded many Indigenous people, cultural groups, and those without English or French. However, to the best of our knowledge, this is the largest population and Web-based survey in the world to date on decisional needs of older adults receiving home care services.<sup>39</sup> Finally, this survey took place during a COVID-19 lockdown in Canada and may thus reflect decisional needs of older adults in the home care sector under exceptional circumstances. However, perhaps this context has served to better highlight their preexisting and future needs.<sup>73,74</sup>

### Conclusion

In our sample, the older adults receiving home care services in all 10 provinces of Canada had unmet decisional needs and a significant proportion experienced CSDC. The most frequently identified type of difficult decision

was about housing and safety but the greatest prevalence of CDCS concerned end-of-life decisions. CDCS can be detected and reduced through decision support interventions and patient involvement in decision making. Our results will help develop strategies for implementing SDM among older adults receiving home care services in Canada, such as decision support tools that address their most difficult decisions, that is, “opt for medical assistance to die or not” or “whether to move or not” and factors that increase their risk of CSDC.

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### Author Contributions

AKT, KVP, and FL contributed to the conception and design of the study. KVP and FL coordinated data collection in collaboration with Leger Marketing. AKT, GN, ABC, CL, and FL contributed to the data analysis. AKT drafted the manuscript overseen by ABC, CL, DS, and FL. All authors revised the manuscript critically for important intellectual content, gave final approval of the version to be published, and agreed to be accountable for all aspects of the study.

### Authors' Note

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### Supplemental Material

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

### References

1. World Health Organization. World report on ageing and health. 2015. Available from: <https://apps.who.int/iris/handle/10665/186463>. Accessed June 5, 2019
2. Newman AB, Cauley JA. *The Epidemiology of Aging*. New York: Springer; 2012.

3. 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 Engagem.* 2016;2(1):26. DOI: 10.1186/s40900-016-0040-0
4. Adekpedjou R, Stacey D, Brière 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. DOI: 10.1093/geront/gnz045
5. Achou B, De Donder P, Glenzer F, Lee M, Leroux M-L. Nursing home aversion post-pandemic: implications for savings and long-term care policy. Working Paper Retirement and Savings Institute; 2021.
6. Akhtar S, Loganathan M, Nowaczynski M, et al. Aging at home: a portrait of home-based primary care across Canada. *Healthcare Q.* 2019;22(1):30–5. DOI: 10.12927/hcq.2019.25839
7. Ganann R, Weeres A, Lam A, Chung H, Valaitis R. Optimization of home care nurses in Canada: a scoping review. *Health Soc Care Community.* 2019;27(5):e604–21. DOI: 10.1111/hsc.12797
8. Rich EC, Lipson D, Libersky J, Peikes DN, Parchman ML. Organizing care for complex patients in the patient-centered medical home. *Ann Fam Med.* 2012;10(1):60–2. DOI: 10.1370/afm.1351
9. Stacey D, Légaré F, Boland L, et al. 20th anniversary Ottawa decision support framework: part 3 overview of systematic reviews and updated framework. *Med Decis Making.* 2020;40(3):379–98. DOI: 10.1177/0272989X20911870
10. Clark JA, Wray NP, Ashton CM. Living with treatment decisions: regrets and quality of life among men treated for metastatic prostate cancer. *J Clin Oncol.* 2001;19(1):72–80. DOI: 10.1200/JCO.2001.19.1.72
11. Janis IL, Mann L. *Decision Making: A Psychological Analysis of Conflict, Choice, and Commitment.* New York: Free Press; 1977.
12. Hibbard JH, Greene J. What the evidence shows about patient activation: better health outcomes and care experiences; fewer data on costs. *Health Aff.* 2013;32(2):207–14. DOI: 10.1377/hlthaff.2012.1061
13. Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Making.* 2015;35(1):114–31. DOI: 10.1177/0272989X14551638
14. Lofland JH, Johnson PT, Ingham MP, Rosemas SC, White JC, Ellis L. Shared decision-making for biologic treatment of autoimmune disease: influence on adherence, persistence, satisfaction, and health care costs. *Patient Prefer Adherence.* 2017;11:947–58. DOI: 10.2147/PPA.S133222
15. Stacey D, Légaré F, Lewis K, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev.* 2017;(4):CD001431. DOI: 10.1002/14651858.CD001431.pub5
16. Légaré F, Adekpedjou R, Stacey D, et al. Interventions for increasing the use of shared decision making by healthcare professionals. *Cochrane Database Syst Rev.* 2018;7:CD006732. DOI: 10.1002/14651858.CD006732.pub4
17. Hoefel L, Lewis KB, O'Connor A, Stacey D. 20th anniversary update of the Ottawa Decision Support framework: Part 2 subanalysis of a systematic review of patient decision aids. *Med Decis Making.* 2020;40(4):522–39. DOI: 10.1177/0272989X20924645
18. Légaré F, Witteman HO. Shared decision making: examining key elements and barriers to adoption into routine clinical practice. *Health Aff.* 2013;32(2):276–84. DOI: 10.1377/hlthaff.2012.1078
19. 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(1):83. DOI: 10.1186/1471-2318-14-83
20. Légaré F, Brière 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. DOI: 10.1136/bmjopen-2016-014023
21. Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med.* 2012;366(9):780–1. DOI: 10.1056/NEJMp1109283
22. Smith MA. The role of shared decision making in patient-centered care and orthopaedics. *Orthop Nurs.* 2016;35(3):144–9. DOI: 10.1097/NOR.0000000000000243
23. Manhas KP, Olson K, Churchill K, Faris P, Vohra S, Wasylak T. Measuring shared decision-making and collaborative goal setting in community rehabilitation: a focused ethnography using cross-sectional surveys in Canada. *BMJ Open.* 2020;10(8):e034745. DOI: 10.1136/bmjopen-2019-034745
24. Rodriguez-Osorio CA, Dominguez-Cherit G. Medical decision making: paternalism versus patient-centered (autonomous) care. *Curr Opin Crit Care.* 2008;14(6):708–13. DOI: 10.1097/MCC.0b013e328315a611
25. Légaré F, Thompson-Leduc P. Twelve myths about shared decision making. *Patient Educ Couns.* 2014;96(3):281–6. DOI: 10.1016/j.pec.2014.06.014
26. Adekpedjou R, Stacey D, Brière 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. DOI: 10.1371/journal.pone.0202975
27. Rostoft S, van den Bos F, Pedersen R, Hamaker ME. Shared decision-making in older patients with cancer: what does the patient want? *J Geriatr Oncol.* 2021;12(3):339–342. DOI: 10.1016/j.jgo.2020.08.001
28. British Columbia Ministry of Health. The British Columbia: Patient-Centered Care Framework. 2015. Available from: [https://www.health.gov.bc.ca/library/publications/year/2015\\_a/pt-centred-care-framework.pdf](https://www.health.gov.bc.ca/library/publications/year/2015_a/pt-centred-care-framework.pdf). Accessed March 3, 2022
29. Ministry of Health Ministry of Long-term Care, Ontario. Patient First: Action Plan for Health Care. 2018. Available from: [https://www.health.gov.on.ca/en/ms/ecfa/healthy\\_change/](https://www.health.gov.on.ca/en/ms/ecfa/healthy_change/). Accessed March 3, 2022

30. Ministère de la Santé et des Services sociaux du Québec. Continuum de soins et de services en douleur chronique - Orientations et lignes directrices 2021-2026. 2021. Available from: <https://publications.msss.gouv.qc.ca/msss/fichiers/2021/21-947-05W.pdf>. Accessed March 3, 2022
31. Ministère de la Santé et des Services sociaux du Québec. Semaine nationale de la sensibilisation à la douleur chronique - Un plan d'action en gestion de la douleur chronique au Québec. November 11, 2021. Available from: <https://www.msss.gouv.qc.ca/ministere/salle-de-presse/communique-3270/>. Accessed March 3, 2022
32. Haesebaert J, Adekpedjou R, Croteau J, Robitaille H, Légaré F. Shared decision-making experienced by Canadians facing health care decisions: a Web-based survey. *CMAJ Open*. 2019;7(2):E210. DOI: 10.9778/cmajo.20180202
33. Bunn F, Goodman C, Russell B, et al. Supporting shared decision making for older people with multiple health and social care needs: a realist synthesis. *BMC Geriatr*. 2018; 18(1):1–16. DOI: 10.3310/hsdr06280
34. Garvelink MM, Groen-van de Ven L, Smits C, Franken R, Dassen-Vernooij M, Légaré F. Shared decision making about housing interventions for persons with dementia: a four-case care network perspective. *Gerontologist*. 2019; 59(5):822–34. DOI: 10.1093/geront/gny073
35. Backman WD, Levine SA, Wenger NK, Harold JG. Shared decision-making for older adults with cardiovascular disease. *Clin Cardiol*. 2020;43(2):196–204.
36. Cranley LA, Slaughter SE, Caspar S, et al. Strategies to facilitate shared decision-making in long-term care. *Int J Older People Nurs*. 2020;15(3):e12314. DOI: 10.1111/opn.12314
37. Finderup J, Lomborg K, Jensen JD, Stacey D. Choice of dialysis modality: patients' experiences and quality of decision after shared decision-making. *BMC Nephrol*. 2020;21(1):1–12. DOI: 10.1186/s12882-020-01956-w
38. Lewis CL, Golin CE, DeLeon C, et al. A targeted decision aid for the elderly to decide whether to undergo colorectal cancer screening: development and results of an uncontrolled trial. *BMC Med Inform Decis Mak*. 2010;10:54. DOI: 10.1186/1472-6947-10-54
39. Hoefel L, O'Connor AM, Lewis KB, et al. 20th anniversary update of the Ottawa Decision Support Framework part 1: a systematic review of the decisional needs of people making health or social decisions. *Med Decis Making*. 2020;40(5):555–81. DOI: 10.1177/0272989x20936209
40. Jull J, Köpke S, Smith M, et al. Decision coaching for people making healthcare decisions. *Cochrane Database Syst Rev*. 2021;(11):CD013385. DOI: 10.1002/14651858.CD013385.pub2
41. 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. DOI: 10.2196/jmir.6.3.e34
42. Légaré F. Scaling up shared decision making for patient-centred care: Canadian Institutes of Health Research. 2018. Available from: [https://webapps.cihr-irsc.gc.ca/decisions/p/project\\_details.html?applId=369259&lang=en](https://webapps.cihr-irsc.gc.ca/decisions/p/project_details.html?applId=369259&lang=en). Accessed September 29, 2020
43. O'Connor AM, Drake ER, Wells GA, Tugwell P, Laupacis A, Elmslie T. A survey of the decision-making needs of Canadians faced with complex health decisions. *Health Expect*. 2003;6(2):97–109. DOI: 10.1046/j.1369-6513.2003.00215.x
44. Légaré F, Stacey D, Dodin S, et al. Women's decision making about the use of natural health products at menopause: a needs assessment and patient decision aid. *J Altern Complement Med*. 2007;13(7):741–9. DOI: 10.1089/acm.2006.6398
45. Jacobsen MJ, O'Connor AM, Stacey D. Decisional needs assessment in populations. 2013. Available from: [https://decisionaid.ohri.ca/docs/implementation/population\\_needs.pdf](https://decisionaid.ohri.ca/docs/implementation/population_needs.pdf). Accessed February 6, 2019
46. Sepucha KR, Mulley AG. Extending decision support: preparation and implementation. *Patient Educ Couns*. 2003; 50(3):269–71. DOI: 10.1016/s0738-3991(03)00048-x
47. Lai C, Holyoke P, Plourde KV, Décary S, Légaré F. 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. DOI: 10.1136/bmjopen-2020-039102
48. Légaré F, Brière N, Stacey D, et al. Improving decision making on location of care with the frail elderly and their caregivers (the DOLCE study): study protocol for a cluster randomized controlled trial. *Trials*. 2015;16:50. DOI: 10.1186/s13063-015-0567-7
49. Boland L, Légaré F, Perez MMB, et al. Impact of home care versus alternative locations of care on elder health outcomes: an overview of systematic reviews. *BMC Geriatr*. 2017;17(1):20. DOI: 10.1186/s12877-016-0395-y
50. Poirier A, Voyer P, Légaré F, et al. Caring for seniors living with dementia means caring for their caregivers too. *Can J Public Health*. 2017;108(5–6):e639–42. DOI: 10.17269/cjph.108.6217
51. O'Connor AM. Validation of a decisional conflict scale. *Med Decis Making*. 1995;15(1):25–30. DOI: 10.1177/0272989X9501500105
52. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAMA*. 1984;252(21): 2990–4.
53. Brehaut JC, O'Connor AM, Wood TJ, et al. Validation of a decision regret scale. *Med Decis Making*. 2003;23(4): 281–92. DOI: 10.1177/0272989X03256005
54. Siebens HC, Tsukerman D, Adkins RH, Kahan J, Kemp B. Correlates of a single-item quality-of-life measure in people aging with disabilities. *Am J Phys Med Rehabil*. 2015;94(12):1065. DOI: 10.1097/PHM.0000000000000298
55. Légaré F, O'Connor AC, Graham I, et al. Supporting patients facing difficult health care decisions: use of the Ottawa Decision Support Framework. *Can Fam Physician*. 2006;52(4):476–77.
56. Roy N, Dubé R, Després C, Freitas A, Légaré F. 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. DOI: 10.1371/journal.pone.0189266
57. O'Connor AM. User Manual—Decisional Conflict Scale. 1993 (update 2010). Available from: [https://decisionaid.ohri.ca/docs/develop/User\\_Manuals/UM\\_Decisional\\_Conflict.pdf](https://decisionaid.ohri.ca/docs/develop/User_Manuals/UM_Decisional_Conflict.pdf). Accessed September 29, 2020
  58. Ferron Parayre A, Labrecque M, Rousseau M, Turcotte S, Legare F. Validation of SURE, a four-item clinical checklist for detecting decisional conflict in patients. *Med Decis Making*. 2014;34(1):54–62. DOI: 10.1177/0272989X13491463
  59. Sarkar S, Midi H, Rana S. Model selection in logistic regression and performance of its predictive ability. *Aust J Basic Appl Sci*. 2010;4(12):5813–22.
  60. Statistics Canada. Care receivers in Canada, 2018. 2020. Available from: <https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2020002-eng.htm>.
  61. Canadian Home Care Association. Safety at home 1990. Available from: <https://cdnhomecare.ca/safety-at-home>. Accessed September 22, 2020
  62. Doran D, Blais R, Harrison MB, et al. Safety at home: a pan-Canadian home care safety study. Canadian Patient Safety Institute. 2013. Available from: <https://www.patientsafetyinstitute.ca/en/toolsResources/Research/commissionedResearch/SafetyatHome/Documents/Safety%20At%20Home%20Care.pdf>. Accessed September 29, 2020
  63. Canadian Institute for Health Information. The impact of COVID-19 on long-term care in Canada focus on the first 6 months. 2021. Available from: <https://www.cihi.ca/sites/default/files/document/impact-covid-19-long-term-care-canada-first-6-months-report-en.pdf>. Accessed March 3, 2022
  64. 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*. 2020;41(2):233–9. DOI: 10.1177/0272989X20979693
  65. Stacey D, Ludwig C, Lavoie J, Sinha S, Phil D. During the COVID-19 pandemic, should I or my family member go to live with family or stay in the long-term care or nursing home? 2020. Available from: <https://decisionaid.ohri.ca/docs/das/COVID-MoveFromLongTermCare.pdf>. Accessed September 29, 2020
  66. Stacey D, Ludwig C, Lavoie J, Sinha S, Phil D. During the COVID-19 pandemic, should I go to live elsewhere or stay in my retirement/assisted living home? 2020. Available from: <https://decisionaid.ohri.ca/docs/das/COVID-MoveFromRetirementHome.pdf>. Accessed September 29, 2020
  67. van de Pol MH, Fluit CR, Lagro J, Slaats YH, Rikkert MGO, Lagro-Janssen AL. Expert and patient consensus on a dynamic model for shared decision-making in frail older patients. *Patient Educ Couns*. 2016;99(6):1069–77. DOI: 10.1016/j.pec.2015.12.014
  68. Picard A. La COVID-19 au Canada : le sujet d'une vie pour André Picard. 2020. Available from: <https://media-s.uottawa.ca/nouvelles/covid-19-au-canada-sujet-dune-vie-andre-picard/>. Accessed February 8, 2021.
  69. O'Connor AM. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Educ Couns*. 2015;33(3):267–79.
  70. Murray SA, Sheikh A. Palliative care beyond cancer: care for all at the end of life. *BMJ*. 2008;336(7650):958–9. DOI: 10.1136/bmj.39535.491238.94
  71. Kates JM. Treatment-related decisional conflict, quality of life, and comorbidity in older adults with cancer. *Asia-Pacific J Oncol Nurs*. 2018;5(4):421. DOI: 10.4103/apjon.apjon\_32\_18
  72. Bruno BA, Choi D, Thorpe KE, Catherine HY. Relationship among diabetes distress, decisional conflict, quality of life, and patient perception of chronic illness care in a cohort of patients with type 2 diabetes and other comorbidities. *Diabetes Care*. 2019;42(7):1170–7. DOI: 10.2337/dc18-1256
  73. Kirkey S. After the COVID-19 crisis ends, what does our 'new normal' look like? 2020. Available from: <https://nationalpost.com/news/canada/covid19-crisis-new-normal-coronavirus/>. Accessed October 12, 2020
  74. Zimonjic P, Barton R, Ling P. Tam says the pandemic will bring a 'new normal' to workplaces, defends WHO's performance. CBC. 2020. Available from: <https://www.cbc.ca/news/politics/tam-who-defend-new-normal-pandemic-covid-coronavirus-1.5548285/>. Accessed October 16, 2020