


Home care providers' perceptions of shared decision-making with older clients (and their caregivers): A cross-sectional study

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Abstract

Interprofessional care teams can play a key role in supporting older adults (and caregivers) in making informed health decisions, yet shared decision making is not widely practiced in home care. Based on an earlier needs assessment with older adults (and caregivers) with home care experience, we aimed to explore the perceptions of home care teams on the decisions facing their clients and their perceived involvement in shared decision making. A cross-sectional study was conducted with 614 home care providers (nurses, personal support workers, rehabilitation professionals) in three Canadian provinces (Quebec, Ontario, and Alberta). Home care providers considered the decision “to stay at home or move” as the most difficult for older adults. Those most frequently involved in decision making with older adults were family members and least involved were physicians. Although all home care providers reported high levels of shared decision-making, we detected an effect of respondent's discipline on self-perceived shared decision-making; nurses and rehabilitation professionals reported significantly higher levels of shared decision making than personal support workers. A more tailored approach is required to support shared decision making in interprofessional care teams.

KEYWORDS

aged, aged, 80 and over, allied health personnel, decision making shared, home care services, participatory research, personal support workers

Key points

- According to interprofessional home care providers, the most difficult decision for older adults is “whether to stay at home or move.”
- Overall, interprofessional home care providers reported high levels of shared decision-making. However, personal support workers reported lower levels than nurses or rehabilitation professionals. Further research is needed to explore what prevents personal support workers from being more involved in shared decision making. This would enable us to develop interventions that enable them to collaboratively support older adults and their caregivers in making decisions together.

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- Our respondents reported that older adults and their caregivers facing difficult decisions needed most help with information about options, feeling pressure from others, and navigating the health system. Interventions that focus on addressing these needs could enable more older people and their caregivers to participate in decision making processes about their care.

1 | INTRODUCTION

Across the world, an increasing number of older adults are living and aging at home where they face multiple and often difficult health decisions (Asthana et al., 2019; Butterworth et al., 2020; Fitzpatrick & Grace, 2019; Hoffmann et al., 2018; Ploeg et al., 2019). Interprofessional care teams who provide home care services can play a key role in engaging in shared decision-making (SDM) with older adults (and their caregivers) at home. We consider “interprofessional” to refer to all healthcare workers with any training, including personal support workers and healthcare aides. SDM is an interpersonal, interdependent process whereby the healthcare provider and the patient relate to and influence each other as they collaborate in making health decisions together informed by best evidence and by what matters most to them (Légaré & Witteman, 2013; Légaré et al., 2014). SDM can improve an individual's health, well-being, independence, and experience of the health and social care system (Hibbard & Greene, 2013; Shay & Lafata, 2015). Although SDM is a core component of patient and family-centered care, it is still not widely practiced in Canada and older adults in home care have been reported as the least likely to experience SDM of all sociodemographic groups (Haesebaert et al., 2019).

Although home care services vary across jurisdictions in Canada, they generally refer to a basket of services provided by skilled professionals (such as nurses, physiotherapists, occupational or speech therapists, nutrition counselors, and social workers) (Akhtar et al., 2019), as well as home support workers or personal support workers who help older adults with declining ability to manage their activities of daily living (ADLs) such as eating, dressing, bathing, and toileting. In the context of home care, SDM is ideally practiced collaboratively by the whole interprofessional care team (Adekpedjou et al., 2020; Légaré et al., 2011, 2013, 2014). To enable older adults and their caregivers to better work with interprofessional home care teams in making decisions together, it is necessary to assess the decisional needs of patients as they perceive them, as their family caregivers perceive them, and as their care providers perceive them. Older adults' decisional needs may be specific to the type of decision, to the characteristics of individuals making the decisions, and to the types of provider caring for them (Jacobsen et al., 1999 [updated 2013]; Stacey et al., 2020).

Numerous decisional needs assessments have been conducted regarding specific conditions, such as complex care (Poitras et al., 2020), heart disease (Loiselle et al., 2016), and advanced kidney disease (Blumenthal-Barby et al., 2015). However, little

consideration has been given to the decision making needs of older adults (and their caregivers) in the home care setting. In this setting, decisions may be about multiple medical conditions and may also relate to issues beyond their medical conditions, such as decisions about safety and daily activities. A systematic review conducted in 2020 found no decisional needs assessments of older adults receiving home care (Hoefel et al., 2020). In addition, no studies have explored the perceptions of interprofessional home care teams regarding difficult decisions for their clients and the extent of their support for their clients making these decisions.

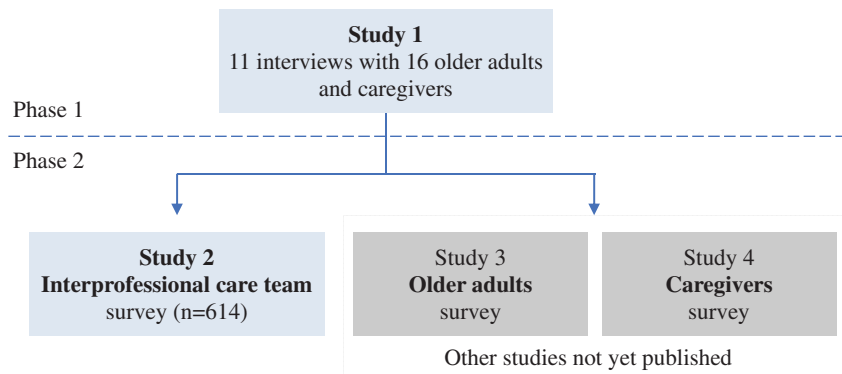
Our two-phase research program began with a needs assessment with older adults and caregivers with home care experience (phase 1). Because home care teams are the front-line providers supporting many older adults at home, in this second phase we aimed to explore their clients' decisional needs through the lens of interprofessional home care providers, as well as the care team members' perceived level of involvement in supporting their clients in making difficult decisions. Results could inform tools for the teams to better support their clients in making decisions together.

Therefore we aimed to explore the perceptions of home care teams regarding the decisions facing their clients and their perceived involvement in SDM.

2 | METHODS

2.1 | Study design

This study is part of a program focusing on the scaling up of SDM across home care services. In phase 1, using a participatory research approach, we conducted 11 open-ended interviews with 16 participants (older adults and caregivers with home care experience) (Lai et al., 2020). The present study, informed by what we learned from phase 1, is a cross-sectional survey of allied health personnel in three provinces (Ontario, Quebec, Alberta) from a Canadian home care company, SE Health (See Figure 1). It complements two other phase-2 cross-sectional studies that assessed decisional needs with older adult respondents and caregiver respondents, respectively, in 10 Canadian provinces (Logon Bomombé et al., 2021; Toi & Légaré, 2021). Ethics approval was obtained from the Research Ethics Board at Southlake Regional Health Centre, Ontario (SRHC REB#016-1920) and Université Laval, Quebec (#2019-221). We used the Checklist for Reporting Results of Internet E-Surveys to report on survey findings (Eysenbach, 2004).

FIGURE 1 Study design

2.2 | Participant advisory group

A participant advisory group consisting of one older adult, one caregiver, and two care providers was created to guide the research process. Members of this advisor group were our research partners and were involved throughout the research process, including reviewing the study protocol and the survey instrument. One of these research partners (LY) took an active role in the data analysis and writing of this manuscript.

2.3 | Survey respondents

Survey respondents were recruited from a Canadian healthcare organization, SE Health, which spans four Canadian provinces. SE Health does not actively promote SDM or offer SDM-related educational programs. We sent emails (with a link to the survey) to allied health personnel at SE Health. At the time of the survey, Ontario, Alberta, and Quebec were the provinces in which the organization had its home care operations. Participants were offered the opportunity to enter a draw for a \$20 gift card (100 gift cards in total) as a token of appreciation for their time and input.

2.4 | Data collection

The web-based survey was conducted from March 10, 2020 to May 5, 2020. The typical response rate for online surveys varies from 10%–20% depending on respondents' occupations (Aitken et al., 2008; Martinez et al., 2017; Surdam et al., 2020). We therefore aimed for a minimal sample size of 10% of the 3000 potential participants (allied health personnel at SE Health).

We collected sociodemographic data (e.g., province, discipline, years of experience, age category, gender, working area). We then asked respondents to assess how often they see older adults faced with 15 decisions (5-item scale of “Always” to “Never”). The 15 decisions were identified from interviews with older adults and their caregivers in phase 1 (Lai et al., 2020). In another question, respondents were asked to indicate which of these 15 decisions they perceived as the most difficult for older adults to make. We also asked respondents to identify elements that might make the decision more difficult, how frequently they support

older adults (and caregivers) with decision-making, and who is involved in the decision process (e.g., wives, husbands, children, friends, care providers).

Informed by the Ottawa Decision Support Framework (Jacobsen et al., 1999 [updated 2013]; Stacey et al., 2020) and previous work in this field (Haesebaert et al., 2019) we also measured respondents' own self-perceived level of SDM involvement using a five-item questionnaire asking them how often they (a) mentioned that clients had a choice of treatment or care plan, (b) presented advantages and disadvantages of the options, (c) asked clients about their care preferences, (d) discussed preferred options, and (e) involved clients (to the extent they wanted to be involved) in the care plan. Responses to the five items were on the same scale, from “Always” to “Never” and “I don't know/prefer not to answer.”

All questions appeared in a one-page survey. There was no randomization of items or questionnaire. The survey was pilot tested by 99 participants before the full survey was launched. The full survey has been published elsewhere by Lai et al. (2020).

2.5 | Data analysis

As our voluntary survey was intended to encourage respondents to provide only what they felt comfortable sharing, most survey questions included an option to select “don't know” or “prefer not to answer”; and respondents could opt to not answer a question at all if it was not relevant to their situation. These options or missed questions appear in the results as “missing data.” When only the sociodemographic questions were answered, data were excluded from the analysis.

Descriptive statistics (e.g., frequencies and percentage) were used to summarize respondents' characteristics and SDM variables. The Likert response choices “always” or “often” were combined, as were “sometimes,” “rarely,” and “never,” for analyzing the following: how often the respondents perceived they saw older adults facing the 15 decisions; how often they supported clients with decision making, and who else was involved in making decisions with the older adult. To see whether decisions selected as most frequent were related to the discipline of the perceiver, a data cross-analysis was performed between the decisions selected as “always” or “often” facing older adults and respondents' disciplines. For statistical analysis, we organized the respondents' practice disciplines into the following four categories:

(1) *personal support workers* (PSWs) (e.g., healthcare aides, health support workers, home care workers), (2) *nurses* (registered practical nurses, licensed practical nurses, registered nurses, nurse practitioners, clinical nurse specialists, registered nurse assistants), (3) *rehabilitation professionals* (physiotherapists, occupational therapists, physiotherapy assistants, occupational therapy assistants, social workers, dietitians, speech language pathologists, recreation therapists, development support workers), and (4) *others* (administrators and respondents who did not specify their discipline). After discussion, authors chose to organize the perceived most difficult decisions into three categories: housing and safety, management of health conditions, and end-of-life, for analyzing statistical associations with respondents' self-perceived levels of SDM.

We calculated the Cronbach alpha for the five items of the SDM questionnaire to verify the reliability of the data in our study sample, which demonstrated high internal consistency ($\alpha = 0.919$). Removal of any of the five questions did not increase reliability. To further assess whether we could aggregate the five SDM involvement items to report a mean SDM score, we conducted a factor analysis (method: principal components; unrotated factor solution; Eigenvalue >1). The factor analysis showed that the five items could be reduced to a single score. Thus, we calculated the mean SDM score for each respondent and the standard deviation (SD) to represent their perceived level of SDM. The mean SDM score ranged from 1 to 5, with higher values representing a higher level of SDM involvement.

Because our dependent variable (SDM mean scores) was left skewed, continuous, as well as bound between 1 and 5, and because the homoskedasticity and normality assumptions were not met when fitting bivariate general linear models, as verified with residuals over fitted values plots and QQ plots, respectively, we chose to use beta regressions to model our data (Hunger et al., 2011). Statistical analyses were carried out using the *betareg* package (v.3.1–4) (Zeileis et al., 2016) in R (v3.6.1, R Studio v1.1.456) (RStudio team, 2020). First, bivariate models were fit. Eight independent variables were tested (age category, province, gender, discipline, years of experience, working area, most difficult decision category, frequency of decision-making support). Significant variables ($p < 0.05$) were then included in the multivariate model and significant effects ($p < 0.05$) were reported. The multivariate model fit the data better than the bivariate models, as indicated by the Akaike information criterion, the Bayesian information criterion, and the Bayes factor. To fit a beta regression, the dependant variable must lie in the]0,1[range. SDM mean scores were thus transformed from their original scale to the open unit interval (0,1) by using the formula $(y-1)/(5-1)$. To avoid zeroes and ones, they were then compressed with the formula $(y \cdot [n - 1] + 0.5)/n$ where n was the sample size (Cribari-Neto & Zeileis, 2010). Transformed SDM scores were beta distributed (α parameter = 2.18, β parameter = 0.68).

3 | RESULTS

3.1 | Characteristics of the interprofessional home care providers

Out of the 3000 potentially eligible respondents (as estimated at the start of study rollout) who were invited to participate via email,

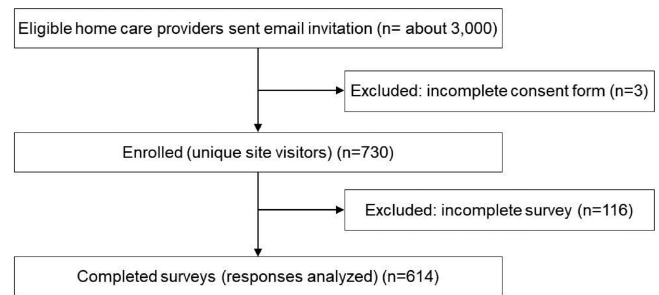


FIGURE 2 Flow chart showing survey respondents

730 (24.3%, 730/3000) unique visitors (based on IP addresses) enrolled in the study. Of these, 116 (15.9%, 116/730) completed sociodemographic questions only and were excluded from the analysis. We did not find any notable sociodemographic differences between those who completed the sociodemographic questions only and those who completed the whole survey. A total of 473 out of the 730 unique visitors answered all the questions (completeness rate 64.8%), including the questions about type of support, their experience in SDM and who is involved in the decision-making, and 614/730 respondents (84.1%) answered at least the first question, about how often their clients faced the proposed difficult decisions (Figure 2), in addition to the sociodemographic questions. As this was our key research question, these 614 respondents were included in the analysis. Average time for survey completion was 15 minutes and 16 seconds. Respondents were mainly from Ontario ($n = 582$, 94.8%) with 31 (5%) from Quebec and Alberta combined. Most respondents were PSWs ($n = 378$, 61.6%), followed by nurses ($n = 173$, 28.2%) and rehabilitation professionals ($n = 54$, 8.8%). Most had provided home care services for 10 years or more ($n = 232$, 37.8%), 558 were female (90.9%), and 235 (38.3%) worked in urban centers (population greater than 500 000) (Table 1). A total of 240 (39.1%) respondents reported that they “always/often” support clients with decision making during home visits.

3.2 | Most frequent and most difficult decisions

Interprofessional home care providers reported seeing older adults faced with all 15 of the decision points identified from phase 1 interviews with older adults and caregivers. Table 2 shows the frequency of the types of decision faced by older adults (and caregivers) as perceived by our survey participants. The three most frequently reported decisions facing older adults receiving home care were “whether to get help with day-to-day activities” (76.7%), the “best options to prevent falls” (75.1%), and the “best options for managing their health condition” (73.8%).

Comparing these results across disciplines, however, interprofessional home care providers tended to report higher frequencies of decisions related to their own field. For example, rehabilitation professionals reported higher frequencies for decisions such as “whether to seek help with ADLs,” “options to prevent falls,” and “best options

TABLE 1 – Characteristics of survey respondents (*n* = 614)

Characteristics	Frequency		
	N	% ^a	
Discipline	Personal support workers	378	61.6
	Nurses	173	28.2
	Rehabilitation professionals	54	8.8
	Others	5	0.8
	Prefer not to answer/missing data	4	0.7
Province	Ontario	582	94.8
	Alberta and Quebec	31	5.1
	Prefer not to answer/missing data	1	0.2
Length of home care experience	Less than 6 months	30	4.9
	6 months to <1 year	43	7.0
	1 year to <2 years	52	8.5
	2 years to <5 years	116	18.9
	5 years to <10 years	138	22.5
	10 years or more	232	37.8
	No answer/missing data	3	0.5
Age	<30 years of age	90	14.7
	31–40	122	19.9
	41–50	151	24.6
	51–60	146	23.8
	61+	94	15.3
	Prefer not to answer/missing data	11	1.8
Gender	Female	558	90.9
	Male	46	7.5
	Other gender	0	0
	Prefer not to answer/missing data	10	1.6
Work area	Urban – population greater than 500 000	235	38.3
	Area population less than 500 000	378	61.6
	No answer/missing data	1	0.2
Frequency of decision-making support for clients	Always/often	240	39.1
	Sometimes/rarely/never	261	42.5
	Missing data	113	18.4
SDM involvement	Mean score (SD)	4.0 (0.93)	
	Median (variance)	4.2 (0.87)	
	Median <4.2	233	45.2
	Median ≥4.2	283	54.8

^aNumbers may not total 100% in all cases due to rounding.
Abbreviations: SD, standard deviation; SDM, shared decision-making.

to stay safe at home” than were reported by the other professionals. They also reported lower frequencies for decisions less in their domain, such as “whether to take medication,” “options to manage pain,” and “options for advance care planning” (Table 3).

When asked to select the one most difficult decision facing older adults (and their caregivers), interprofessional home care providers identified the decision “to stay at home or move” as the most difficult (*n* = 283, 46.1%) (Table 4).

3.3 | Decision support and factors affecting SDM

Respondents identified a number of elements that might make the decision more difficult for older adults (and their caregivers), including the “lack of information about options, risks, and benefits,” (*n* = 354, 57.7%), “confused from information overload” (*n* = 347, 56.5%), “feeling pressure from others” (*n* = 300, 48.9%), and “lacking ability to navigate the health system” (*n* = 278, 45.3%) (Table 5).

TABLE 2 Interprofessional healthcare providers' perceptions of frequency of decisions facing older adults ($n = 614$)

Decisions	Always/often frequency		Sometimes/rarely/never frequency		Missing data frequency
	N	%	N	%	N
Decisions relating to housing and safety					
Whether they should get assistance with day-to-day activities or not?	471	76.7	139	22.6	4
What is the best option for them to prevent falls?	461	75.1	140	22.8	13
What is the best option for them to stay safe at home?	446	72.6	155	25.2	13
Whether they should stay at home or move (e.g., nursing home, assisted living, closer to family)	421	68.6	191	31.1	2
Whether they should seek immediate care or not (e.g., call ambulance, go to hospital)	348	56.7	262	42.7	4
Whether they should stop driving or not	255	41.5	350	57.0	9
Decisions relating to management of condition					
What is the best option for them to manage their health condition(s)?	453	73.8	145	23.6	16
What is the best option for them to manage pain?	411	66.9	190	30.9	13
Whether they should take medication or not	392	63.8	217	35.3	5
Whether they should get surgery or not	152	24.8	451	73.5	11
End-of-life decisions					
What is the best option for them for advance care planning?	357	58.1	240	39.1	17
What is the best option for their location of death (e.g., hospital, at home)?	282	45.9	308	50.2	24
Whether they should choose a palliative approach to care or not	275	44.8	334	54.4	5
Whether they should be resuscitated/intubated or not	229	37.3	372	60.6	13
Whether they should choose medical assistance in dying (MAID) or not	121	19.7	479	78.0	14

In terms of who was involved in decision making with older adults, individuals who were reported as “always” or “often” involved included wives (60.7%, $n = 373$), husbands (54.7%, $n = 336$), daughters (50.0%, $n = 307$), and sons (35.7%, $n = 219$) (Table 5). Interprofessional care providers were reported as less frequently involved in decision making with older adults than family members: including doctors (25.9%, $n = 159$), case managers (24.3%, $n = 149$), and other care providers (19.5%, $n = 120$) (Table 6).

3.4 | Perceived SDM with clients

Respondents reported high self-perceived levels of SDM with their clients, with mean SDM scores 4.0 out of 5.0 ($n = 513$, $SD = 0.93$) (Table 1). As detailed in Table 7, two predictive factors of the mean SDM score were included in our generalized linear model. The first factor was the respondents' discipline: nurses and rehabilitation professionals had higher mean scores for SDM than PSWs (nurses: odds ratio [OR] 1.74 [95% confidence interval (CI) 1.39, 2.17], $p < 0.001$; rehabilitation professionals: $OR = 2.12$ [95% CI 1.51, 2.97], $p < 0.001$). A significant difference in perceived levels of SDM was detected between the PSWs and the “Others” group but was not

considered. Note that only two respondents from the latter group were included in the model and that results pertaining to it might be misleading owing to the small sample size. The second predictive factor was how often the interprofessional home care providers perceived that they themselves supported clients in decision making. The SDM score was higher when the respondents self-perceived that they supported older adults (and caregivers) more frequently than the group that considered themselves as giving less frequent support ($OR 2.09$ [95% CI 1.71, 2.56]; $p < 0.001$). No statistical difference was found between perceived levels of SDM among respondents who worked in urban centers (population $> 500\,000$; $n = 235$) and respondents who worked in nonurban centers (population $< 500\,000$; $n = 378$). Further studies are needed to explore perceptions of home care teams in rural settings (population $< 10\,000$), which have fewer healthcare resources and less medical facility capacity (Nielsen, 2017).

4 | DISCUSSION

We conducted a cross-sectional web-based survey with interprofessional home care providers across a large home care organization spanning three Canadian provinces (Quebec, Ontario, and

TABLE 3 – Decisions selected as often or always faced by older adults, by respondent discipline

Discipline Decision	PSW (n = 378) frequency		Nurse (n = 173) frequency		Rehabilitation professionals (n = 54) frequency	
	N	%	N	%	N	%
Decisions relating to housing and safety						
Whether they should get assistance with day-to-day activities or not	292	77.3	127	73.4	44	81.5
What is the best option for them to prevent falls?	290	76.7	119	68.8	48	88.9
What is the best option for them to stay safe at home?	272	72.0	122	70.5	45	83.3
Whether they should stay at home or move	255	67.5	125	72.3	34	63.0
Whether they should seek immediate care or not	218	57.7	100	57.8	24	44.4
Whether they should stop driving or not	159	42.1	73	42.2	19	35.2
Decisions relating to management of condition						
What is the best option for them to manage their health condition(s)?	283	74.9	126	72.8	39	72.2
Whether they should take medication or not	257	68.0	109	63.0	19	35.2
What is the best option for them to manage pain?	246	65.1	127	73.4	31	57.4
Whether they should get surgery or not	98	25.9	43	24.9	9	16.7
End-of-life decisions						
What is the best option for them for advance care planning?	228	60.3	106	61.3	18	33.3
Whether they should choose a palliative approach to care or not	172	45.5	87	50.3	11	20.4
What is the best option for their location of death?	171	45.2	90	52.0	16	29.6
Whether they should be resuscitated/intubated or not	138	36.5	78	45.1	9	16.7
Whether they should choose medical assistance in dying (MAID) or not	82	21.7	30	17.3	4	7.4

Abbreviation: PSW, personal support worker.

Alberta). We sought their views on decisions facing older adults (and caregivers) in the home care setting and assessed their perceived level of involvement in SDM. “Should I get assistance with day-to-day activities or not?” was considered the decision most often faced, and “Should I stay at home or move?” was considered the most difficult decision, regardless of the respondent’s discipline. Lack of information about options, confusion due to information overload, and feeling pressure from others were the three most frequently reported obstacles to decision-making in older adults (and their caregivers). Family members, especially spouses, were those most frequently reported as involved in making decisions with older adults. Female family members tended to be more involved than males, with wives more frequently involved than husbands and daughters more frequently involved than sons. Overall, respondents reported high levels of SDM. The factors associated with the highest level of SDM were the respondent’s discipline and how often they report supporting older adults (and caregivers) with decision-making. Our results lead us to make the following observations.

First, although several decisions faced by older adults (and caregivers) in the home care setting were mentioned by respondents, the decision about whether or not to get help with day-to-day activities was perceived as the most frequent. This could reflect the

predominance of PSWs in the sample: we noticed that inter-professional care providers reported higher frequencies of decisions related to their own field. This lack of interprofessional awareness of what other team members perceive as frequent decisions facing their clients could result in conflicting priorities and calls for further investigation. Improving this mutual awareness is critical, as the broad scope of home care services requires that diverse allied health personnel collaborate to support older adults (and their caregivers) in making evidence-informed value-congruent decisions together (Légaré et al., 2013; Schot, 2020; Wei et al., 2022).

Second, the decision “to stay at home or move” was found to be the most difficult decision facing older adults (and their caregivers), regardless of the respondent’s discipline. This finding adds to the body of literature on difficulties facing older adults in choosing to stay at home or move (Elidor et al., 2020; Roy et al., 2018). In other studies, older adults and caregivers have independently identified this decision as one of the most difficult they have faced (Logon Bomombé et al., 2021; Toi & Légaré, 2021). Although Boland et al. found insufficient evidence to determine the impact of alternative care locations on the health of older adults (Boland et al., 2017), our findings support the argument that older adults and their caregivers have strong preferences about their home environment, and thus the decision about

TABLE 4 Most difficult decision for older adults (and their caregivers) as perceived by interprofessional care team ($n = 614$)

Decisions	Frequency		Categories
	N	%	Frequency N (%)
Whether they should stay at home or move	283	46.1	Decisions relating to housing and safety
What is the best option for them to stay safe at home?	79	12.9	
Whether they should get assistance with day-to-day activities or not	28	4.6	430 (70.0)
Whether they should seek immediate care or not	22	3.6	
What is the best option for them to prevent falls?	11	1.8	
Whether they should stop driving or not	7	1.1	
What is the best option for them to manage their health condition(s)?	23	3.7	Decisions relating to managing their condition
Whether they should take medication or not	7	1.1	
Whether they should get surgery or not	4	0.7	38 (6.2)
What is the best option for them to manage pain?	4	0.7	
Whether they should choose medical assistance in dying (MAID) or not	19	3.1	Decisions relating to death and dying
What is the best option for them for advance care planning?	17	2.8	71 (11.6)
Whether they should choose a palliative approach to care or not	12	2.0	
Whether they should be resuscitated/intubated or not	12	2.0	
What is the best option for their location of death?	11	1.8	
Missing data	75	12.2	

housing can have a major impact on their well-being and health. Our study results highlight the urgent need to expand our views on health-related decisions faced by older adults and to design effective decision support interventions to address these decisions, which are about much more than medical care.

Third, lack of information about options and confusion due to information overload were the most frequently reported obstacles for older adults and their caregivers facing difficult decisions. This apparent contradiction between lack of information and information overload has been noted in earlier studies (Agbadje et al., 2021) and points to the need for more refined decision aids, especially for older adults in home care, that will better meet their information needs and those of their caregivers. These findings add to the extensive body of literature on decision-making needs (Hoefel et al., 2020; Poitras et al., 2020) that has been driving the recent rapid development of decision aids. Yet our findings highlight the equally important role for interprofessional home care providers in personally explaining and clarifying information on the risks and benefits of options.

Fourth, family members (wives and husbands, followed by daughters and sons) were the people most frequently reported to be involved in decision-making with older adults. Other reports confirm that family members represent the group of caregivers who most frequently support older adults receiving home care (Statistics

Canada, 2018, 2020); however, many older adults do not want to burden their children with their care (Cahill et al., 2009) or else feel pressure from their families – the third most important obstacle to decision making, according to our respondents. Also, families themselves often feel overburdened and unsupported in caring for their relatives. A lack of acknowledgement by healthcare providers of the involvement of families in caring for older adults has been reported in other studies (Manias et al., 2019). Our study adds to the body of literature calling for interventions that recognize family involvement in SDM with their older relatives and that strengthen support for families to play this role. Also, older adults should have the choice to receive the decision support they need from their interprofessional home care providers and not always have to depend on family.

Fifth, our respondents reported high levels of SDM with their clients. This is in sharp contrast with a recently published population-wide survey of Canadians that reported low levels of SDM among older adults receiving home care services (Haesebaert et al., 2019). This difference is not surprising, as self-reporting by clinicians on their own adoption of best practices tends to be high (Creed et al., 2016; Waltman et al., 2016). This result highlights the need for more patient-reported measures of their experience of the healthcare system (Nelson et al., 2015) and also of third-party or observer-reported measures (Basch & Bennett, 2014; Benjamin et al., 2017). Also, we

observed that PSWs reported lower levels of self-perceived involvement in SDM than nurses and rehabilitation professionals. PSWs are

TABLE 5 Obstacles faced by older adults and their caregivers in making difficult decisions (decision-making need, $n = 614$)

Decision-making need	Frequency	
	N	%
Lacking information about options, benefits, risks	354	57.7
Confused from information overload	347	56.5
Feeling pressure from others	300	48.9
Lacking ability or skills to effectively navigate health system (e.g., find appropriate care providers)	278	45.3
Lacking motivation or not feeling ready to make a decision	266	43.3
Confused by conflicting information from healthcare providers	244	39.7
Lacking support from family, friends, and community	243	39.6
Lacking the ability or skill to make a decision	234	38.1
Lacking information on the chances of benefits and harms	212	34.5
Feeling unsupported in decision-making	200	32.6
Unclear about what is important to them	191	31.1
Lacking advocacy skills	163	26.5
Lacking ability or skills to effectively communicate	161	26.2
Lacking support from doctor(s)	145	23.6
Lacking support from case manager(s)	136	22.1
Lacking support from care providers	97	15.8
Participant did not select any of the 16 choices	85	13.8

at the core of services and relations with home care clients (Estabrooks et al., 2015), and they can make significant contributions to the quality of care and outcomes. Our findings point to the urgency of involving PSWs in decision support. Further research is needed to explore what prevents PSWs from being more involved in SDM. Focusing SDM efforts on PSWs offers great promise for meeting the decisional needs of older adults in home care.

5 | LIMITATIONS

Our study has a few limitations. First, this survey took place online, which may have reduced our response rate and completion rate. A relatively low response rate is not unusual for online surveys, and although we do not know why 35.2% of respondents did not complete the whole survey, eligible participants were registered as active healthcare providers and the time required to answer all the questions may therefore have played a role. To the best of our knowledge, this remains one of the largest samples of interprofessional providers to offer their perspectives on SDM in home care. Second, our reminder email to encourage interprofessional home care providers to complete our survey was sent out at the start of the COVID-19 pandemic. We do not know how this affected our response rate. A heavy workload may have deterred interprofessional providers from answering the survey, or else they might have seen it as an opportunity to share their views during a difficult time. Third, our respondents were limited to allied health personnel whom we could access through SE Health. Although respondents were from three Canadian provinces, most were from Ontario, because that is where SE Health predominantly operates. This limits the generalizability of our data. Further research is needed to explore differences across provinces, which is particularly complex because jurisdictions have differing levels of decisional needs and varying resources available for SDM and SDM-related policies. Lastly, we acknowledge that our survey data could be subjected to bias from (1) the nonrepresentative nature of our survey respondents (most were PSWs), and (2) their self-

TABLE 6 Other people involved in decision making with older adults, as perceived by care team ($n = 614$)

	Always/often frequency		Sometimes/rarely/never frequency		Missing data frequency
	N	%	N	%	N
Wife	373	60.7	148	24.1	91
Husband	336	54.7	185	30.1	91
Daughter (s)	307	50.0	214	34.9	91
Designated decision maker (POA)	289	47.1	235	38.3	88
Son (s)	219	35.7	303	49.3	90
Doctor (s)	159	25.9	354	57.7	98
Case managers	149	24.3	369	60.1	94
Other care providers	120	19.5	389	63.4	102
Other family members	77	12.5	442	72.0	93
Friends, neighbors, church members	25	4.1	491	80.0	94

Abbreviation: POA, power of attorney.

TABLE 7 Factors associated with healthcare professionals' reported SDM mean score (multivariate beta regression)

Variables	OR	95% CI	p value
Intercept (N = 489)	1.77	1.52–2.05	6.98 ⁻¹⁴ ***
Discipline			
PSWs (N = 294)	Ref		
Nurses (N = 146)	1.74	1.39–2.17	1.12 ⁻⁶ ***
Rehabilitation professionals (N = 47)	2.12	1.51–2.97	1.26 ⁻⁵ ***
Others (N = 2)	0.10	0.02–0.47	3.14 ⁻³ **
Support for decision making			
Sometimes/rarely/never (N = 253)	Ref		
Always/often (N = 236)	2.09	1.71–2.56	7.95 ⁻¹³ ***

Note:

***Significant to 0.001.

**Significant to 0.01.

Abbreviations: CI, confidence interval; OR, odds ratio; PSW, personal support worker.

selection (volunteer effect) (Eysenbach, 2004). However, PSWs represent a large proportion of the home care work force and few studies have ever documented their perceptions of their clients' decisional needs or their involvement in decision support. Moreover, as SDM was not part of the education program of the healthcare organization, there was less likelihood of social desirability bias. As our exploratory approach enabled us to produce rich data and draw inferences on this understudied population, our findings will enable us to further test what we learned in other home care environments.

6 | CONCLUSION

Interprofessional home care providers reported seeing older adults (and caregivers) most frequently making difficult decisions relating to housing and safety, with the most difficult being about “whether to move or not.” Most team members perceived that they fully engaged in SDM with clients, except for PSWs, who engaged less. Home care providers of different disciplines perceived different decisions as difficult. These findings could shape future interventions to improve interprofessional collaboration in home care teams, tailor SDM training to PSWs, and focus decision support on the most common and difficult decisions for older adults in the home care context.

7 | RELEVANCE FOR CLINICAL PRACTICE

Now that experienced home care teams across Canada have identified the most common and difficult decisions facing older adults in their care, as well as the issues that most frequently block informed decision making, clinicians can better focus their decision-making support for older clients and interventions such as decision guides can be custom-designed at scale to uphold this support. Our results could also be used to guide home care organizations in designing interprofessional SDM training programs tailored for home care teams caring for older adults living at home.

AUTHOR CONTRIBUTIONS

Study design: Claudia Lai, Karine V Plourde, Paul Holyoke, France Légaré. Data collection: Claudia Lai, Paul Holyoke. Data analysis: Claudia Lai, Lily Yeung, Paul Holyoke, Karine V Plourde, France Légaré. Manuscript writing: Claudia Lai, Lily Yeung, Karine V Plourde, Paul Holyoke, France Légaré. All authors listed meet the authorship criteria according to the latest guidelines of the International Committee of the Medical Journal Editors and that all authors are in agreement with the final version of this manuscript.

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CONFLICT OF INTEREST

The authors declared no potential conflicts of interest with respect to the research, authorship, and publication of this article.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author (France Légaré) by email. The data are not publicly available due to privacy and ethical restrictions.

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