Gaps in public preparedness to be a substitute decision maker: time for high school education on resuscitation and end-of-life care?

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Gaps in public preparedness to be a substitute decision maker

Abstract

OBJECTIVES: When a patient is incapable of making medical decisions for themselves, a substitute decision-maker (SDM) makes choices according to the patient's previously expressed wishes, values, and beliefs. Little is known about public readiness to act as an SDM in Canada. This study assessed preparedness, enablers, and barriers to acting as an SDM, and support for a population-level curriculum on the role of an SDM in end-of-life and resuscitative care.

METHODS: From November 2017 to June 2018, a mixed-methods street intercept survey was conducted in Ottawa, Canada at twelve pedestrian areas. Descriptive statistics and logistic regression analysis were used to assess predictors of preparedness to be an SDM and determine support for high school education. Responses to open-ended questions were analyzed using inductive thematic analysis.

RESULTS: The 430 respondents were mostly female (56.5%), residents of Ontario (84.6%) with an average age of 33.9. Although 73.0% of respondents felt prepared to be an SDM, 48.1% reported never having meaningful conversations with loved ones to understand their wishes in the event of critical illness. 68.1% identified important barriers to feeling prepared.

Most respondents (71.9%) agreed that high school students should learn about SDMs, citing age appropriateness, potential societal benefit, and improved decision making, while cautioning the need to respect different maturity levels, cultures and experiences.

INTERPRETATION: The lack of conversation between loved ones on this issue reveals a gap between perceived and actual preparedness to be an SDM for a loved one suffering critical illness, and warrants further exploration of population-level education.

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Introduction

When a patient is incapable of making decisions for their own medical care, choices are made by their substitute decision-maker (SDM) in the spirit of their previously expressed wishes, values and beliefs.[1] Conforming to an established advance care plan (ACP) is associated with better quality of life for patients, positive emotional outcomes for families, and reduced health resource utilization near the end-of-life.[2–5] Too often, however, patient wishes have not been addressed ahead of time and these difficult choices make for challenging conversations in the time pressures of critical illness.

These decisions are increasingly common with an aging demographic – in one American study, 67.8% of patients above 65 years of age required a decision made by SDMs within 48h of admission to hospital.[6] Many barriers to having these conversations remain. A multicentre Canadian study noted the greatest barriers to goals of care discussions, as perceived by clinicians, included families and patients having "difficulty understanding the limitations/complications of life sustaining therapies, [and] lack of agreement among family members."[7]

While there are many studies that report interventions to engage patients in their own ACP, no studies to our knowledge have described public readiness to act as an SDM on behalf of patients. The Ontario government has prioritized "support for more public education about [ACPs] so that patients' wishes for end-of-life care are understood,"[8] with the Auditor General underlining this as an unmet need.[9] Recent media coverage in the New York Times[10] and CBC[11] have discussed initiatives by an American physician in delivering an intervention to high school students, however, to our knowledge no published studies have conducted a formal needs assessment or explored its acceptability in the North American setting.

In this study, we aim to describe public self-reported preparedness to act as an SDM, identify factors associated with public preparedness, and identify barriers and enablers for preparedness. Secondly, we

aim to describe public support for a population-level curriculum centered on substitute decision-making in end-of-life and resuscitative care.

Methods

Study Design

This mixed-methods, cross-sectional public intercept survey was based on the Health Belief model and optimized according to the method described by Dillman et al.[12,13] The questionnaire (Appendix A) was pilot tested on fifteen volunteers and revised for clarity.

Participants provided basic demographics and indicated whether they were a health care provider. Questions explored self-reported preparedness to be an SDM in the context of critical illness or end-of-life, including open-ended questions that asked participants to describe barriers and enablers of their own preparedness. Respondents were also asked about the acceptability of an educational intervention for 16 year-old students regarding SDMs and critical and end-of-life care. Open-ended questions were probed using standardized verbal prompts for clarity and detail.

This triangulation mixed-methods design was chosen to deepen and broaden our understanding of the attitudes and beliefs around SDMs in critical care beyond demographic and experiential factors associated with SDM preparedness and acceptability of public education.

Ethics

This study was approved by the Ottawa Hospital Research Institute Ethics Board (#20170653-01H). Consent was obtained verbally through a standardized script. Results were reported as aggregates.

Participants and Sampling

For the quantitative analysis, the sample size needed to estimate the proportion of the population who felt prepared to be an SDM was estimated using Cochran's formula for large populations.[14] Based on a

5% margin of error and an estimated proportion of 0.5, the minimum sample size was 385. To allow for potential missing data, we chose *a priori* to continue data collection to 400 fully complete surveys.

Eligible participants were aged 16 or older, which is the minimum age to act as an SDM in Ontario. Potential participants were excluded if they did not reside in Canada, if they were unable to provide informed consent, or if unable communicate in either English or French.

Data Collection and Procedures

From November 2017 to June 2018, the survey was conducted in Ottawa, Canada at twelve locations, including transit hubs, shopping malls, and high volume pedestrian areas. A random number generator was used to evenly distribute random start times between 0700h and 1900h among the twelve locations. Each location was visited 3-4 times for 2 hours at a time. A total of 31 weekday and 9 weekend-day excursions were necessary to reach the target sample size.

At each excursion, two investigators approached every 3rd person in the area using a standardized script. The survey was completed in English or French (participant preference). The two investigators also recorded field notes when a participant elaborated on their answers or experiences verbally.

Analysis

Participant socio-demographics and responses to binary and Likert scale questions were analyzed descriptively. For Likert scale items, binary variables were constructed by grouping agree and strongly agree together, and neutral, disagree, and strongly disagree together.

Socio-demographics and responses to other questions were presented descriptively stratified based on the two main outcome variables – self-reported SDM preparedness and the acceptability of a high school curriculum. Multivariate logistic regression was conducted with covariates selected *a priori*. For preparedness to be an SDM, selected predictor variables included socio-demographics, previous SDM

experience, having engaged in ACP for oneself, belief that one will have to act as SDM someday, having had a conversation with loved ones about their values, and comfort in initiating a conversation. For belief that 16 year olds should be taught about SDMs, the selected predictor variables included socio-demographics, SDM preparedness, having engaged in ACP for oneself, previous SDM experience, belief that one will have to act as SDM someday, having had a conversation with loved ones about their values, and belief that substitute decision-making is a learnable skill. All statistical analyses were conducted using SAS 9.4 (SAS Institute Inc., Cary, NC, USA).

Inductive thematic analysis was conducted for open-ended questions that explored perceived enablers and barriers to acting as an SDM and whether or not high school students should learn about SDMs. This was completed by two independent reviewers following the approach described by Braun and Clarke.[15] The two reviewers conducted line-by-line coding of the field notes and survey responses. Through joint discussions between the two reviewers, codes were synthesized and general themes identified. Integration of the qualitative and quantitative results occurred during interpretation and manuscript preparation. Representative quotations are provided below.

Results

Of 873 individuals encountered, 217 were excluded based on activity or group size, and the remaining 656 were approached, of whom 626 were eligible. The overall response rate among eligible participants of 68.7%, with 404 persons fully, and 26 persons partially, completing the survey (Figure 1).

Overall, our sample had an average age of 33.9, with 83.5% of respondents completing at least some college/university (Table 1). Most respondents were residents of Ontario (84.7%) or Quebec (12.1%), with a slight preponderance of female participants (56.5%). Only 15.6% of respondents (age range 18-79, mean 47.9 years) had previously acted as an SDM for an adult loved one. 31.9% had previously created ACPs for themselves.

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SDM preparedness

Although 73.0% of respondents felt prepared to be an SDM, 41.0% of those prepared and 48.1% of all respondents never had a meaningful conversation about their loved one's wishes in the event of critical illness. 75.6% of respondents believed that they would act as an SDM in the future. 74.0% of participants felt comfortable initiating a conversation with loved ones about values in critical illness, and 83.3% of participants believed that having these conversations is a learnable skill.

Figure 2 demonstrates self-reported preparedness to be an SDM. Older age groups, participants who were health care professionals, reported previous SDM experience, previous ACP experience, or a belief that they would act as an SDM in the future, trended towards higher rates of self-reported preparedness. Although those who had participated in a previous conversation with loved ones about their wishes in a critical care scenario, or reported willingness to initiate such a conversation, had a higher rate of preparedness, it did not reach significance (OR 1.23, 95% CI 0.72-2.08). Only two potential factors described above were significantly associated with SDM preparedness – age 50-64 (OR 7.46 95% CI 1.25-44.51) when compared to the under 18 group, and the belief that one would have to act as an SDM in the future (OR 2.36 95% CI 1.34-4.17) (Table 2).

Thematic enablers and barriers for preparedness to be an SDM and representative quotations are shown in Table 3. Key enablers included an understanding of a patient's pre-existing wishes, the role of the SDM and its legal framework, the medical information, as well as strong relationships between the SDM, patient, and family, and trust in the medical team. Of all participants, 68.1% were able to identify barriers to becoming more prepared, which included potential for family conflict, the daunting nature of high stakes decisions, social or cultural barriers to communication and need for time and a quiet setting.

Support for Population Level Education

71.9% of respondents felt that 16 year old students should learn about SDMs for resuscitation and end-

of-life care. This included 95.5% of those aged 16-17. Principally, there was strong agreement between those who believed such topics can be taught, and those who believed it should be taught (Spearman's correlation coefficient of 0.60). Participants who believed that the skill to have a conversation with loved ones about values in critical illness was learnable, had previously had such a conversation, or believed they would be an SDM in the future trended towards agreeing with high school education (Figure 3). In a logistic regression, however, the only significant predictor in the belief that 16 year olds should learn about being an SDM was the belief that having conversations about values around end-of-life and critical illness was learnable (OR 2.57, 95%CI 1.37-4.80). Conversely, age 35-49 was a negative predictor (OR 0.07, 95%CI 0.01-0.78) compared to the under 18 age group (Table 2).

Table 4 demonstrates themes and representative quotations in discussing why 16 year olds should learn about SDMs in resuscitative and end-of-life care. These included the age appropriateness of teaching 16 year olds, a potential developmental benefit, and an overall societal benefit in breaking taboos and raising awareness of what is a universal issue for an aging population. Other participants noted concerns and encouraged a nuanced approach respectful of different maturity levels, cultures and individual experiences and readiness.

Discussion

Of all respondents, 73.0% felt prepared to be an SDM, of whom 41.0% reported having never had a meaningful conversation with their loved ones about their wishes in the event of critical illness. As a key component of an SDM's understanding of the patient's previously expressed wishes, values and beliefs, lack of this conversation strongly suggests a discrepancy between actual and perceived preparedness. We postulate that this is due to poor awareness of the difficulty of real life scenarios, and an optimism bias that it is unlikely to occur in the near future. This is consistent with respondents who described

their inexperience during a loved one's critical illness, and with well-documented unrealistic expectations of survival and quality of life following resuscitative efforts among the general public.[7,16] This may also partially explain why those with previous SDM experience were not more likely to feel prepared to act as one in the future (OR 0.98 95% CI 0.37-2.57).

SDM preparedness was associated with age 50-64 and the belief that one would have to act as an SDM in the future. We posit that 50-64 year olds would be the group with parents and loved ones most likely need an SDM, and most likely to prepare. However, there is likely an element of self-serving and social desirability bias whereby participants who responded that acting as an SDM is likely in the future have a bias towards presenting oneself in a favourable way – i.e. reporting preparedness.[17]

Many of the elements described by our participants as necessities to be a prepared SDM have been enshrined by Canadian provincial laws describing capacity, informed consent, and decision making based on previously known wishes, values and beliefs in the best interest of the patient. Yet a common theme emerging from our interviews is a need for more effective communication – to facilitate an effective relationship between health care providers and patients/SDMs, to know the pre-existing wishes of loved ones, and to better negotiate family conflicts. This is consistent with previous work highlighting effective communication as the most important element of end-of-life care.[18,19] Our study underlines the need for greater public education on these topics as well as emphasis on training to improve health care provider communication.

Past work has demonstrated that although physicians often trigger discussions regarding end-of-life and critical care when a patient's disease becomes severe, disease severity does not predict patient readiness for a discussion.[20] Furthermore, members of the public generally welcome the opportunity to discuss their wishes, even when well.[16] In our cohort, 75.6% of our participants believed they would have to act as an SDM in the future; the universality of this issue warrants consideration of a more

population based solution. Although interventions to facilitate ACPs have been described,[21] preparation to be an SDM on behalf of loved ones would likely be synergistic.

Similar to sexual education, the high school setting provides an opportunity for universal education among generally mature individuals. This also seems warranted given that Canadian law bestows the right to act as an SDM on individuals at the age of 16-19 depending on province or territory. Indeed, several of our participants described their experiences as an SDM at a young age, and the age range of respondents reporting past SDM experience was 18-79.

To our knowledge, this is the first study to quantify the acceptability of high school education around palliative and critical care concepts in a North American setting and explore public attitudes towards it. Some pioneers, however, have begun to deliver such programs. Beccaro et al. have described a pilot program in Italy,[22,23] and an intensive care physician has also delivered classes and advocated for the idea in California.[10]

Limitations

The street intercept methodology is inherently biased towards persons likely in high pedestrian areas of Ottawa, Canada. We did however, take steps to minimize any selection bias through our protocolized interception of every 3rd person in the area. We chose not to recruit persons in a health care setting as we believe that a needs assessment should encompass all individuals – not only those actively using services. The external validity of our findings to Ontario, Quebec, and Canada as a whole remains to be established.

Conclusions and Future Directions

Our study reveals a gap between actual and perceived preparedness to be an SDM and provides preliminary support for the development of a high school curriculum around these issues. Our study is

encouraging, and supports future studies to characterize SDM preparedness, barriers, and support for educational interventions on a national level with an eye towards eventual curriculum design. We hope this will normalize the conversation around resuscitation, end of life care, death, and caregiving. This has the potential to inform education policy and formal curriculum development in Ontario, Canada, and worldwide.

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Contributors

MKYW produced the idea for the study. MKYW, MJ, JRF, LMF, and WJC designed the study and survey. MKYW, KYL, and MCM designed the protocol to intercept participants and gathered data. MJ conducted statistical analysis, MKYW and WJC conducted qualitative analysis. All of the authors contributed substantially to the manuscript, drafted the article or revised it critically for important intellectual content, approved the final version submitted for publication and agree to act as guarantors of the work.

Figure Legend:

Figure 1. Recruitment of street intercept participants, *includes those who chose to skip a question

Figure 2. Self-reported preparedness to be a substitute decision maker for a loved one suffering critical illness, by demographics and potential predictors; SDM, substitute decision maker; ACP, advance care planning, conversation refers to conversation regarding wishes of loved ones in the event of critical illness or end-of-life

Figure 3. Participant reported belief that 16 year old students should learn about substitute decision making in the context of critical illness; SDM, substitute decision maker; ACP, advance care planning, conversation refers to conversation regarding wishes of loved ones in the event of critical illness or end-of-life

Tables

Table 1. Characteristics of 430 Survey Respondents

	Number (%)
Age	
Under 18	23 (5.3%)
18-34	253 (58.8%)
35-49	62 (14.4%)
50-64	53 (12.3%)
Over 64	36 (8.4%)
Gender	
Female	243 (56.5%)
Male	186 (43.1%)
Other	1 (0.2%)
Health Care Professional	34 (7.9%)
Province of Residence	
Ontario	364 (84.7%)
Quebec	52 (12.1%)
Other	8 (1.9%)
Missing Data	6 (1.4%)
Education	
Did not complete high school	20 (4.6%)
High school	49 (11.4%)
Some college / university	124 (28.8%)
Completed college / university diploma	166 (38.6%)
Working on or completed post-graduate studies	48 (11.2%)
Professional degree	21 (4.9%)
Previously acted as an SDM	67 (15.6%)
Previously participated in ACP for self	137 (31.9%)

Table 2. Logistic regression models identifying associations with preparedness to act as a substitute decision maker and acceptability of high school education around substitute decision making and critical care

	Self reported preparedness to act as a substitute decision maker for an adult loved one, OR (95%CI) [p value]	Reported belief that 16 year olds should learn about resuscitation and end-of-life, OR (95%CI)
Age		
Under 18	Reference	Reference
18-34	1.13 (0.30-4.17)	0.11 (0.01 - 1.16)
35-49	3.29 (0.69-15.57)	0.07 (0.01 - 0.78)
50-64	7.46 (1.25-44.51)	0.10 (0.01 - 1.08)
Over 64	3.44 (0.64-18.52)	0.11 (0.01 - 1.23)
Gender		
Female	Reference	Reference
Male	1.64 (0.98-2.74)	1.16 (0.71-1.89)
Health Care Professional		
Yes	1.74 (0.53-5.75)	0.67 (0.28-1.59)
No	Reference	Reference
Province		
Ontario	Reference	Reference
Quebec	0.53 (0.26-1.08)	1.02 (0.50-2.07)
Other	1.70 (0.19-15.14)	1.16 (0.20-6.87)
Education		
Did not complete high school	Reference	Reference
High school	0.76 (0.18-3.24)	1.30 (0.20-8.62)
Some college / university	0.86 (0.20-3.70)	1.01 (0.16-6.23)
Completed college / university diploma	0.66 (0.15-2.90)	1.22 (0.20-7.52)
Working on or completed post-graduate studies	1.46 (0.25-8.43)	0.90 (0.13-6.02)
Professional degree	0.35 (0.05-2.29)	1.24 (0.15-10.11)
Previously acted as an SDM	0.98 (0.37-2.57)	0.77 (0.37-1.60)
Previously participated in ACP for self	2.01 (1.06-3.83)	1.71 (0.96-3.07)
Belief that will have to act as SDM	2.36 (1.34-4.17)	1.90 (1.07-3.37)
Had conversation with loved ones about wishes in critical illness	1.23 (0.72-2.08)	1.20 (0.72-2.01)
Willingness to initate conversation with loved ones about wishes in critical illness	1.47 (0.84-2.57)	Not included in model
Learnable skill	Not included in model	2.57 (1.37-4.80)
Self-reported preparedness	Not included in model	0.98 (0.55-1.74)

Abbreviations: SDM, substitute decision maker; ACP, advance care planning

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Table 3. Self-reported Enablers and Barriers of Substitute Decision Maker Preparedness

Theme	Sub-themes	Representative Quotations
Real-life experience	- Difficulty in knowing how to prepare oneself	*Participant 217 (describing her experience with changing the code status of her parent from DNR to full code as she died): My mother had advanced dementia. When [she died] we did not know what to expect. We wanted her to be comfortable but she didn't look comfortable [when she died]. If we had known how difficult it would be to watch CPR [cardiopulmonary resuscitation] we would have stopped. [We need] more guidelines on how to prepare oneself. What questions to ask a parent. We thought we were prepared and we weren't [...] we really didn't know what questions to ask.*
Information necessary for decision making	- Understanding pre-existing wishes through conversation, living wills, etc.	*Participant 100: I watched my dad go through this with my grandfather and he had Alzheimer's but they had discussed this sort of things beforehand so it made things a lot easier on him because he already knew what my grandfather wanted and how to handle the situation.*
Understanding the role of the SDM	- Understanding capacity and SDM legislation - Clarity of who the legal SDM is - Voluntary - No secondary gain	*Participant 45: Need to have legal rights [explained] especially if you were to come at odds with medical team.* *Participant 399: It's not clear what we expect from the SDM - it's important to know and understand the different options that are available to help guide the SDM.*
Relationships between SDM / patient / family	- Family consensus - Fear of family conflict and social pressures	*Participant 217: We [made] some bad decisions for my mother trying to keep some of my siblings happy [...] Experience is a huge factor in empathy and understanding, and differentiating between what a loved one is saying and what they need.*

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Attributes of the SDM	- Maturity, strong value system - Willingness to separate personal and patient values - Previous life experience - Ability to act rationally despite distress of situation	*Participant 218: [You] need to be a good listener so you can understand the situation, need to be considerate of what the loved one would want, need to be rational and not too emotional.*
Relationship with medical team	- Clear communication of medical information – quality of life prognosis; risks, benefits, and alternatives of treatments - Trusting relationship with medical team	*Participant 223: My mother didn't have a POA in place before getting sick and I was the SDM, but the healthcare team treated me as if they didn't think I had a right to be making decisions so this made it very difficult. I had to advocate on her behalf to the medical team.*
External influences on the SDM	- Social and cultural barriers to communication - Time and calm decision environment - Previous training	*Participant 223: I am more open than the rest of my family to having conversations about end-of-life. Every time I try to initiate conversations about their wishes they stop me. They are not open to discussing these kinds of things.*
Fears	- Fear of guilt post-decision - High stakes / burden of responsibility	*Participant 244: [Barriers include the] uncertainty of you making the final decision for someone else [...and the] responsibility of living with that decision for the rest of your life.*

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Table 4. Reported Benefits and Disadvantages of High School Education

Theme	Sub-themes	Representative Quotations
Age appropriateness	- Existing experience within families - Legal right denotes societal responsibility to prepare - Cognitive and emotional maturity - Subset of immature students who may not be ready	*Participant 71: I agree because I think that if someone can legally make a decision, they should know all the information that comes with that right. People are taught about sex at 14, this is just as important and they are mature enough to understand this as well* *Participant 414: Some 16-year olds are pretty immature and they would have to be mature to be taught this.*
Developmental benefit	- Improved decision making - Increased sense of responsibility and maturity - Developing personal beliefs	*Participant 361: By 16 they understand that death happens [...] they will walk out of learning this and have bigger conversations with their friends and family about this topic.*
Decreases stress or distress at the time of a real decision	- Unpredictability in timing of a real-life situation	*Participant 220: I had to make these decisions as a 24-year-old. My mom as a health care provider always let me know what she wanted. From when I was young (10 and onwards) I felt equipped to support her and her decisions when the time came regardless of my personal feelings.*
Societal benefit	- Universal issue – awareness needed - Breaking taboos - Taking care of parents	*Participant 399: It's like sex ed - are you going to hide it from them? It's important to have these conversations because they can be put in this situation at any time. If you see your parents going through it you might wonder what's going on so it's good to be educated on this topic. It shouldn't be a taboo subject.*
Potential difficulties or harm in select students	- Mandatory vs. opt in vs opt out	*Participant 45: People are having kids later these days and this could come up sooner in a person's life. Someone could be an only child and would need this info. No one is ever prepared for the psychological and emotional stress that comes with this.*
Risk of bias	- Teacher and facilitator dependent	*Participant 414: Have to consider religious [implications], family members, customs, language, and country of origin.*

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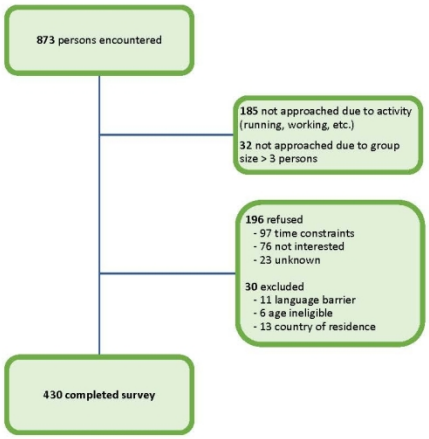
Figure 1. Recruitment of street intercept participants, *includes those who chose to skip a question



215x279mm (200 x 200 DPI)

Figure 2. Self-reported preparedness to be a substitute decision maker for a loved one suffering critical illness, by demographics and potential predictors; SDM, substitute decision maker; ACP, advance care planning, conversation refers to conversation regarding wishes of loved ones in the event of critical illness or end-of-life

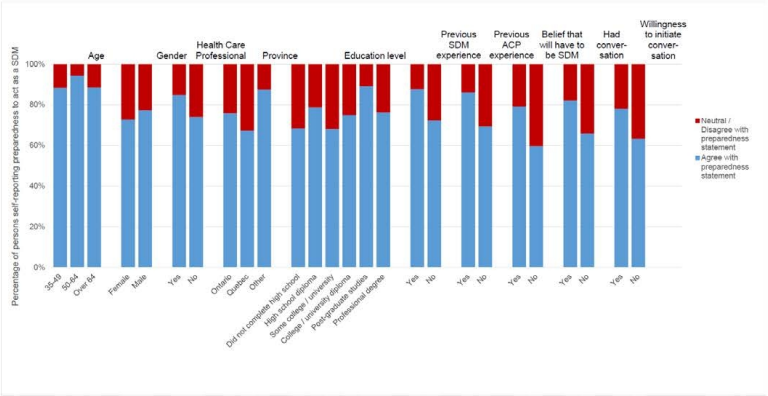


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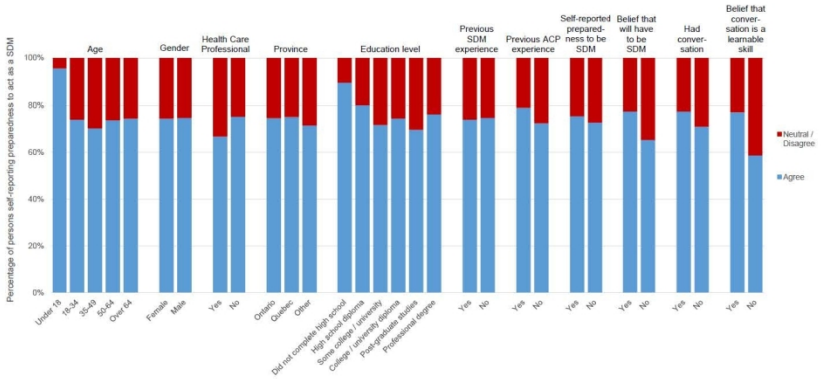
Figure 3. Participant reported belief that 16 year old students should learn about substitute decision making in the context of critical illness; SDM, substitute decision maker; ACP, advance care planning, conversation refers to conversation regarding wishes of loved ones in the event of critical illness or end-of-life



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