Proxy medical decision-making: national survey

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ABSTRACT

Objectives Population ageing and increased care needs lead to adults making consequential medical decisions for others, potentially impacting treatment and end of life. We aim to describe the prevalence of medical decision-making by proxy among the national population and associated demographic and care factors.

Methods We designed a cross-sectional online survey with a nationally representative adult cohort with an 80% participation rate. 311 Singapore residents completed the survey.

Results 73% of respondents reported having ever assisted others with medical decisions, while 58% have ever assisted with activities of daily living (ADLs), and 88% with instrumental ADLs (IADLs). Having a digital caregiver account, having a lasting power of attorney as a donee and assisting with ADLs and IADLs are significantly associated with proxy medical decision-making. Gender, ethnicity, income and age did not appear to have a significant impact.

Conclusions A majority of Singapore adults assist others with caregiving tasks and medical decision-making. These helping behaviours are often performed informally, which may increase decisional burden for caregivers and potential abuse of power.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ It is known that caregivers often make decisions on behalf of patients, but the prevalence, type of medical decisions and factors associated with making such decisions are not known. A study on the characteristics of individuals who make medical decisions on behalf of others was needed to understand the prevalence of helping behaviours and factors associated with them.

WHAT THIS STUDY ADDS

⇒ This study provides data on caregiving and medical decision-making by Singapore adults on behalf of others, demonstrating higher-than-expected rates. Making medical decisions by proxy is associated with having a digital caregiver account, having a lasting power of attorney (LPA) as a donee, and assisting in caregiving. This study also grants a picture of healthcare and caregiving literacy in the Singapore population and finds informal caregiving and decision-making (without an LPA or digital proxy account) prevalent, highlighting an opportunity to increase uptake of formalised care arrangements.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Given the high prevalence of assisting others with care duties and decisions, and at times informally as well, support via increasing uptake of digital caregiver accounts, advance care directives and formalising medical decision-making may contribute towards reducing the decisional burden on caregivers and respecting patients' wishes.

INTRODUCTION

In addition to direct physical care, individuals may support friends or loved ones through capacity transfer in financial aspects (such as sharing joint accounts),[1] medical decision-making (such as advanced care plans (ACPs)), and financial or legal arrangements; such arrangements include digital caregiver accounts which allows one to access health data and make treatment or care placement decisions for another and lasting power of attorney (LPA), which appoints a donee to make decisions on a donor's behalf if they lose mental capacity.[2] These arrangements document patients' preferences, reduce contention and improve patient care/satisfaction[3] and are increasingly needed in ageing Singapore due to higher care needs.[4]

Most of these capacity transfers are made to informal (ie, unpaid) caregivers[5] and are increasingly engaged digitally, as exemplified in the 'Gift of Certainty', a government website encouraging ACP and LPA applications.[6] As digital health technologies expand, so do caregivers' roles and responsibilities, including managing home-based care technologies and navigating patients' increasing marginalisation as society grows more digitised.[7]

RELATIONSHIP BETWEEN CAREGIVING AND MEDICAL DECISION-MAKING

Caregivers are more likely to be female, often daughters[8] and chosen by care recipients.[9] Caregivers are often involved in making important, high-stakes medical decisions (defined as those surrounding care or end of life (EOL)) for patients[10]; their involvement in decision-making has been linked with illness care involvement.[11] There are concerns about caregivers abusing such decision-making power, acting against patients' wishes or overriding professionals' authority.[12] Research on medical decision-making delegation is often patient-centric, finding that patients often choose companions or children as proxy decision-makers[13] and delegation to informal caregivers occurs more often with older, male, less educated and poorer patients.[14] Surveys on caregivers' perspectives of their involvement in care roles and decision-making for other adults are rare.

In Singapore, the most common informal caregivers are adult children of seniors,[15] with about half receiving assistance with care tasks from an employed domestic worker/maid.[16] However, formal paid caregivers largely do not make decisions for patients, retaining this decisional burden for informal family caregivers.[17] Locally, informal caregivers are involved in making medical decisions with and for patients, especially around EOL and life-extending treatment.[12 18] However, less is known about how demographic, legal arrangement and care involvement factors are associated with medical decision-making on behalf of others. Hence, it would be worthwhile to study in Singapore the factors associated with high-stakes medical decision-making on behalf of others. As mentioned above, the literature suggests that making medical decisions for others would be influenced by age, gender, income, ethnicity and involvement with physical caregiving.

RESEARCH AIMS

Our team was interested in ascertaining (1) the prevalence of proxy medical decision-making and formalised care arrangements (such as LPA and digital finance or caregiving accounts) among adults in Singapore and (2) the demographic and behavioural factors associated with proxy medical decision-making. Thereafter, we would ascertain the extent of such helping behaviours and whether they are engaged formally or informally. Answering these questions would help explore implications such as caregiving or decision-making burden by caregivers, lack of accountability or even potential abuse of power, which may help guide clinicians and policy-makers in supporting patients and their caregivers.

METHODS

Our team undertook a survey of the Singapore adult population focused on involvement with caregiving assistance, proxy medical decision-making and formalised care arrangements, with 107 questions. The findings in this paper focus on adults making medical decisions on behalf of other adults aged 21 years and above. The survey is available in online supplemental material A. The Checklist for Reporting Results of Internet E-Surveys Checklist can be seen in the Research Checklist.

In this section, we describe the definitions of the terms used, the survey design and sources of the items we used, where available. Where possible, we have rounded percentages to whole numbers for clarity.

Language and definitions

In this survey, we defined a proxy as someone who carries out tasks on behalf of another adult. Tasks were divided into physical and digital tasks. A delegator is an adult who requires help with these tasks; however, a simpler language of 'helping another adult' is used to identify the delegator in the survey. Additionally, we used this phrasing because we wanted participants to distinguish helping behaviour from parenting duties where a person below 21 years old is helped.

We define delegation formally through established authorisations such as LPA, ACP and digital caregiver accounts. Practically, proxies or caregivers may assist in medical decision-making through less formalised methods, such as sharing credentials/using the account of a delegator or influencing medical decisions without formal agreements.

Survey design

We included predictors previously identified in the literature, such as gender, ethnicity, education, as well as other potential factors like housing, age, religion, marital status and sibling order. Survey items were not randomised, and adaptive questioning was employed to make the survey less complex for respondents. Completeness checks were built into the survey instrument. Participants could review and change their responses with the review function.

We adapted the activities of daily living (ADLs) and instrumental ADL (IADLs) scales to assess respondents' assistance with others' care needs. These measure functional assistance in six basic activities (washing, dressing, feeding, toileting, walking/moving and transferring) that comprise independent living and eight additional functional areas of living (such as

housekeeping, cooking and managing laundry, among others), respectively. We added an item on assisting with digital tasks (such as logging onto mobile apps, operating applications, checking emails and changing device settings) under the IADL basket. In adapting these scales for respondents, we first describe the task, then ask the highest frequency ever of help respondents have offered to others, ranging from daily, weekly, monthly, yearly and never.

We next asked about owning a caregiver digital account, which grants respondents decision-making power through an online portal, and whether respondents have LPA arrangements with the person they are helping. We also asked about how they help other adults with financial tasks, taking reference from a survey by Latulipe et al in Canada exploring similar tasks, such as online banking.[19]

We then asked whether respondents have ever helped another adult with high-stakes medical decisions, such as discussing what would make an adult's life worth living and being involved with EOL decisions, with responses being 'yes,' 'no, but I should have,' and 'no, because I didn't need to.' These were coded to indicate a decreasing magnitude of assistance with medical decision-making. Our survey focused on any instance of help as opposed to regular help, to gain a more comprehensive view of the helping landscape among adults; limiting ourselves to those helping regularly may miss out on those who had helped episodically or in times past.

To conceptualise high-stakes medical decision-making, we aggregated 13 items regarding becoming a medical decision-maker for another adult, signing documents on behalf of another adult, conversations about what makes another adult's life worth living, conversations about what another adult would want near EOL and the respondents' flexibility in making medical decisions for another adult (see online supplemental material B). This resulted in a continuous variable ranging from 0 to 26. These items were based on a caregiver decision-making scale by Van Scoy et al,[20] which helped condense questions assessing consequential outcomes for both care recipients and givers. For instance, signing documents on behalf of a care recipient grants considerable power and agency to the caregiver, potentially affecting life-changing decisions. An example survey question coded for high-stakes medical decision-making is:

Have you ever talked to another adult about what that adult would want if they were very sick or near the end of life?

To conceptualise low-stakes medical decision-making, we aggregated four items comprising assistance with more routine and less consequential medical tasks, such as making appointments for another adult or helping with medications for another adult (see online supplemental material B). These tasks maintain the status quo of care but have less impact on consequential, life-changing decisions. Similar to the items of ADLs and IADLs, respondents are asked the highest frequency they have assisted in such tasks, including daily, weekly, monthly, yearly and never. A sample question is:

I have helped to make appointments for another adult's medical care.

Recruitment

Survey respondents were recruited through an online survey company between December 2022 and February 2023. We endeavoured to recruit a sample similar to the resident Singapore population by applying demographic constraints aligned to Singapore's national census during recruitment. Respondents' demographics were later compared with census data, demonstrating broad similarity (refer to table 1). Informed consent was taken; participants were informed about study purpose and investigators, that personal information would not be taken, the survey would take approximately 40 min to complete, and their response data would be stored for 10 years before disposal. Respondents were compensated with vouchers for their time. Unique participants were ensured using IP addresses. Exclusion criteria were not being residents of Singapore (verified by comparing respondents' self-report and IP addresses) and being below 21 years of age.

Participation rate was 80%. Of those who accessed the survey link, 97% completed the first page and 59% completed the entire survey (overall completion of 47%). Attention checks were built in to ensure response robustness. Cookies were used on the last page, valid for a week, with duplicate entries avoided by preventing users with the same IP address access to the survey twice. A manual log file was also checked for multiple entries. No minimal timestamp was used—we grouped related items across multiple pages and mixed mandatory and optional items to maintain engagement.

Participants

A total of 311 Singapore residents completed the survey, with their demographics summarised in table 1. Only complete surveys were analysed. The survey population was largely similar to the Singapore population based on available census/ministry data,[21] so weighing was not applied. Survey respondents had slightly more males proportionally (53% compared with the national 49%), slightly fewer married individuals (57% compared with 62%) and more singles (36% compared with 29%). Those 70 and above were under-represented in the survey, at 1% of the survey population compared with about 12% of the Singapore population. The income curve followed the national pattern, with the largest proportion of individuals in the US$50 000–US$99 000 yearly income bracket, although a relatively higher proportion of survey respondents were in the US$100 000–US$149 000

Table 1 Summary of demographics of survey respondents

Variable	Respondents (%)	Singapore Census (%)
Sex		Year 2023
Male	164 (53%)	49%
Female	147 (47%)	51%
Marital status		Year: 2022
Married	177 (57%)	62%
Single	113 (36%)	29%
Divorced/separated/widowed	21 (7%)	9%
Age		Year: 2023
21–24 years	32 (10%)	(20–24 years): 6%
25–29 years	30 (10%)	7%
30–34 years	36 (12%)	7%
35–39 years	33 (11%)	6%
40–44 years	26 (8%)	7%
45–49 years	35 (11%)	7%
50–54 years	25 (8%)	7%
55–59 years	45 (14%)	7%
60–64 years	36 (12%)	8%
65–69 years	10 (3%)	7%
70 years and above	3 (1%)	12%
Housing		Year: 2022
Condominium/landed	54 (17%)	5%
3/4/5-room flat	243 (78%)	88%
1/2-room flat	14 (5%)	(HDB 1 and 2-room flats): 7%
Sibling order		
Oldest	122 (39%)	NA
Middle	108 (35%)	
Youngest	81 (26%)	
Income		Year: 2022
<US$30 000 yearly	57 (18%)	20%
US$30 000–US$49 999 yearly	42 (14%)	22%
US$50 000–US$99 999 yearly	88 (28%)	33%
US$100 000–US$149 999 yearly	75 (24%)	14%
US$150 000–US$199 999 yearly	31 (10%)	4%
>US$200 000 yearly	18 (6%)	7%
Ethnicity		Year: 2023
Chinese	251 (81%)	73%
Malay	39 (12%)	14%
Indian	15 (5%)	9%
Others	6 (2%)	4%
Education		Year: 2022
Degree and above	183 (59%)	36%
High school	121 (39%)	43%
Below high school	7 (2%)	21%
Religion		Year: 2020
No religion	62 (20%)	20%
Buddhism	106 (34%)	31%
Catholicism	14 (4%)	Not available

Continued

Table 1 Continued

Variable	Respondents (%)	Singapore Census (%)
Christianity	60 (19%)	19%
Hinduism	11 (4%)	5%
Islam	46 (15%)	16%
Taoism	12 (4%)	9%

yearly income bracket (24%) than the national average (14%). Chinese were slightly over-represented (81% to the national 73%), while Indians were slightly under-represented (5% to the national 9%). Survey respondents were more educated, with proportionally more (59%) having degrees or higher qualifications compared with the nation (36%).

Analysis
Linear regression was performed by using R V.4.3.1 to assess the impact of demographic and care arrangements on proxy medical decision-making. We first examined independence of our various demographic and behavioural factors by inspecting correlation matrices.

Figure 1 shows the correlation matrix between variables, which found that assisting with ADLs, assisting with IADLs, and making proxy low-stakes medical decisions were moderately correlated (0.69–0.73). Conceptually, ADLs and IADLs describe distinct sets of tasks. From a caregiver's perspective, assisting with ADLs involves more direct physical care compared with assisting with IADLs, so we retained both in the regression model. Conversely, as IADLs and low-stakes medical decision-making covered similar tasks, and the latter was less comprehensive with only four items, it was removed from the model due to its correlation with IADLs (0.72).

Only three variables had missing values: gender (<1% missing), ethnicity (3% missing) and siblings (24% missing). The mice package was used to impute missing values using classification and regression trees.[22] Thereafter, univariate analysis of association with proxy medical decision-making was run for each variable. We used linear regression for continuous variables, t-test for sex and Krusak-Willis test for categorical variables. Variables with a p value of 0.25 or less were selected for potential inclusion in a multivariate logistic regression model to predict proxy medical decision-making. This p value threshold was suggested to avoid inadvertently excluding important variables.[23] We evaluated global fitness of the final model by examining the R-squared and Akaike information criterion (AIC).[24]

RESULTS
Helping behaviours
Figure 2 shows the prevalence of respondents having assisted with ADLs/IADLs, digital caregiver accounts,
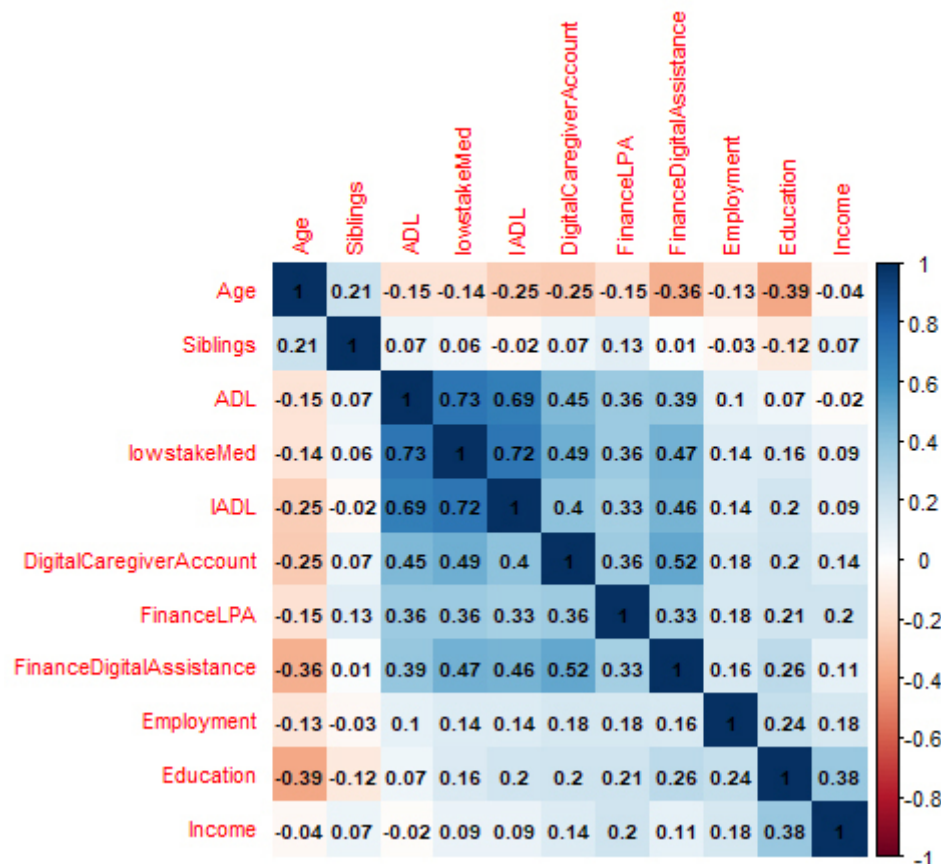
Figure 1 Correlation matrix of predictors for high-stakes medical decision-making on behalf of others, prior to adjustment, demonstrating moderate correlation between assisting with ADLs, assisting with IADLs and making proxy low-stakes medical decisions (0.69–0.73). ADLs, activities of daily living; IADLs, instrumental ADLs.

LPAs or high-stakes and low-stakes medical decision-making. More Singapore residents assist others in IADLs (88%) than with ADLs (58%). The rate of respondents having ever assisted with care tasks is higher than expected in the adult population, compared with 8% of respondents of the National Health Survey 2010 reporting they provided regular care or assistance to others (more recent figures are lacking). In addition, 43% of respondents have ever assisted with digital finance tasks, while 26% have an LPA, and 29% have a digital caregiver account.

Factors associated with assisting in high-stakes medical decision-making

Regression analysis of factors influencing assisting in high-stakes medical decision-making resulted in the following findings in table 2

Backwards stepwise removal of variables was applied to the model using AIC. Having a digital caregiver account, having LPA as someone's donee and assisting in ADLs and IADLs emerged as factors significantly associated with proxy medical decision-making (table 3) in the multivariate model. Gender, ethnicity, religion, marital status and sibling order did not appear to have a significant impact.

DISCUSSION
Principal findings
Roughly 73% of respondents assist others with high-stakes and low-stakes medical decisions, which is comparable with literature on caregivers' involvement with decision-making for patients.[25] 58% of respondents assisted with ADLs, and 88% with IADLs, higher than the National Health Survey 2010 which found 8% of Singapore adults aged 18–69 provided regular care to friends or family.[26] This could be explained by our survey asking if respondents had ever assisted rather than regular and current assistance.

More respondents assist others in IADLs than with ADLs. Adults with established care arrangements, such as digital caregiver accounts or LPA donees, are also involved with making high-stakes medical decisions on behalf of others. Hence, respondents are more likely to assist in less direct/physical forms of care, such as help with finances and medical decision-making, as opposed to physical care tasks. This could be due to formalised or employed caregiving, such as domestic helpers or maids, tasked to meet the physical care needs of patients.[15]

Prevalence of helping behaviours, including proxy medical decision-making, among adult respondents (%)
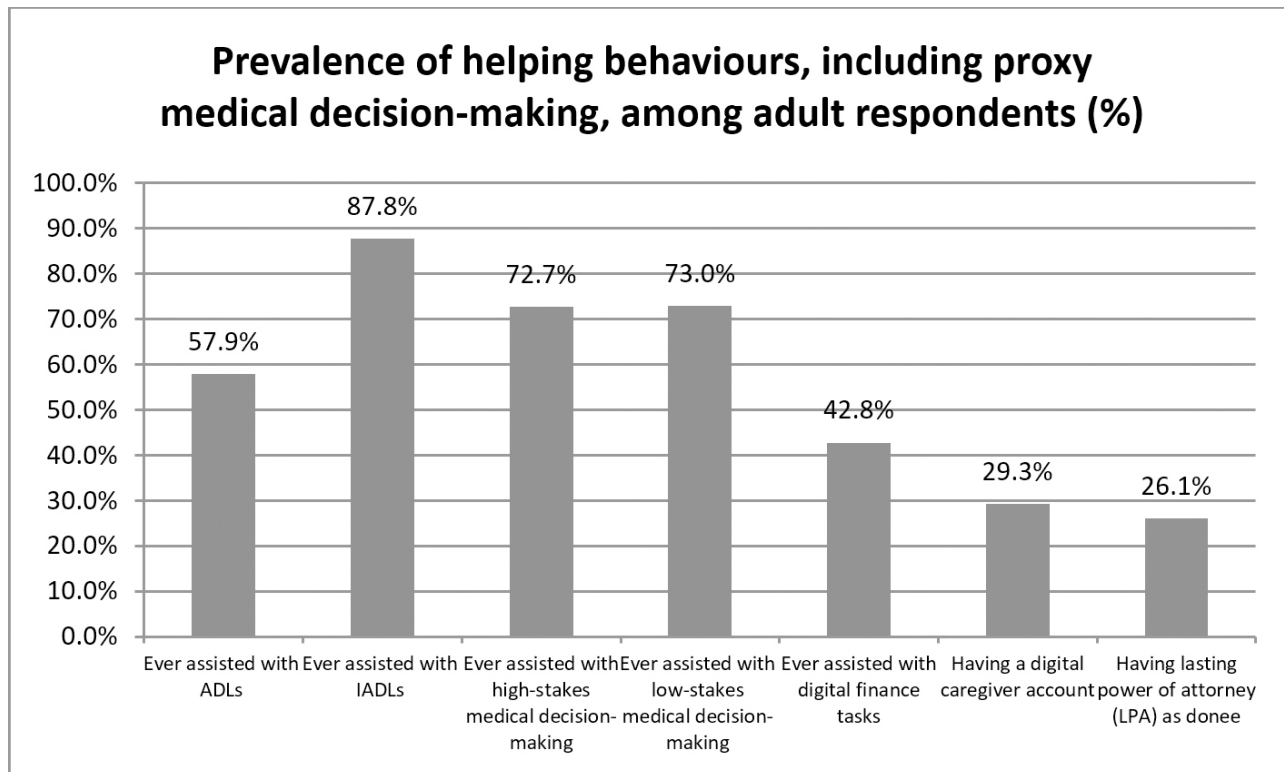
Figure 2 Univariate association of proxy high-stakes medical decision-making with other factors found age, education, number of siblings, assisting with ADLs, assisting with IADLs, ethnicity, having LPA as donee, assisting with digital finance tasks and having a digital caregiver account to be significantly associated, prior to multivariate analysis. ADLs, activities of daily living; IADLs, instrumental ADLs.

Our data revealed a significant gap between formalised and actual proxy medical decision-making. Out of the 226 respondents who make proxy medical decisions for others, only 90 (40%) actually had a digital caregiver account and 73 (32%) are actual LPA donees. Close to half of those making proxy medical decisions (48%) do not have any form of formalised care arrangement such as an LPA or digital caregiver account (see figure 3), revealing much of these medical decisions are made informally or without oversight. Ideally, caregiving accounts and formalised delegation through LPA should go hand-in-hand. This disparity highlights the need for increased uptake of formalised arrangements and initiatives to improve education and reduce barriers to such arrangements.

In line with existing literature,[11 27] making medical decisions by proxy is associated with involvement with caregiving. However, unlike previous studies,[14 27] gender, education, ethnicity and age were not significantly associated. This could hint at a more egalitarian societal with less rigid social norms in determining proxy medical decision-making.

Implications for clinicians and policy-makers
A majority of respondents assist others with medical decisions, which likely increases decision-making burden[28] and anxiety/stress on informal caregivers. As Singapore also faces a rapidly ageing society and concurrent increase in caregiving burden, the proportion of those involved in such roles is only likely to increase. This may also increase patient abuse; locally, caregiver stress is a factor commonly implicated in cases of elder abuse.[29]

In Singapore, support for caregivers is often fragmented, dependent on individuals' knowledge and uncoordinated.[30] We suggest increasing education around the implications of proxy medical decision-making and offering digital caregiving accounts as a way to enhance care delivery while upholding patients' wishes; this can be done online with caregivers granted tailored access rights,[31] through a one-stop portal such as HealthHub, verified by Singpass, a national government digital identity portal.[32] Further, crafting advance care directives reduces caregiver decisional burden by establishing patients' wishes prior to illness or incapacity[33]—there are opportunities to increase education about and uptake of advance directives, especially in primary care.[34]

Another finding from our survey is that respondents help others informally—for example, while a majority assist others with medical decisions, 48% do not have any sort of formalised care

Table 2 Univariate association of proxy high-stakes medical decision-making with other factors

Continuous variables				
Variable	Per cent missing	Estimate	SE	P value
Age	0	−0.13	0.04	<0.001*
Education	0	2.28	0.95	0.017*
Income	0	0.59	0.36	0.104
Number of Siblings	24	1.27	0.58	0.029*
Assisting with ADLs	0	0.59	0.05	<0.001*
Assisting with IADLs	0	0.66	0.06	<0.001*
Categorical variables				
Variable	Per cent missing	Test Value	df	P value
Gender	<1	0.98	1	0.327
Ethnicity	3	13.18	3	0.004*
Marital status	0	0.33	2	0.847
Sibling order	0	5.14	2	0.077
Housing	0	0.91	2	0.635
Religion	0	5.48	6	0.484
Having LPA as donee	0	55.89	1	<0.001*
Assisting with digital finance tasks	0	64.74	1	<0.001*
Having a digital caregiver account	0	106.96	1	<0.001*

*P<0.05
ADLs, activities of daily living; IADLs, instrumental activities of daily living; LPA, lasting power of attorney.

formalised care arrangements may be due to a lack of awareness or difficulty navigating such platforms—both targeted and national education campaigns can prime caregivers and patients to discuss and document important medical, legal and financial decisions before loss of capacity.
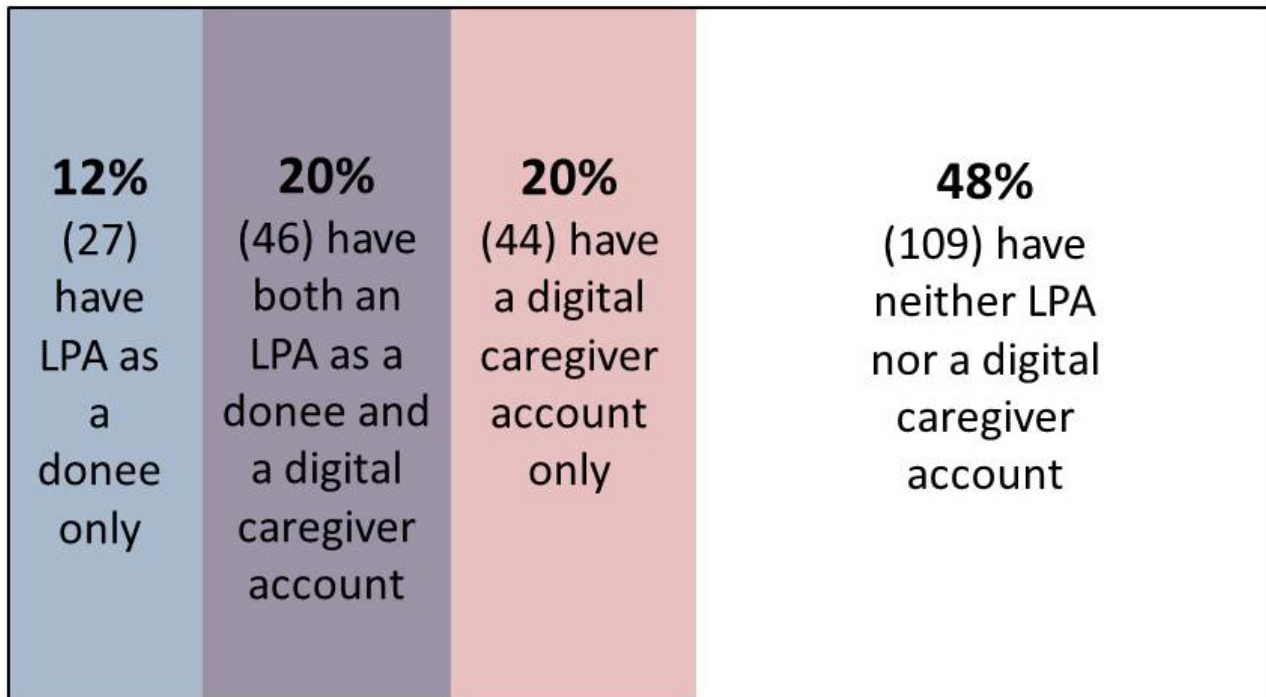
Age, gender, income and ethnicity are not significant determinants of who makes high-stakes medical decisions on behalf of others in Singapore. Instead, those who make such decisions are those who assist with physical and decisional caregiving tasks. This observation may be helpful for clinicians and policy-makers who want to increase uptake of formalised care arrangements like ACPs by targeting education to households with aged dependents. Policy-makers in Singapore have been pushing for increased uptake of such arrangements through campaigns like the 'Live Well. Leave Well.' campaign advocating EOL conversations[37] and systematic training in hospitals engaging patients or caregivers in ACPs.[38] However, ACPs are usually only broached in hospital settings when patients are ill or perhaps already have impaired capacity.[39] Hence, it would be helpful to bring advance care discussions into the community, primary care[34] and online.[40] For example, bringing ACP discussions to current Healthier SG visits, community sites like senior activity centres or active ageing centres, or other important national administrative procedures (such as renewing travel or identification documents), can increase touchpoints for ACP uptake.

arrangement such as an LPA or digital caregiver account. This may lead to abuse of power and loss of autonomy,[35] such as financial abuse or acting against patients' wishes.[4] With the growing use of technologies like cloud computing and digital account sharing, patients' data (including medical records) may face threats to data security and privacy against their wishes.[36] Low uptake of

Table 3 AIC regression analysis of factors impacting high-stakes medical decision-making

Variable	Estimate	P value
Number of siblings	0.80	0.059
Assisting with ADLs	0.25	<0.001*
Assisting with IADLs	0.15	0.041*
Having LPA as a donee	3.35	<0.001*
Having a digital caregiver account	6.98	<0.001*
Assisting with digital finance tasks	1.42	0.120

*P<0.05
ADLs, activities of daily living; AIC, Akaike information criterion; IADLs, instrumental activities of daily living; LPA, lasting power of attorney.

LIMITATIONS

Owing to the use of an online survey instrument that was conducted in English, there is possibly a bias towards English-speaking, educated and younger survey respondents, which may reduce the representativeness of findings. However, this is mitigated by the effort to assemble a cohort resembling the national population through recruitment constraints. Our goal was to assess the prevalence of helping behaviours and proxy medical decision-making in the general population, not just among identified caregivers, to offer insights into informal caregiving.

Second, this study was based on self-reported helping behaviours, which may suffer from recall or social desirability bias. Some participants may over-report their helping behaviours, which may explain our high prevalence of assisting with care activities or decision-making. However, the prevalence of more formal care arrangements like ACPs or LPAs is comparable with regional and local studies, demonstrating concurrence; hence, the high prevalence of care and decision-making helping behaviours may truly be explained by

Among 226 respondents who make proxy medical decisions:

| 12% (27) have LPA as a donee only | 20% (46) have both an LPA as a donee and a digital caregiver account | 20% (44) have a digital caregiver account only | 48% (109) have neither LPA nor a digital caregiver account |

Figure 3 The Venn diagram shows that among those making proxy medical decisions, 48% do not have an LPA nor a digital caregiver account, demonstrating a gap between formalised care arrangements and actual proxy decision-making. LPA, lasting power of attorney.

our question framing as 'ever-helped' rather than 'regularly helping' in other surveys.

CONCLUSION

Our research shows a high prevalence of assisting with high-stakes medical decision-making on behalf of others and residents helping more with IADL and decisional caregiving as opposed to physical caregiving. Making high-stakes medical decisions for others is associated with involvement with ADLs and IADLs (potentially adding to caregiver stress), and also with having a digital caregiver account, and having an LPA as a donee. Age, gender, ethnicity and other demographic factors were not significantly associated. Increasing education around the implications of proxy medical decision-making and formalised care arrangements may help increase their uptake, thereby reducing caregiver decisional burden and risk of patient abuse while respecting patient preferences.

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NUS-IRB-2022-412). Participants gave informed consent to participate in the study before taking part.

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<u>**Study on Understanding Caregiver Delegation**</u>

Introduction

Q1.1. We appreciate your interest in the survey. We will now ask you some questions to ensure you are eligible to proceed. Not qualifying for the survey will mean you cannot complete the study and receive reimbursement for participation.

Q1.2. Are you above 21 years of age?

○ Yes
○ No

Demographics

Q3.1. **SECTION 1: About you and your socio-economic details**

Q3.2. How old are you?

○ 21-24
○ 25-29
○ 30-34
○ 35-39
○ 40-44
○ 45-49
○ 50-54
○ 55-59
○ 60-64
○ 65-69
○ 70 and above

Q3.3. What type of housing do you live in?

○ Single-family house (detached house)
○ Townhouse (attached house)
○ Apartments/Condos
○ Mobile home/trailer
○ Dorm or institutional housing
○ [   ] Others

Q3.4. What is your annual Household Income?

○ Less than $30,000 US dollars

○ $30,000 – $49,999 US dollars

○ $50,000 – $99,999 US dollars

○ $100,000 – $149,999 US dollars

○ $150,000 – $199,999 US dollars

○ $200,000+ US dollars and more

Q3.5. What is your gender?

○ Male

○ Female

○ [   ] Others

Q3.6. What is your marital status?

○ Single

○ Married

○ Widowed

○ Separated

○ Divorced

○ Not reported

Q3.7. What best describes your ethnic origin?

☐ American Indian or Alaska Native

☐ Asian

☐ Black or African American

☐ Hispanic or Latino

☐ Native Hawaiian or other Pacific Islander

☐ White

☐ [   ] Others

Q3.8. What is your religion?

○ Protestant (e.g., Baptist, Methodist, Presbyterian, Reformed, Church of Christ, etc.)

○ Roman Catholic

○ Mormon (Church of Jesus Christ of Latter-day Saints or LDS)

○ Jehovah's Witness

○ Jewish

○ Muslim

○ Buddhist

○ Hindu

○ No Religion

○ [   ] Others

Q3.9. Besides English, what other languages do you speak?

Q3.10. What is the highest level of education you have completed?

○ No Degree

○ High School Degree

○ Some College, did not graduate

○ Associate's Degree Occupational/Academic

○ Bachelor's Degree

○ Master's, Professional or Doctorate Degree

Q3.11. Which statement best describes your current employment status?

○ Full-time employment

○ Part-time employment

○ Unemployed, but currently seeking job opportunities

○ Unemployed, and not seeking job opportunities

○ Retired

○ [   ] Others

Q3.12. What is your residency status in the United States of America?

○ US Citizen

○ US Permanent Resident (i.e., Green card holder)

○ Others

Q3.13. How many siblings do you have?

Q3.14. In terms of birth order, which sibling are you?

○ Oldest

○ Middle

○ Youngest

Physical Care Tasks

Q4.1. **Section 2: Helping with Physical Care**
This section contains questions about your experience providing physical care to another adult. We are asking about activities where you have helped to make decisions

about physical care matters or have been given authority to make physical care decisions on behalf of another adult.

An adult is anyone aged over 21 years of age. You may have done this this formally or informally. You may also have helped more than one adult in this way.

Even if the person you have helped has passed away, please include them in your answers.

Q4.2. Based on this definition, could you please give us a breakdown of how many adults you have helped with **physical care** matters in terms of …

	Number
Immediate Family	
Extended (relatives)	
Friends	
Others (please specify)	

Q4.3. Of these adults, how many have passed away?

[dropdown selector   ]

Q4.4. In this section, we are asking about the frequency of help you have offered for physical care tasks. Please choose the **highest frequency** you have ever done.

Q4.5.

IADLs, also known as **Instrumental activities of daily living (IADLs),** are things one does every day to take care of themselves and their home. They are one way to measure how well one is on their own. The following questions will help us understand how much help you have provided for an adult in carrying out their instrumental activities of daily living.

Q4.6.

Food Preparation: These are tasks where you prepare, serve, heat, or prepare ingredients for meals.

At the most frequent, I have helped **another adult** with

food preparation...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.7. You answered **Never**. Considering the adults around you, how likely will you be helping them with food preparation tasks in the coming year?

○ Very Unlikely

○ Somewhat Unlikely

○ Somewhat Likely

○ Very Likely

○ Unsure

Q4.8.

Housekeeping Tasks. These tasks include dishwashing, bed making, sweeping, and cleaning.

At the most frequent, I have helped **another adult** with housekeeping tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.9. You answered **Never**. Considering the adults around you, how likely will you be helping them with food preparation tasks in the coming year?

○ Very Unlikely

○ Somewhat Unlikely

○ Somewhat Likely

○ Very Likely

○ Unsure

Q4.10.

Laundry Tasks: These are tasks such as washing clothes, hanging and folding clothes.

At the most frequent, I have helped **another adult** with laundry tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.11. You answered **Never**. Considering the adults around you, how likely will you be helping them with food preparation tasks in the coming year?

○ Very Unlikely

○ Somewhat Unlikely

○ Somewhat Likely

○ Very Likely

○ Unsure

Q4.12.

Transportation Tasks: These are tasks for moving between destinations, such as giving rides, helping to take public transportation, or accompanying a person to take a vehicle.

At the most frequent, I have helped **another adult** with transportation tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.13. You answered **Never**. Considering the adults around you, how likely will you be helping them with food preparation tasks in the coming year?

○ Very Unlikely

○ Somewhat Unlikely

○ Somewhat Likely

○ Very Likely

○ Unsure

Q4.14.

Medical Tasks: These tasks include ensuring correct medication is taken at the right time, dispensing medication, or securing a sufficient supply of medication.

At the most frequent, I have helped **another adult** with medical tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.15. You answered **Never**. Considering the adults around you, how likely will you be helping them with food preparation tasks in the coming year?

○ Very Unlikely

○ Somewhat Unlikely

○ Somewhat Likely

○ Very Likely

○ Unsure

Q4.16.

Financial Tasks: These are tasks such as making budgets, writing checks, paying rent, and going to the bank.

At the most frequent, I have helped **another adult** with financial tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.17. You answered **Never**. Considering the adults around you, how likely will you be helping them with food preparation tasks in the coming year?

○ Very Unlikely

○ Somewhat Unlikely

○ Somewhat Likely

○ Very Likely

○ Unsure

Q4.18.

Digital tasks: These are tasks such as logging on to mobile apps, operating applications, checking emails, and changing settings on devices.

At the most frequent, I have helped **another adult** with digital tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.19. You answered **Never**. Considering the adults around you, how likely will you be helping them with these tasks next year?

○ Very Unlikely

○ Somewhat Unlikely

○ Somewhat Likely

○ Very Likely

○ Unsure

Q4.20. **ADLs**, also known as **Activities of daily living (ADLs),** are the basic self-care tasks one does every day. They are used to measure how much help one needs.

The following questions will help us understand how much help you have provided for an adult in carrying out their activities of daily living.

Q4.21.
Bathing: These tasks include helping with bathing more than one part of the body, getting in or out of the tub or shower; or helping with total bathing

At the most frequent, I have helped **another adult** with bathing tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.22.

Grooming: These tasks include helping with dressing a person partially or entirely.

At the most frequent, I have helped **another adult** with grooming tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.23.

Toileting: These tasks include helping with transferring to the toilet, cleaning self, using a bedpan, or using a

commode.

At the most frequent, I have helped **another adult** with toileting tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.24.

Transferring: These tasks include helping with moving a person from a bed to a chair or a complete transfer.

At the most frequent, I have helped **another adult** with transferring tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.25.

Incontinence: Incontinence refers to the difficulty of another adult passing stool or urine. These tasks include helping to manage incontinence, from following treatment recommendations to assisting them in using protective undergarments.

At the most frequent, I have helped **another adult** with continence tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q4.26.

Feeding: These tasks include partially or entirely helping get food from their plates into their mouth.

At the most frequent, I have helped **another adult** with feeding tasks...

○ Daily

○ Weekly

○ Monthly

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○ Yearly

○ Never

Legal/Financial Delegation

Q5.1. **Section 3: Helping with Legal/Financial Matters**

This section contains questions about your experience helping another adult with legal or financial matters. We are asking about activities where you have helped to make decisions about legal/financial matters and/or have been given authority to make legal/financial decisions on behalf of another adult.

An adult is anyone aged over 21 years of age. You may have done this this formally or informally. You may also have helped more than one adult in this way.

Even if the person you have helped has passed away, please include them in your answers.

Q5.2. Based on this definition, could you please give us a breakdown of how many adults you have helped with **legal/financial** matters in terms of …

	Number
Immediate Family	0
Extended (relatives)	0
Friends	0
Others (please specify)	
	0

Q5.3. Of these adults, how many have passed away?

Q5.4. This section contains several questions about your **experience of having legal and/or financial authority while caring for another adult.** Please read each statement carefully, and answer the following questions.

Q5.5.

Legal/Financial Decision Support: These tasks include advising on investment, deciding to buy a piece of property, and deciding to open a new bank account. It is important to note that you are **NOT acting on behalf** of

the adult but rather **helping to make such decisions**.

At the most frequent, **in the past 12 months**, I have helped **another adult** to make legal/financial decisions...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q5.6. You answered **Never**. Considering the adults whom you may potentially help, how likely will you help them with legal/financial decision support in the coming year?

○ Very unlikely

○ Somewhat unlikely

○ Somewhat likely

○ Very likely

○ Unsure

Q5.7.

Legal/Financial Action #1: I have helped another adult perform legal-financial actions, such as **withdrawing cash from a bank** or **performing digital banking** or

taking legally binding actions(i.e. signing contracts, and bank documents)

At the most frequent, **in the past 12 months**, I have helped **another adult** with withdrawing cash from a bank ...

○ Daily
○ Weekly
○ Monthly
○ Yearly
○ Never

Q5.8. You answered **Never**. Considering the adults whom you may potentially help, how likely will you help them with legal-financial actions such as **withdrawing cash from a bank** or **performing digital banking** or **taking legally binding actions** in the coming year?

○ Very unlikely
○ Somewhat unlikely
○ Somewhat likely
○ Very likely
○ Unsure

Q5.9.

The **LPA** is a legal document that allows a person aged 21 years and above ('**donor**') to voluntarily appoint one or more persons ('**donee**(s)') to make decisions and act on their behalf if they lose mental capacity one day.

A **donee** can be appointed to serve in the two broad areas of:

(a) **personal welfare**

and/or

(b) **property** and **affairs matters**.

Q5.10. Have you signed **Lasting Power of Attorney (LPA)** in the US?

○ Yes

○ No

Q5.11.

How frequently have you used the lasting power of attorney (LPA) for **personal welfare matters** over the **past 12 months?**

Examples of **personal welfare matters** include :

Where donor should live

Day to day care decisions (what to wear and eat)

Handling donor's letters / mail

Who donor may have contact with

Healthcare and medical treatment decision

○ Never

○ Rarely

○ Sometimes

○ Frequently

○ Always

Q5.12.

How frequently do you currently use the lasting power of attorney (**LPA**) for **property and affairs** over the **past 12 months**?

Examples of **property and affairs** include :

Buying, selling, renting and mortgaging donor's property

Operating donor's bank accounts

Managing donor's CPF monies

Paying household expenses

Purchasing any equipment donor may need

○ Never

○ Rarely

○ Sometimes

○ Frequently

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○ Always

Q5.13. When was the **first time** you signed a lasting power of attorney (**LPA**) as a donee? (Please indicate the year)

[   ]

Q5.14. **Legal/Financial Digital Delegation**

Q5.15. Do you have any joint bank accounts with someone in order to help them with digital transactions?

☐ Yes, I have a **joint-alternate** account (where account holders can perform transactions independently, and you do not need consent from the other account holders.)

☐ Yes, I have a **joint-all** account (where all account holders must agree to all transactions)

☐ Yes, I have a **joint-alternate** account and joint-all account account

☐ No, I do not have any **joint account** for helping purposes.

☐ Unsure

Q5.16. **Legal/Financial Digital Delegation Method**

This section contains questions about how you act on behalf of another adult who may rely on you to **access digital Legal and/or Financial services**. By digital services, we mean using a website or a mobile app to do transactions.

Some examples in US may be accessing or managing their *my Social Security* or mobile app bank apps and paying bills using a company's website.

Q5.17. Have you ever assisted **another adult** with their **legal/financial digital services**?

○ Yes
○ No

Q5.18. Provide the reason(s) why you think your help was needed to manage a **digital service** for another adult. You may choose more than one answer.

☐ The app was not user-friendly for them
☐ They see using the app as a difficult task that should be avoided
☐ They are unfamiliar with using a technology device to access the app

- ☐ They have concerns about sharing their data with third parties
- ☐ They do not have a device or equipment to access their digital accounts
- ☐ They have physical limitations (e.g., poor vision and poor motor skills) that constrain their ability to use the app
- ☐ They have cognitive limitations (e.g., existing conditions and cognitive decline with age) that constrain their ability to use the app
- ☐ Others (please specify)

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Q5.19. How have you helped another adult to **log on to their financial/legal digital services**? You may select more than one option.

- ☐ I know the username and password for their online account(s)
- ☐ The adult uses their fingerprint (or other biometrics) to log in
- ☐ The adult logs in with a username and password and I help them (I don't know the username and password)
- ☐ The institution has given me my own separate login and password to help manage their online account(s)

Q5.20. How have you helped **another adult use their financial/legal digital services** online? You may select more than one option.

☐ I offer some help, but the person does it mostly independently

☐ I provide ongoing assistance while next to the person

☐ I use the person's account on their behalf, while they are present

☐ I use the person's account on their behalf, even when they are not present

☐ Not Applicable

Medical Delegation

Q6.1. **Section 4: Helping with Medical Matters**
This section contains questions about your **experience helping another adult with medical matters**. We are asking about activities where you have helped to **make decisions about medical matters** or have been **given authority to make medical decisions** on behalf of another adult.

An adult is anyone aged over 21 years of age. You may be doing this formally or informally. You may also have more than one adult you help with in this way.

Even if the person you have helped has passed away, please include them in your answers.

Q6.2. Based on this definition, could you please give us a breakdown of how many adults you have helped with **medical care** matters in terms of …

	Number
Immediate family	0
Extended (relatives)	0
Friends	0
Others (please specify relationship)	0

Q6.3. Of these adults, how many have passed away?

Q6.4. This section contains several questions about your **experience of providing medical delegation for another adult**. Please read each statement carefully, and answer the following questions.

Q6.5. **Medical Delegation Action (Low-Stake Activities)**

Q6.6.

I have helped to **make appointments for another adult's medical care.**

At the most frequent, **in the past 12 months**, I have helped **another adult** with medical appointment tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q6.7. You answered **Never**. Considering the adults around you, how likely will you be helping them with medical appointment tasks in the coming year?

○ Very unlikely

○ Somewhat unlikely

○ Somewhat likely

○ Very likely

○ Unsure

Q6.8. I have **accompanied another adult to a medical**

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care appointment.

At the most frequent, **in the past 12 months**, I have helped **another adult** with medical appointment tasks...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q6.9. You answered **Never**. Considering the adults around you, how likely will you be accompanying them for medical care appointment in the coming year?

○ Very unlikely

○ Somewhat unlikely

○ Somewhat likely

○ Very likely

○ Unsure

Q6.10.

I have helped **ensure proper medication intake for another adult**.

At the most frequent, **in the past 12 months**, I have helped **another adult** with ensuring proper medication intake...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q6.11. You answered **Never**. Considering the adults around you, how likely will you be helping them ensure proper medication intake in the coming year?

○ Very unlikely

○ Somewhat unlikely

○ Somewhat likely

○ Very likely

○ Unsure

Q6.12.

I have helped **oversee proper medical treatment procedures for another adult.**

At the most frequent, **in the past 12 months**, I have

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helped **another adult** oversee medical treatment procedures...

○ Daily

○ Weekly

○ Monthly

○ Yearly

○ Never

Q6.13. You answered **Never**. Considering the adults around you, how likely will you be helping them oversee medical treatment procedures in the coming year?

○ Very unlikely

○ Somewhat unlikely

○ Somewhat likely

○ Very likely

○ Unsure

Q6.14. **Medical Delegation Action (High-Stake Activities): Medical Decision Making**

Q6.15. Have you ever **talked to another adult** about being a medical decision maker for that adult?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.16. Have you ever **talked to the doctor of another adult** about being a medical decision maker for that adult?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.17. Have you ever signed official papers naming you or a group of people to make medical decisions for that adult?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.18. **Medical Delegation Action (High-Stake Activities): Quality of Life (Health Situations)**

Q6.19. Have you ever **talked to another adult** about what would make that adult's life worth living or otherwise?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.20. Have you ever **talked to the doctor of another adult** about what would make that adult's life worth living or otherwise?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.21. Have you ever **talked to family members of another adult** about what would make that adult's life worth living or otherwise?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.22. **Medical Delegation Action (High-Stake**

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Activities): Quality of Life (Medical Care)

Q6.23. Have you ever **talked to another adult** about what that adult would want if they were very sick or near the end of life?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.24. Have you ever **talked to the doctor of another adult** about what that adult would want if they were very sick or near the end of life?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.25. Have you ever **talked to family members of another adult** about what that adult would want if they were very sick or near the end of life?

○ Yes

○ No, but I should have

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○ No, because I didn't need to

Q6.26. **Medical Delegation Action (High-Stake Activities): Flexibility for surrogate decision making**

Q6.27. Have you ever **talked to another adult** about what flexibility you have to make medical decisions for that adult?

○ Yes
○ No, but I should have
○ No, because I didn't need to

Q6.28. Have you ever **talked to the doctor of another adult** about what flexibility you have to make medical decisions for that adult?

○ Yes
○ No, but I should have
○ No, because I didn't need to

Q6.29. Have you ever **talked to family members of another adult** about what flexibility you have to make

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medical decisions for that adult?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.30. **Medical Delegation Action (High-Stake Activities): Asking Questions of medical providers**

Q6.31. Have you ever **asked doctors questions** on behalf of another adult?

○ Yes

○ No, but I should have

○ No, because I didn't need to

Q6.32. **Medical Digital Delegation**

Q6.33. A caregiver account is a digital account where you have access to another adult's medical records. Have you ever had a caregiver account for that adult?

○ Yes

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○ No, but I should have

○ Unsure

Q6.34. How many caregiver accounts have you ever had?

[   ]

Q6.35. **Medical Digital Delegation Method**

This section contains questions about how you act on behalf of another adult who may rely on you to **access digital medical services**. By digital services, we mean using a website or a mobile app for matters related to medical treatment.

Some examples in the US may be booking medical appointments, getting information about medical care, consulting doctors, or doing therapy.

Q6.36. Have you ever assisted another adult with their **digital medical services**?

○ Yes

○ No

Q6.37.

Provide the reason(s) why you think your help was needed to manage a **digital** medical service for another adult.

You may choose more than one answer.

☐ The app was not user-friendly for them

☐ They see using the app as a difficult task that should be avoided.

☐ They are unfamiliar with using a technology device to access the app.

☐ They have concerns about sharing their data with third parties.

☐ They do not have a device or equipment to access their digital accounts.

☐ They have physical limitations (e.g., poor vision and poor motor skills) that constrain their ability to use the app.

☐ They have cognitive limitations (e.g., existing conditions and cognitive decline with age) that constrain their ability to use the app.

☐ Others (Please Specify)

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[                    ]
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Q6.38. How do you assist another adult in accessing their **digital** medical services? You may select more than one

option.

- ☐ I know the username and password for their online account(s)
- ☐ The adult uses their fingerprint (or other biometrics) to log in
- ☐ The adult logs in with a username and password and I help them (I don't know the username and password)
- ☐ The institution has given me my own separate login and password to help manage manage their online account(s)

Q6.39. How have you helped another adult use their **digital medical services** online? You may select more than one option.

- ☐ I offer some help, but the person does it mostly independently
- ☐ I provide ongoing assistance while next to the person
- ☐ I use the person's account on their behalf, while they are present
- ☐ I use the person's account on their behalf, even when they are not present
- ☐ Not Applicable

Supplemental material

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BMJ Support Palliat Care

SUPPLEMENTAL MATERIAL B

Questions relating to high-stakes medical decision-making:

Question	Scale
1. *Have you ever talked to another adult about being a medical decision maker for that adult?* 2. *Have you ever talked to the doctor of another adult about being a medical decision maker for that adult?* 3. *Have you ever signed official papers naming you or a group of people to make medical decisions for that adult?* 4. *Have you ever talked to another adult about what would make that adult's life worth living or otherwise?* 5. *Have you ever talked to the doctor of another adult about what would make that adult's life worth living or otherwise?* 6. *Have you ever talked to family members of another adult about what would make that adult's life worth living or otherwise?* 7. *Have you ever talked to another adult about what that adult would want if they were very sick or near the end of life?* 8. *Have you ever talked to the doctor of another adult about what that adult would want if they were very sick or near the end of life?* 9. *Have you ever talked to family members of another adult about what that adult would want if they were very sick or near the end of life?* 10. *Have you ever talked to another adult about what flexibility you have to make medical decisions for that adult?* 11. *Have you ever talked to the doctor of another adult about what flexibility you have to make medical decisions for that adult?* 12. *Have you ever talked to family members of another adult about what flexibility you have to make medical decisions for that adult?* 13. *Have you ever asked doctors questions on behalf of another adult?*	*(1) Yes* *(0) No, but I should have* *(0) No, because I didn't need to*

Questions relating to low-stakes medical decision-making:

Question	Scale
1. *I have helped to make appointments for another adult's medical care* 2. *I have accompanied another adult to a medical centre appointment* 3. *I have helped ensure proper medication intake for another adult* 4. *I have helped to oversee proper medical treatment procedures for another adult*	*In the past 12 months, I have helped:* *(4) Daily* *(3) Weekly* *(2) Monthly* *(1) Yearly* *(0) Never*