Nebraska End-of-Life Survey Report

Prepared: November 2022

The contents of this report conform to our highest standards for data collection and reporting. If you should have any questions or concerns regarding the information reported within, please contact us.

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Nebraska End-of-Life Survey

Introduction

This report presents a detailed account of the design and fielding of the Nebraska End-of-Life Survey, commissioned by the Nebraska Hospice and Palliative Care Association (NHPCA) and conducted by the Bureau of Sociological Research (BOSR). Users of the Nebraska End-of-Life Survey data will find it an important reference source for answers to questions about methodology.

Sampling Design

The sampling design of the Nebraska End-of-Life survey used a postal delivery sequence based sample of household addresses (ABS). The sample includes addresses for individuals and households who have an address according to the US Postal Service. To maintain a probability sample, the adult (age 19 or older) in the household with the next birthday was asked to complete the survey.

The End-of-Life Survey used a probability-based stratified sample, drawn throughout Nebraska with an unequal probability of selection within each of the six strata. The strata are the six Nebraska Behavioral Health Regions. The counties in each region can be found in Figure 1 in Data Weights.

Residents of sampled households were then asked to have the adult 19 or older in their household who will have the next birthday to complete the survey. In total, 3,000 households were sampled. The sample was purchased from Dynata and provided on June 9, 2022. Known vacant addresses were excluded from the sampling frame. PO Boxes were only included in the sampling frame if those were the only delivery point for an address.

Strata	n
Behavioral Health Region 1	500
Behavioral Health Region 2	500
Behavioral Health Region 3	500
Behavioral Health Region 4	500
Behavioral Health Region 5	500
Behavioral Health Region 6	500
Total	3000

Questionnaire Design

The Nebraska End-of-Life Survey is administered as a mail and web survey. The questionnaire is based on the survey used in the previous studies, which were designed by NHPCA in consultation with BOSR and formatted by BOSR. All materials were in English.

Data Collection Process

Data were collected between July 11, 2022 and September 30, 2022. The initial survey packet was sent to all sampled addresses on July 11, 2022. Each survey packet contained a cover letter that provided a link and QR code to access the web survey online (Appendix A), survey booklet (Appendix B), cash incentive of $1, and large postage-paid business reply envelope. Reminder postcards were sent to each household on July 18, 2022 (Appendix C). Non-responders were mailed replacement packets (contents discussed above omitting the $1

incentive) on August 1, 2022. Completed surveys were collected by BOSR through September 30, 2022.

Response Rate

A total of 635 adults returned the survey (490 via mail and 145 via web). The overall response rate for this survey, calculated using AAPOR's standard definition for response rate 2 is 21.2%. It should be noted, however, that due to the mode of recruitment (mail), it is uncertain if surveys reached the entire sample. This response rate is lower than previous administrations, which is likely due to the declining rate of survey responses overall, which can be seen across the U.S. Of the 3,000 addresses sampled, 10.5% (n=314) were deemed ineligible due to housing vacancies, business addresses, or no eligible respondent living in the household. Refusals (e.g., blank survey returned; letter, phone call, or email stating refusal to participate) were obtained from 0.8% (n=23) of the sample.

Data Processing

Mail survey data were entered using SurVADE software with data saved on BOSR's secure networked file server. Data entry was completed by experienced data-entry staff. All of the data-entry workers had previous experience in data entry using SurVADE on other mail survey projects. The data-entry staff was supervised by full-time BOSR project staff.

Data entry was completed in two steps. First, one data-entry worker would enter responses from a single survey. Second, another data-entry worker would re-key the survey and be alerted to any discrepancies with the first entry. Supervisory staff members were available to answer questions about discrepancies or illegible responses. The data-entry staff is paid by the hour, not by the number of surveys entered. This method of payment is used so that we can ensure the high quality of the data collected by our staff.

For web, respondents entered their responses directly into a computerized instrument. Therefore, this survey required no additional data entry or data processing steps. The web survey data were recorded in Qualtrics and the dataset was exported from Qualtrics into an SPSS system file.

Data Cleaning

The data were recorded and stored on a secure server located within the Sociology Department at UNL. The Statistical Package for the Social Sciences (SPSS) software package was used to process and document the dataset. The mail survey dataset was exported from SurVADE into an SPSS system file. BOSR first removed any cases that were duplicate or blank. The next step in data cleaning was to run frequency distributions on each of the variables in the survey and check for out-of-range values on all survey items. Recoding was done to correct for the most obvious errors/inconsistencies in the data. Next, open-ended questions were checked for accuracy and to ensure they were not cut off. The final step was to merge both the web and mail datasets together. Cases were de-duplicated across modes and the more complete response was taken. If both web and mail responses matched in amount complete, then the response that was received first was kept. No other validity checks were done.

Data Weights

The data were weighted in four ways to account for the stratified sample design, within household probability of selection, nonresponse, and population characteristics. First, data were weighted by stratum in order to account for the disproportionate stratified sample design (basewat). Then, the data were weighted by the number of adults living in the household (Hwat) in order to adjust for within-household selection probability. Then the data were weighted for

nonresponse (NRwt) by state Behavioral Health Region (reg). Please refer to Figure 1 for a description of the regions. Third, poststratification weights were applied based on, age (age_grp), and sex (sex) in order for the data to more closely resemble the population (post_cat). Hotdeck imputation was used to provide complete data on age and sex for weighting. Table 1 shows the poststratification groups and the population counts from the 2018 American Community Survey (ACS) for each group. The ACS age category for early adults includes 18 year olds. However, the age of majority in Nebraska is 19 years old meaning that the given ACS age categories do not perfectly provide the necessary data. As a result, the number of 19 year olds was calculated as 1% of the overall Nebraska population.

Figure 1
Definitions of Regions

Region	Counties		
Region 1 - Panhandle	Banner Box Butte Cheyenne Dawes	Deuel Garden Kimball Morrill	Scotts Bluff Sheridan Sioux
Region 2 - Southwest	Arthur Chase Dawson Dundy Frontier Gospel	Grant Hayes Hitchcock Hooker Keith Lincoln	Logan McPherson Perkins Red Willow Thomas
Region 3 – South Central	Adams Blaine Buffalo Clay Custer Franklin Furnas Garfield	Greeley Hall Hamilton Harlan Howard Kearney Loup Merrick	Nuckolls Phelps Sherman Valley Webster Wheeler
Region 4 - North	Antelope Boone Boyd Brown Burt Cedar Cherry Colfax	Cuming Dakota Dixon Holt Keya Paha Knox Madison Nance	Pierce Platte Rock Stanton Thurston Wayne
Region 5 - Southeast	Butler Fillmore Gage Jefferson Johnson Lancaster	Nemaha Otoe Pawnee Polk Richardson Saline	Saunders Seward Thayer York
Region 6 - Midland	Cass Dodge	Douglas Sarpy	Washington

Table 1. Population counts by age group and sex

Group	N
19-44 Female	329,703
19-44 Male	331,562
45-64 Female	241,512
45-64 Male	230,495
65+ Female	175,101
65+ Male	135,463

Table 2 displays ACS frequencies and its comparison to End-of-Life Survey weighted and unweighted frequencies. Sampling (sampwat), nonresponse (NRwt), and poststratification (post_cat) weights were multiplied together and rescaled (Rescale) to create the final weight. The variables used in weighting are included in the dataset. The final weight in the dataset is called Pwate.

Table 2. Representativeness of 2022 End-of-Life Sample by Age and Sex (Percentage Distribution in Age and Sex Categories)*

Category	Based on 2018 ACS Estimate	End-of-Life, Unweighted	End-of-Life, Weighted By Pwate
Age Group:			
19 – 44	45.8%	18.9%	47.0%
45-64	32.7%	33.6%	32.1%
65+	21.5%	47.5%	20.9%
Sex:			
Males	48.3%	34.1%	48.2%
Females	51.7%	65.9%	51.8%
Total	100%	100%	100%

*Weighted estimates are calculated using imputed variables. The frequencies above are of the variables before imputation. As a result, the weighted frequencies do not exactly match the 2018 ACS estimates.

Throughout this report, 2022 data is presented in weighted form, so it is more representative of the population. For consistency with previous years' data, unweighted responses are used when comparing changes over time.

Design Effects

The design effect due to weighting adjustments is 3.32, which represents the loss in statistical efficiency that results from unequal weights[1].

Disproportionate stratification was used for the 2022 End-of-Life Survey, as discussed earlier. The use of this type of sampling resulted in a sampling design effect of 0.82[2].

[1] The formula used is: $1 + \mathrm{cv}^2(\mathrm{w}) = \frac{\mathrm{n}(\sum_1^n \mathrm{w}_i^2)}{(\sum_1^n \mathrm{w}_i)^2}$

[2] The formula used is: $deff = \frac{\mathrm{var}_{complex}(\bar{y})}{\mathrm{var}_{SRS}(\bar{y})}$. Used Q1 (Prior to reading the definition for this survey, have you heard of hospice services?) to calculate.

Appropriate adjustments need to be incorporated into statistical tests when using the Nebraska End-of-Life Survey data. See Estimate of Sampling Error in Appendix D.

Limitations

All surveys contain errors that cannot be directly measured. These errors may arise when response rates are less than 100%, when weights do not fully account for potential differences in the representation of the respondents to the target population, or when respondents do not understand or cannot answer all of the questions that are asked in the survey. This survey was only offered in English and excludes those who do not understand English.

Due to the nature of ABS surveys, only people with a household address could be sampled. Households that only receive mail by PO boxes are still included. Address-based samples excludes the homeless and those living in group homes or institutions. Web-only surveys exclude those who do not have a computer or other internet-enabled device, easy internet access, or may not know how to use a computer. This study provided a paper survey. By providing a paper survey, lack of internet access was not a limitation of this study.

Questions

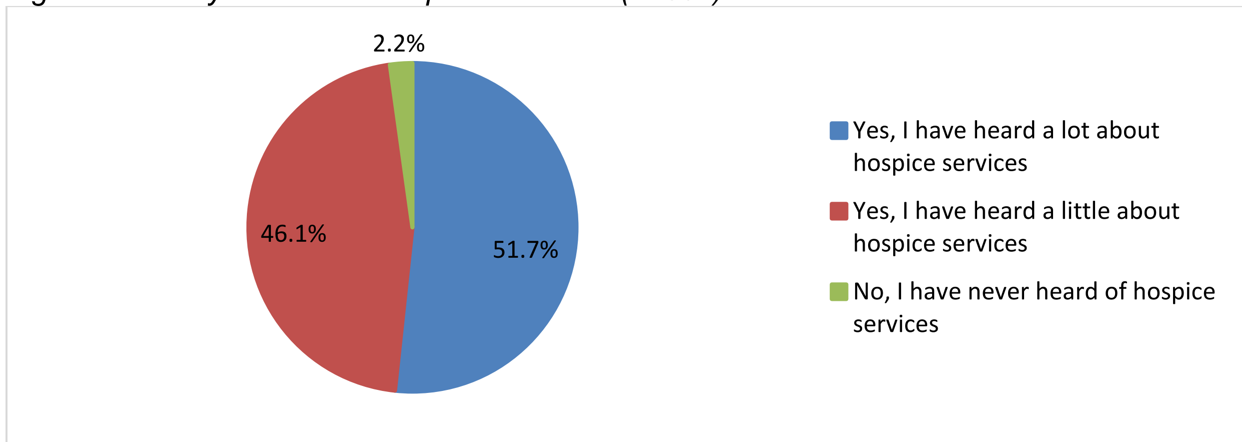
Any questions regarding this report or the data collected can be directed to the Bureau of Sociological Research at the University of Nebraska-Lincoln by calling (402) 472-3672 or by sending an e-mail to bosr@unl.edu.

Findings

Section 1: Hospice Services

As seen in Figure 2, when respondents were asked if they had heard of hospice services nearly all (97.8%) reported they knew of hospice services. Of those who knew of hospice services, 51.7% have heard a lot about hospice services and 46.1% had heard a little about hospice services. A small number of respondents (2.2%) had not heard of hospice services (Figure 2).

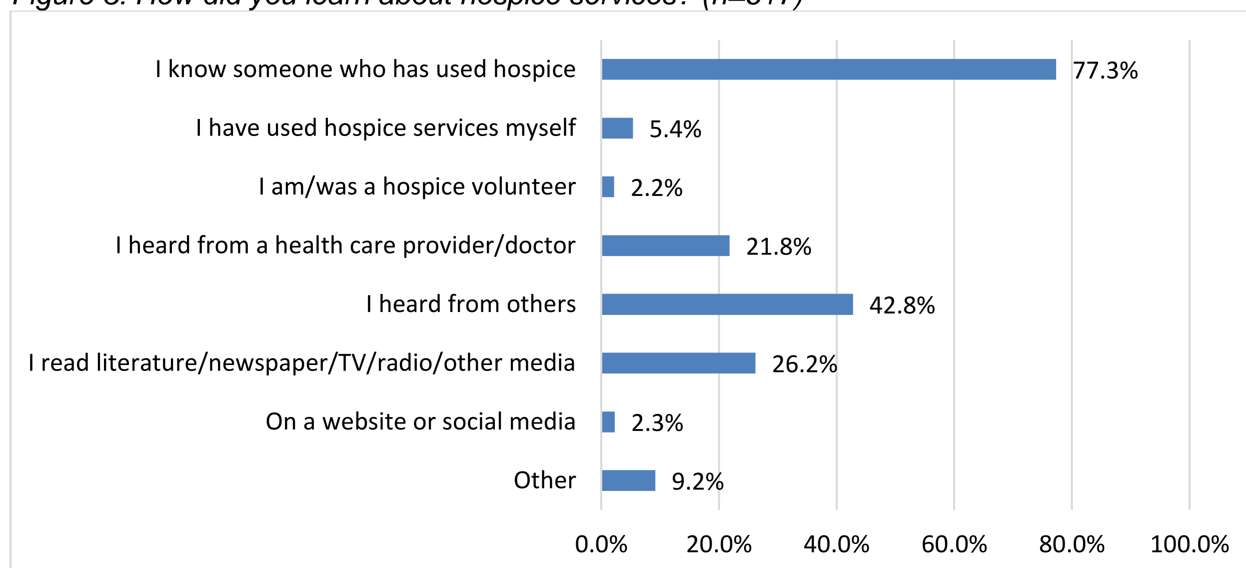
Figure 2. Have you heard of hospice services? (n=634)



Of the respondents who had heard about hospice, most (77.3%) learned about it because someone they knew used hospice. Others knew about hospice from hearing about it from others (42.8%), followed by through reading about it (26.2%), from a health care professional (21.8%), other sources (9.2%), through using hospice themselves (5.2%), on a website or social media (2.3%), and as a hospice volunteer (2.2%) (Figure 3).

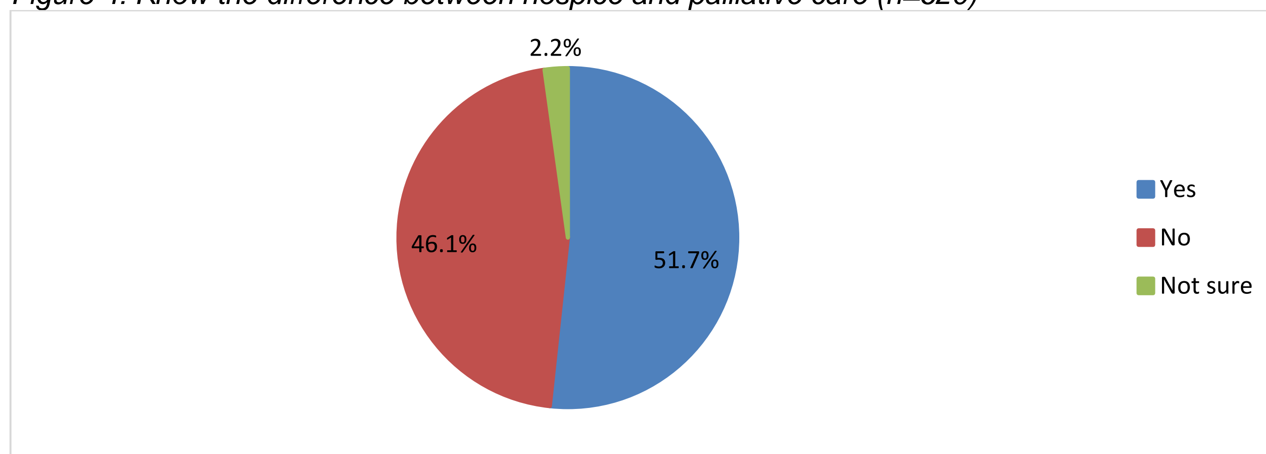
Some respondents knew about hospice through a website or social media. For these respondents, the most common location to learn about hospice was through their own research, a general website, or specific social media (i.e. Facebook). Of the respondents who knew about hospice from other sources, most knew of hospice through their careers and training in the fields of healthcare and social services.

Figure 3: How did you learn about hospice services? (n=617)



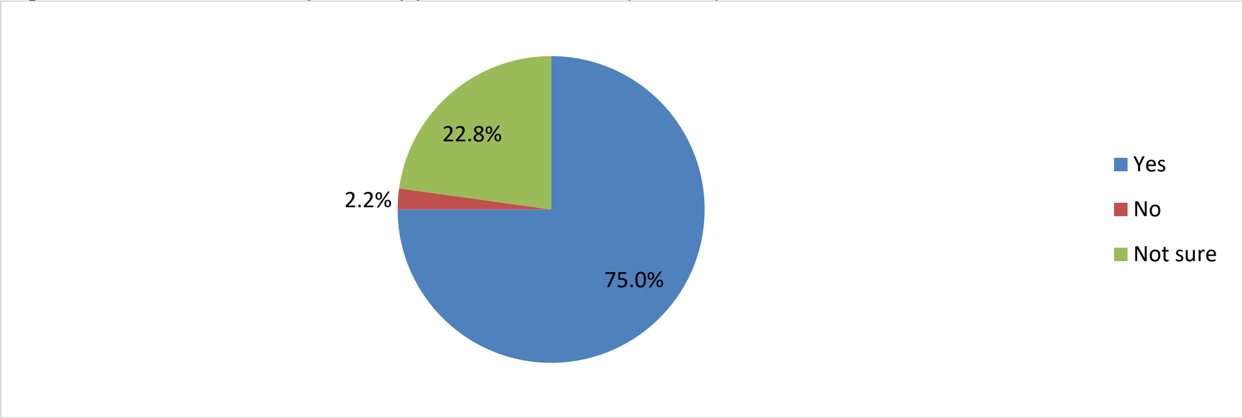
Over half (51.7%) of respondents reported that they know the difference between hospice and palliative care, 46.1% reported that they did not know the difference between hospice and palliative care, and a small number (2.2%) reported that they were not sure if they know the difference between hospice and palliative care (Figure 4).

Figure 4: Know the difference between hospice and palliative care (n=620)



The majority (75.0%) of respondents reported that they would like hospice if they were dying. Some respondents are not yet sure if they would like to use hospice (22.8%) and a small number (2.2%) do not want hospice at the end of their life (Figure 5).

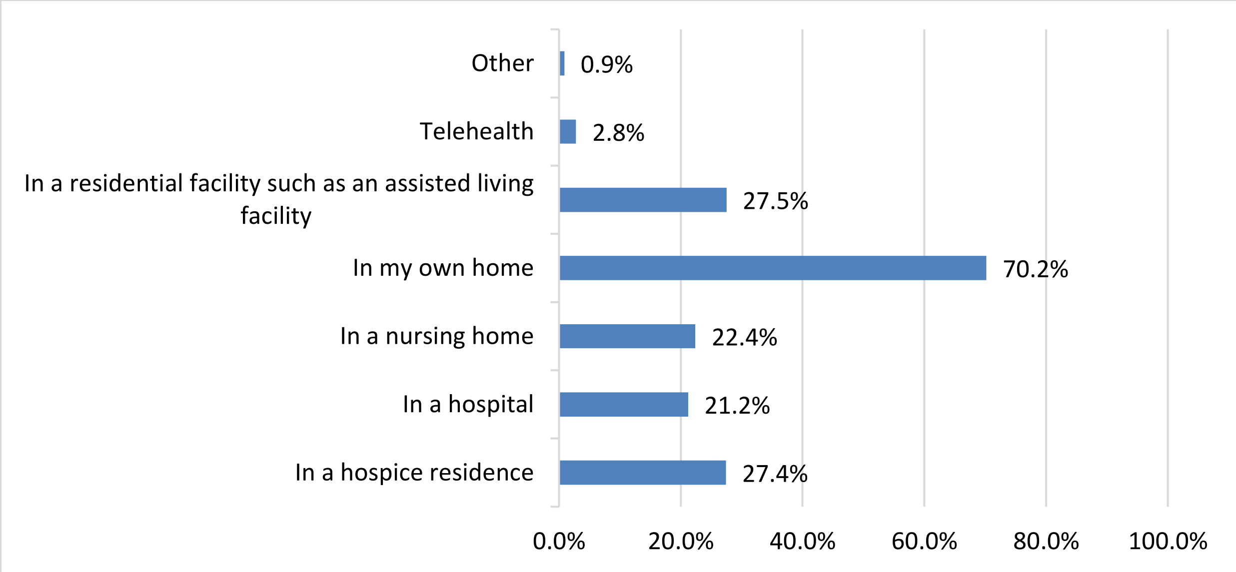
Figure 5: Desire for hospice support near death (n=629)



Of those respondents who do want to use hospice care, the majority (70.2%) would prefer for the care to happen in their own home, followed by in a residential facility such as an assisted living facility (27.5%), in a hospice residence (27.4%), in a nursing home (22.4%), a hospital (21.2%), through Telehealth (2.8%), or other location (0.9%) (Figure 6).

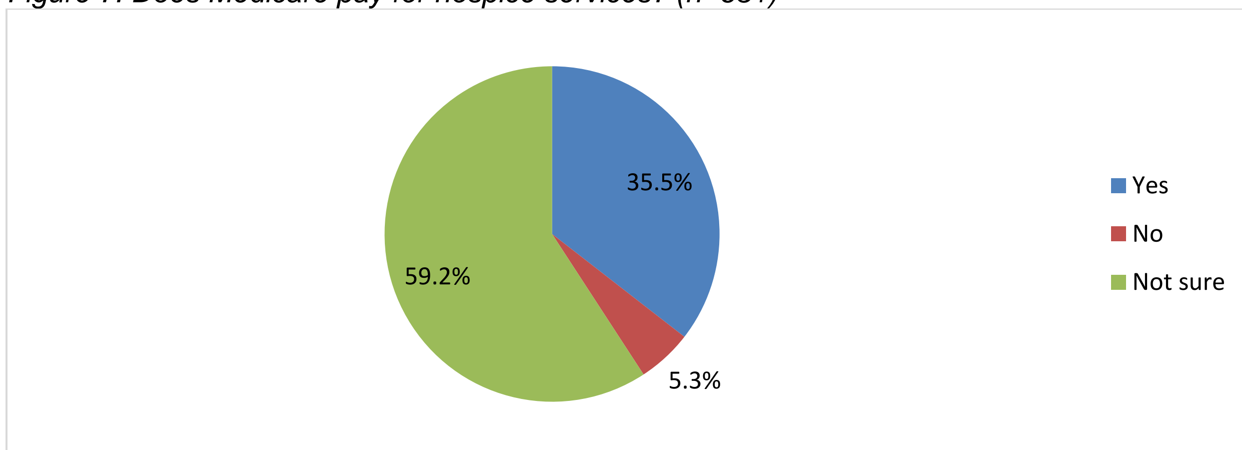
Some respondents answered that they would want hospice care at a location other than those listed in Figure 6. Among these respondents, many indicated that their location would depend on their current health condition and situation, others would like to be in a family member or a friend's home, and some are unsure as to which location they would like to have hospice care.

Figure 6: Location of desired hospice care (n=492)



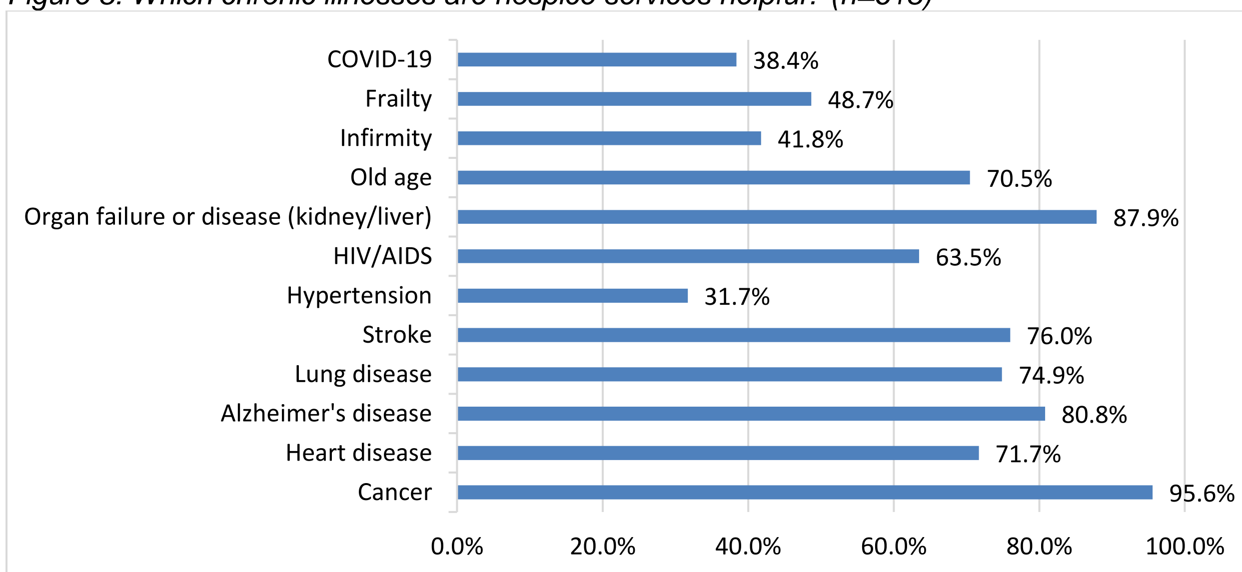
Respondents identified to the best of their knowledge if Medicare pays for hospice services. Over half (59.2%) of respondents were unsure if Medicare would pay for hospice, while some (35.5%) thought Medicare would pay for hospice, and only a small amount (5.3%) stated that Medicare would not pay for hospice (Figure 7).

Figure 7: Does Medicare pay for hospice services? (n=631)



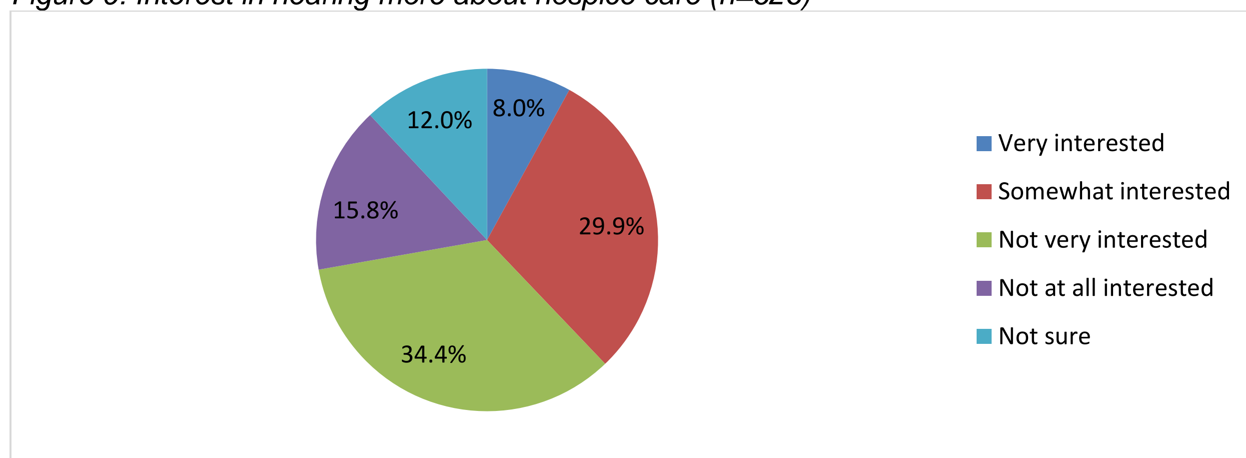
When thinking about which chronic illnesses hospice services would be helpful for, respondents overwhelmingly identified cancer (95.6%) followed by organ failure or disease (87.9%), Alzheimer's disease (80.8%), stroke (76.0%), lung disease (74.9%), heart disease (71.7%), Old age (70.5%), HIV/AIDS (63.5%), Frailty (48.7%), Infirmity (41.8%), COVID-19 (38.4%), and hypertension (31.7%) (Figure 8).

Figure 8: Which chronic illnesses are hospice services helpful? (n=618)



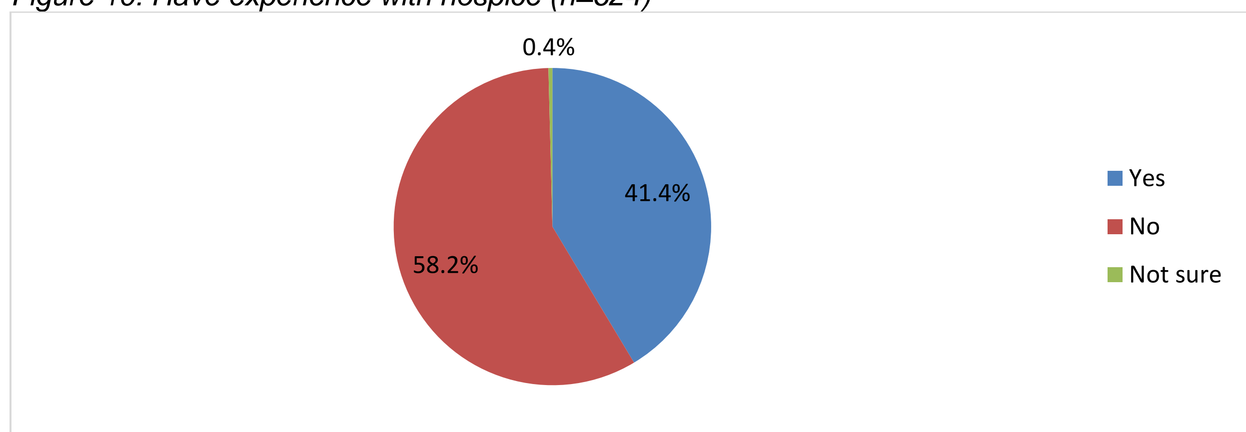
A combined 37.9% of respondents were very interested or somewhat interested in hearing more about hospice care. Some respondents (12.0%) were unsure if they would like to have more information about hospice. Over half of respondents (50.2%) were not very interested or not at all interested in hearing more about hospice care (Figure 9).

Figure 9: Interest in hearing more about hospice care (n=626)



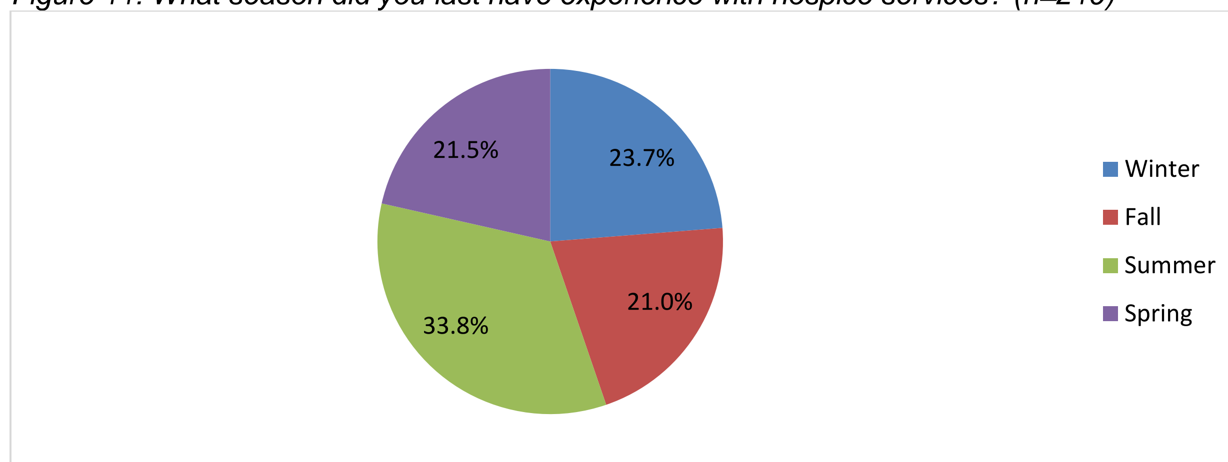
When asked if they had experience with hospice some respondents reported having had experience (41.4%), the majority (58.2%) reported that they did not have experience with hospice, and a few (0.4%) reported that they were not sure if they had experience with hospice (Figure 10).

Figure 10: Have experience with hospice (n=624)



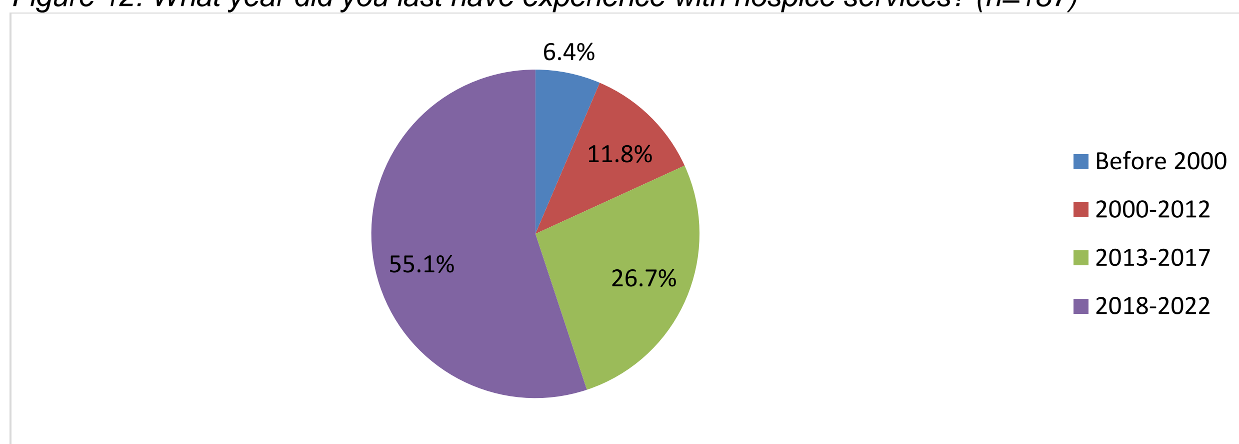
When asked for the last time they have had experience with hospice services, about one-third (33.8%) of respondents reported their latest experience with hospice services having occurred during the summer months, nearly one-fourth (23.7%) reported their latest experience with hospice services having occurred during the winter months, followed by spring (21.5%) and fall (21.0%) (Figure 11).

Figure 11: What season did you last have experience with hospice services? (n=219)



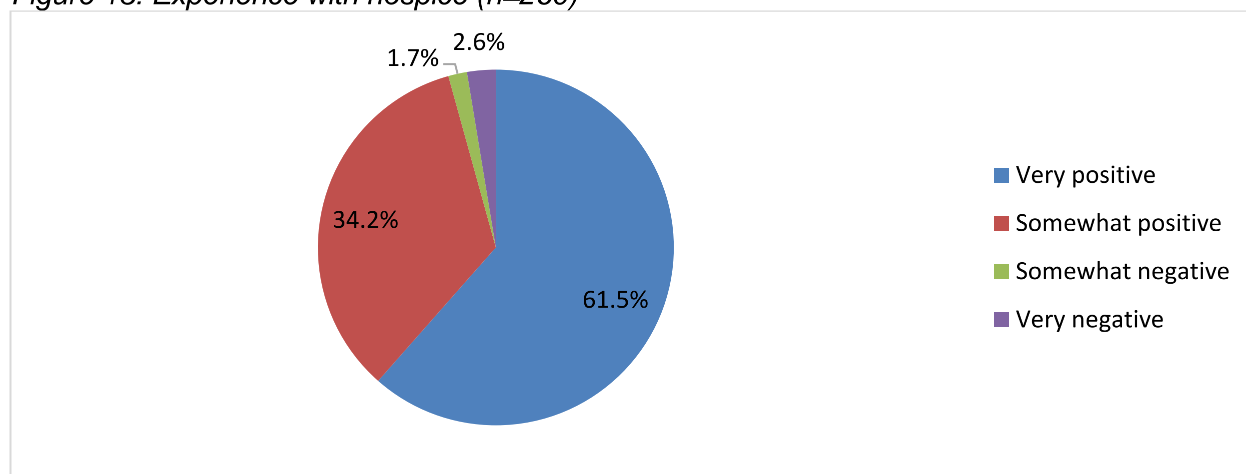
The majority of respondents (55.1%) had last had experience with hospice within the past five years (2018-2022). Slightly over one-fourth of respondents (26.7%) had last experienced hospice more than five years ago, but less than 10 years ago (2013-2017), some (11.8%) had last experienced hospice more than 10 years ago, but less than 22 years ago (2000-2012), and a few (6.4%) had last experienced hospice prior to the year 2000 (Figure 12).

Figure 12: What year did you last have experience with hospice services? (n=187)



Among respondents who have had experience with hospice, the majority (95.7%) reported their experience as very positive or somewhat positive. A few (4.3%) reported their experience as very negative or somewhat negative (Figure 13).

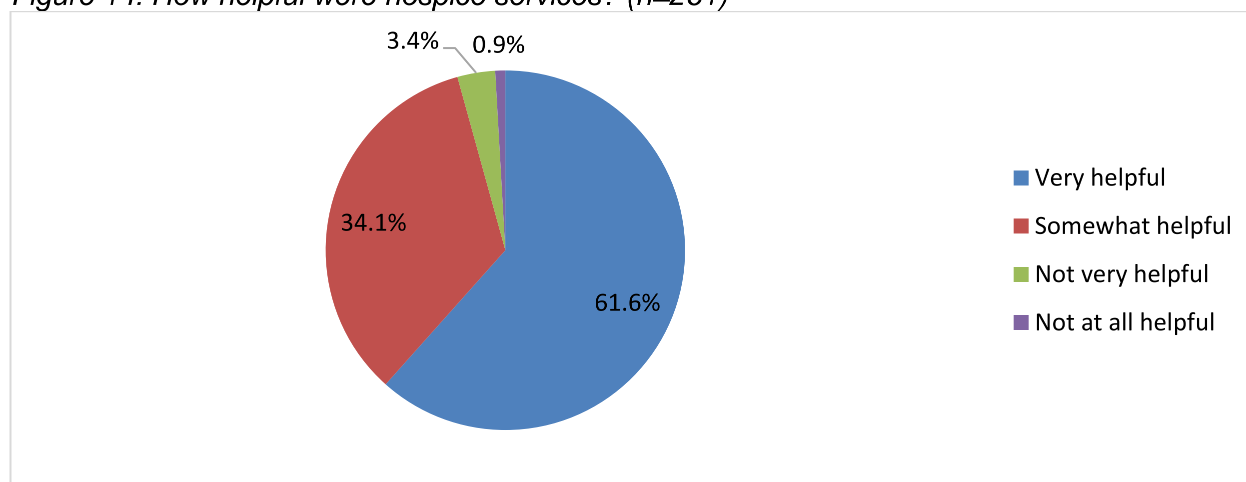
Figure 13: Experience with hospice (n=260)



Among the respondents who reported having had a positive experience with hospice, many reported having found the service they experienced as helpful, while others mentioned hospice as a service in and of itself is useful. Others related their positive experience to the caring staff. Among the respondents who reported having had a negative experience with hospice, some reported discontent with the level of care provided. Others mentioned that the services were not available at their desired location, such as in the home of the patient or in a hospice facility.

Among the respondents who reported having had experience with hospice, the majority (95.7%) reported finding the services very helpful or somewhat helpful. Some (4.3%) reported finding the services not very helpful or not at all helpful (Figure 14).

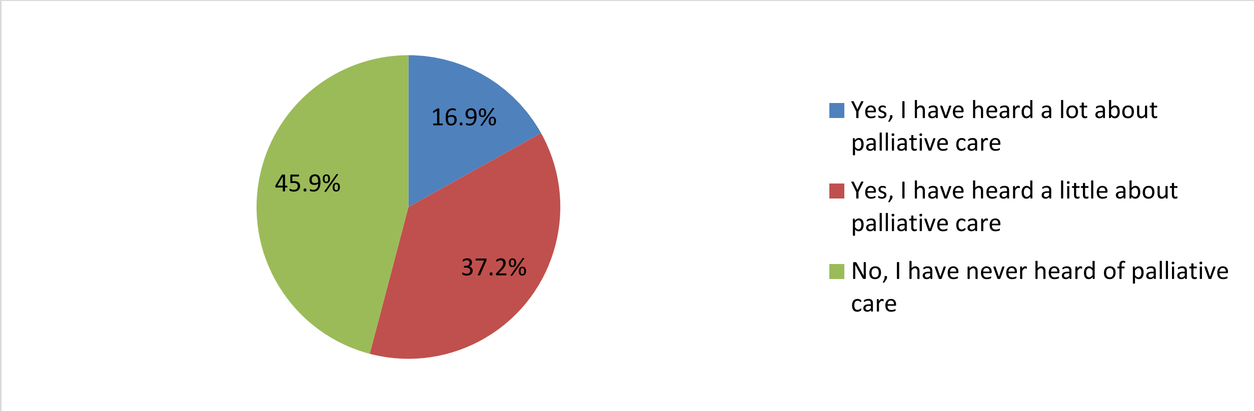
Figure 14: How helpful were hospice services? (n=261)



Section 2: Palliative Care

When asked if they knew about palliative care, nearly half of respondents (45.9%) had never heard of palliative care. Some (37.2%) of respondents have heard a little about palliative care followed by a smaller percentage of respondents (16.9%) who have heard a lot about palliative care (Figure 15).

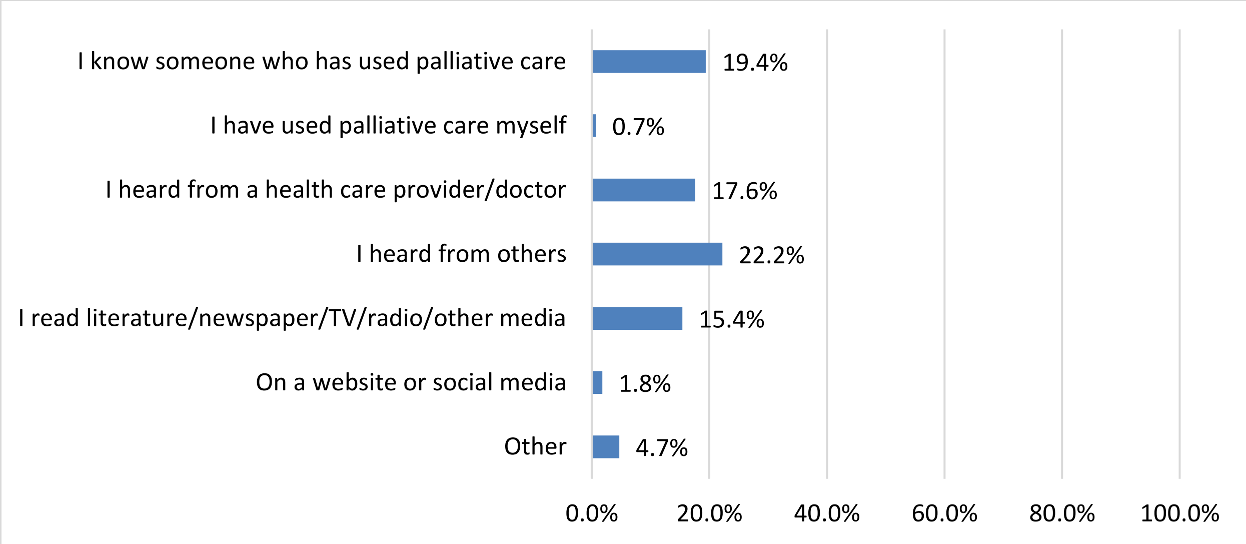
Figure 15: Have you heard of palliative care? (n=617)



Respondents who had heard of palliative care knew of it in a myriad of different manners. The largest group (22.2%) were aware of palliative care because they heard of them from others, followed by knowing someone who used these services (19.4%), followed by hearing from a healthcare professional (17.6%), through reading about it (15.4%), another source (4.7%), a website or social media (1.8%), and using palliative care themselves (0.7%) (Figure 16).

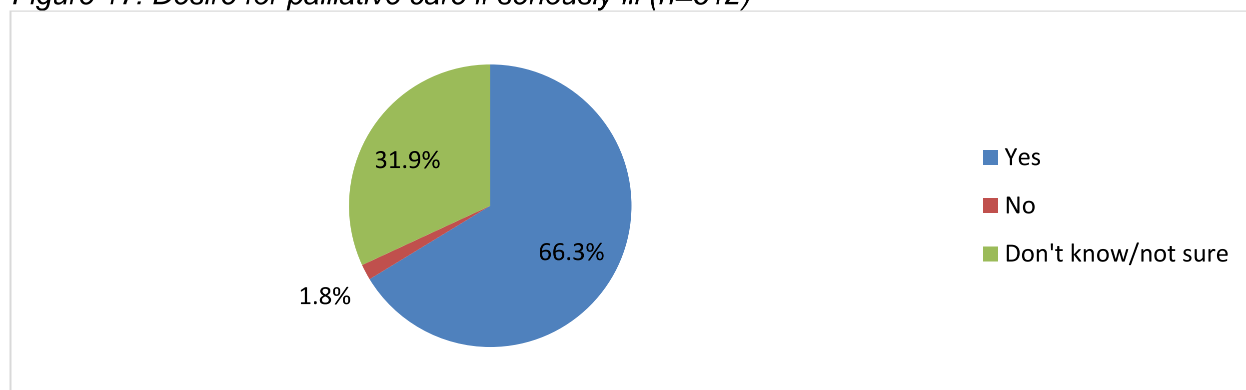
Of those who learned about palliative care on a website or social media, most found their information through a general Google search or medical website. Respondents who knew about palliative care from other sources largely learned their information through professional lives within the medical field working in general medicine and with geriatric groups.

Figure 16: How did you learn about palliative care? (n=315)



When asked if they wanted palliative care, most respondents (66.3%) reported that they would like to have palliative care. Several (31.9%) are not yet sure if they would like to use palliative and a small percent (1.8%) would not want palliative care if they were seriously ill (Figure 17).

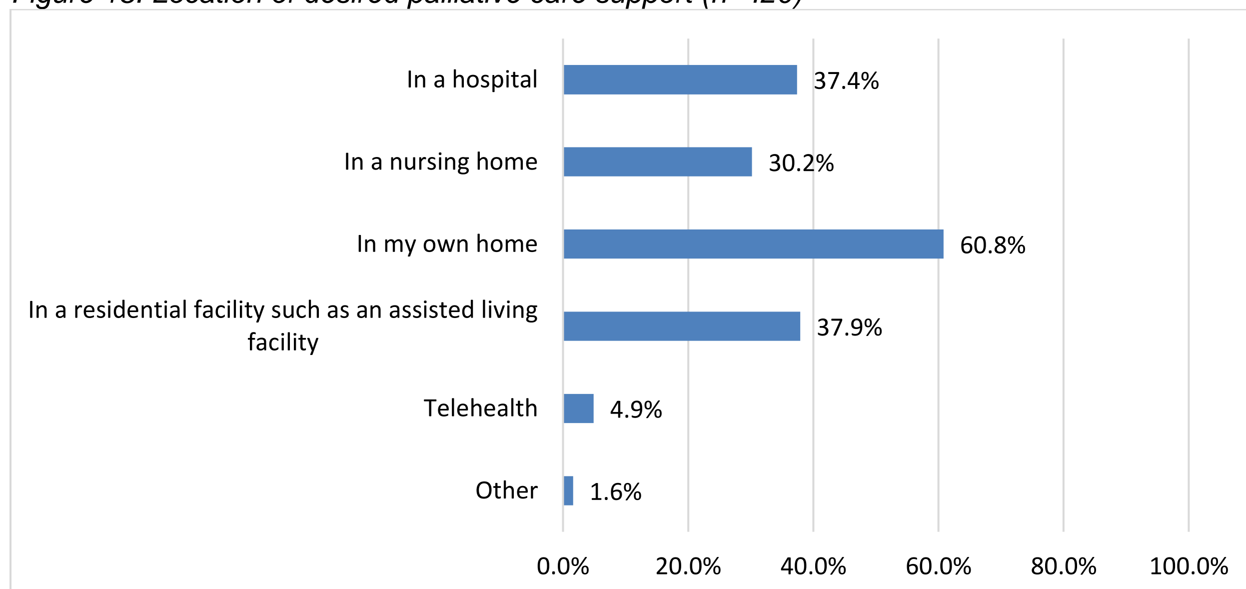
Figure 17: Desire for palliative care if seriously ill (n=612)



Of those respondents who do want to use palliative care, most (60.8%) would prefer for the care to happen in their own home, followed by a residential facility such as an assisted living facility (37.9%), a hospital (37.4%), a nursing home (30.2%), through Telehealth (4.9%), and another location (1.6%) (Figure 18).

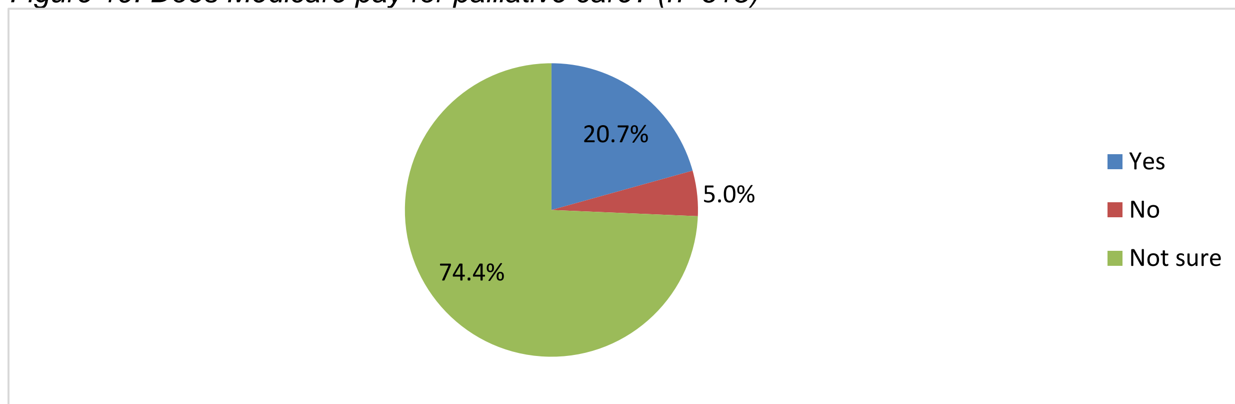
Some respondents answered they would want palliative care at a location other than those listed in Figure 18. Most indicated that their desired location would depend on their current health condition and current residence, others stated the home of a friend or family member.

Figure 18: Location of desired palliative care support (n=420)



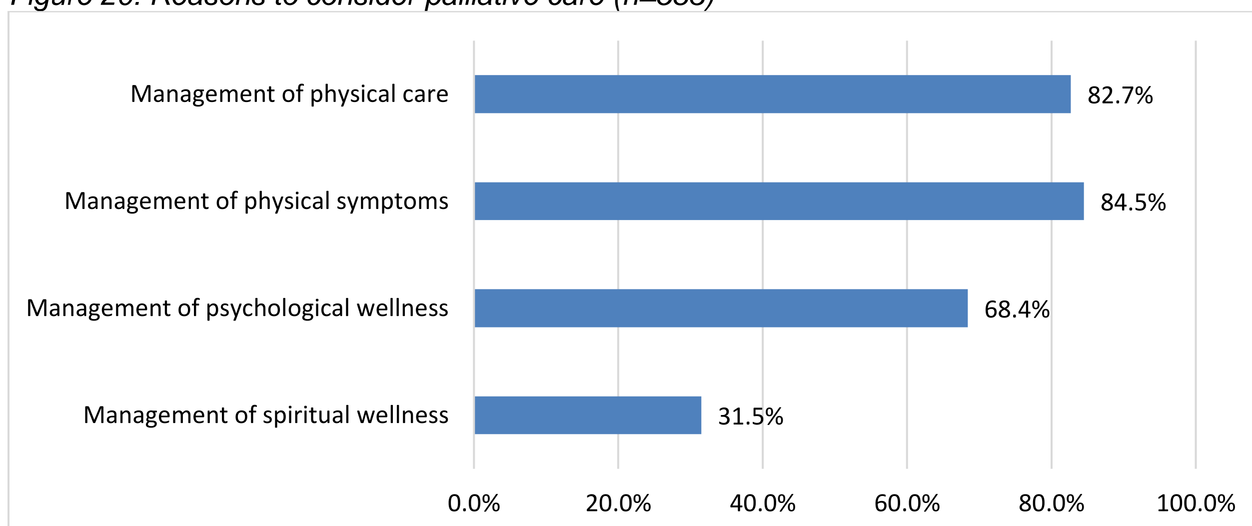
Respondents identified to the best of their knowledge if Medicare pays for palliative care. The majority (74.4%) of respondents were unsure if Medicare would pay for palliative care while some (20.7%) thought Medicare would pay for palliative care, and only a small amount (5.0%) stated that Medicare would not pay for palliative care (Figure 19).

Figure 19: Does Medicare pay for palliative care? (n=615)



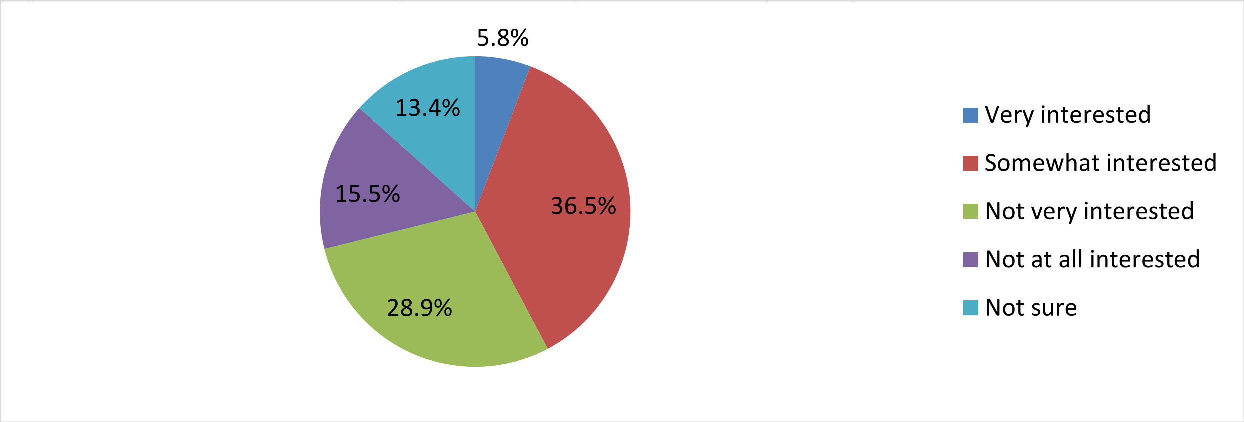
Respondents were asked to identify which courses of a chronic illness they would consider palliative care for. The majority identified management of physical symptoms (84.5%), followed by management of physical care (82.7%), management of psychological wellbeing (68.4%) and management of spiritual wellness (31.5%) (Figure 20).

Figure 20: Reasons to consider palliative care (n=583)



A combined 42.3% of respondents were very interested or somewhat interested in hearing more about palliative care. Some respondents (13.4%) were unsure if they would like to have more information about palliative care. Many (44.4%) were not interested in hearing more about palliative care (Figure 21).

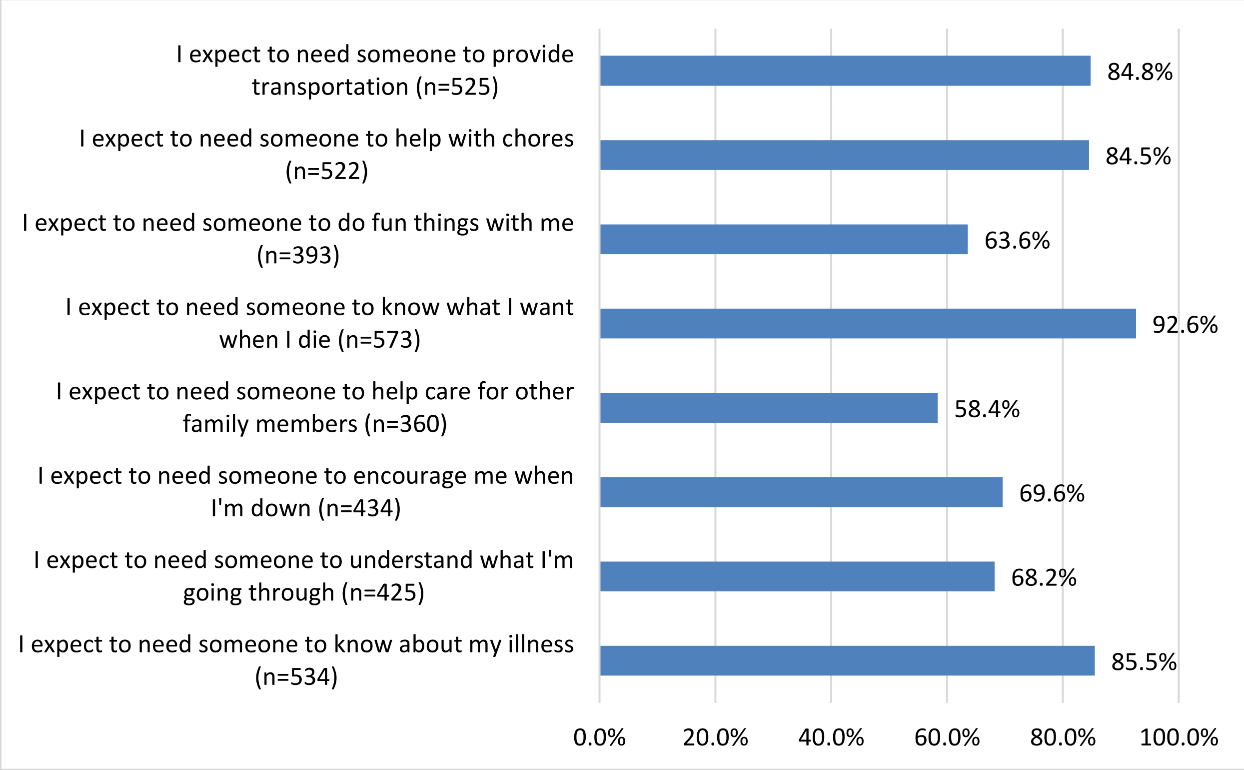
Figure 21: Interested in hearing more about palliative care (n=615)



Section 3: Support near the End of Life

When thinking about what their support expectations were near the end of life, respondents identified which types of support they think they will need. The overwhelming majority (92.6%) indicated that they will need someone to know what they want when they die, followed by needing someone knowing about their illness (85.5%), providing transportation (84.8%), helping with chores (84.5%), giving encouragement (69.6%), understanding what they are going through (68.2%), engaging in fun activities (63.6%), and caring for other family members (58.4%). For each of the support expectations given, over half of respondents indicated that they expected to need support (Figure 22).

Figure 22: Support expectations from others needed at the end of life



As seen in Table 3, respondents identified who would provide the specific support needed by selecting all that apply among spouse/partner, children, other family, friends/neighbors, health providers, work associates, community organizations, church/place of worship, or other. The majority of respondents (70%) plan for their spouse/partner and children (69%) to provide transportation. Several respondents identified they would use taxi services or public transit. Thinking of help with chores, most people (71%) selected that they plan to rely on their spouse/partner to help with chores as well as their children (70%). Many respondents intend to hire professional cleaning services to complete chores. When planning to do fun things, most people plan on doing these activities with friends and family either with their spouse/partner (56%), children (55%), friends/neighbors (47%), and other family (45%). Several people indicated that they plan to do fun activities with their caregivers. Knowing desires after they have died rests firmly with spouses (80%) and children (79%). Many noted that they have taken legal steps, such as a will or power of attorney. Near the end of their life, respondents expect that their children (49%), spouse/partner (47%), and other family members (42%) will provide remaining care for family members. Many respondents expect health care providers or hired help to care for their family members.

When looking for encouragement, respondents plan to turn largely to their spouse/partner (60%) and children (59%) for support. Additionally, many noted that they intend to go to professionals within the health and social services fields such as their home health care or counselors for encouragement. For understanding of what they are going through, respondents predict that they will go to their spouse/partner (43%), children (35%), and health providers (31%). Some respondents wrote in that they plan to engage with their communities. Respondents identify that their spouse/partner (68%), health providers (64%), and children (62%) will have knowledge about their illness. Furthermore, several respondents plan to turn to health professionals or social supports such as groups and family members for understanding about their specific illnesses.

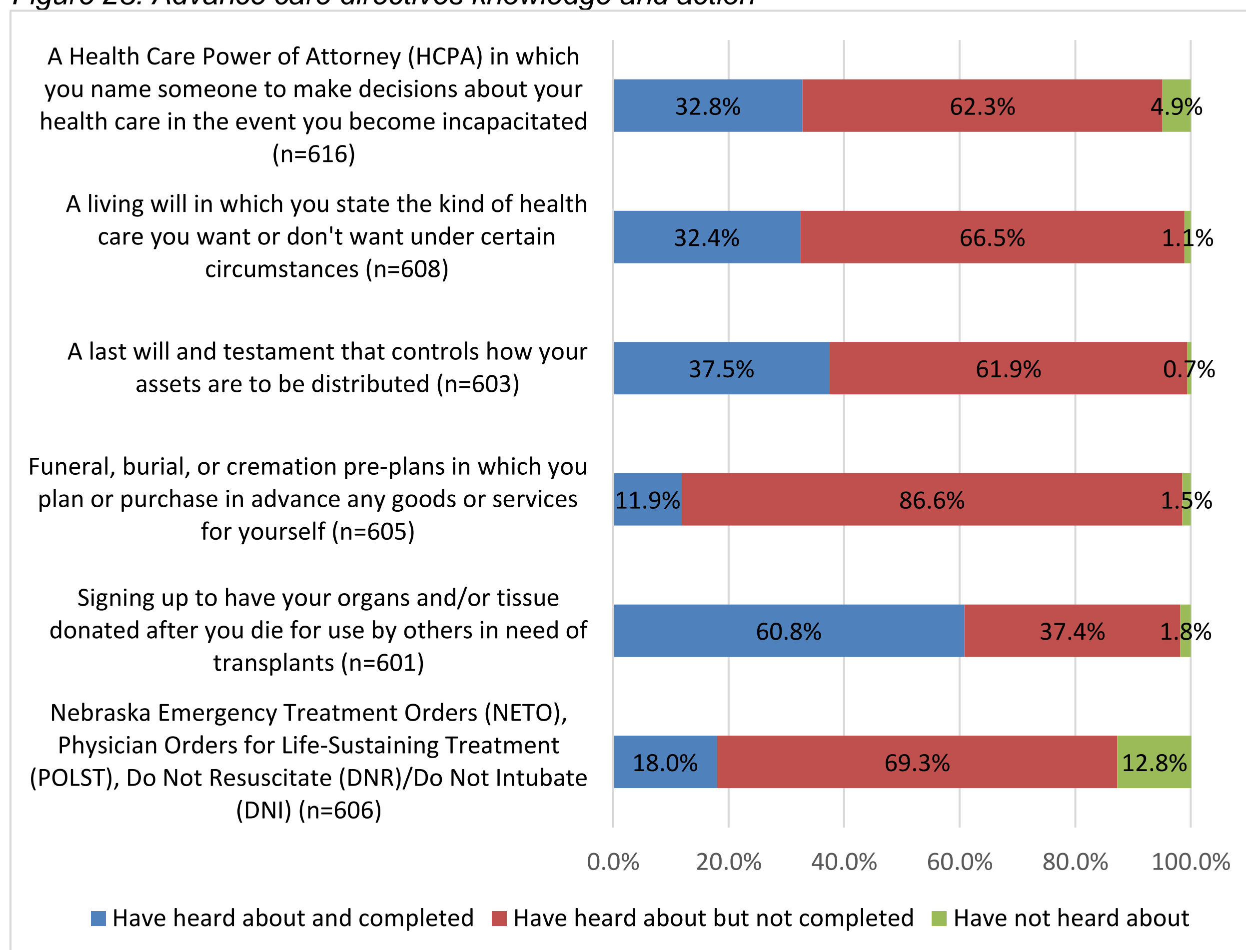
Table 3: Support needed at the end of life and expected providers (n=550)

Providers of support		Support needed							
		Transport	Chores	Fun things	Know desires	Care for family	Encourage	Understand	Know about illness
	Spouse/ partner	70%	71%	56%	80%	47%	60%	43%	68%
	Children	69%	70%	55%	79%	49%	59%	35%	62%
	Other family	53%	52%	45%	39%	42%	49%	26%	42%
	Friends/ neighbors	64%	44%	47%	15%	28%	52%	21%	30%
	Health providers	28%	15%	5%	25%	15%	29%	31%	64%
	Work associates	7%	6%	11%	1%	3%	11%	5%	4%
	Community organization	39%	38%	24%	2%	20%	16%	12%	9%
	Church/ place of worship	31%	26%	21%	16%	18%	30%	19%	15%
	Other	4%	7%	1%	8%	1%	2%	2%	2%

Section 4: Advance Directives

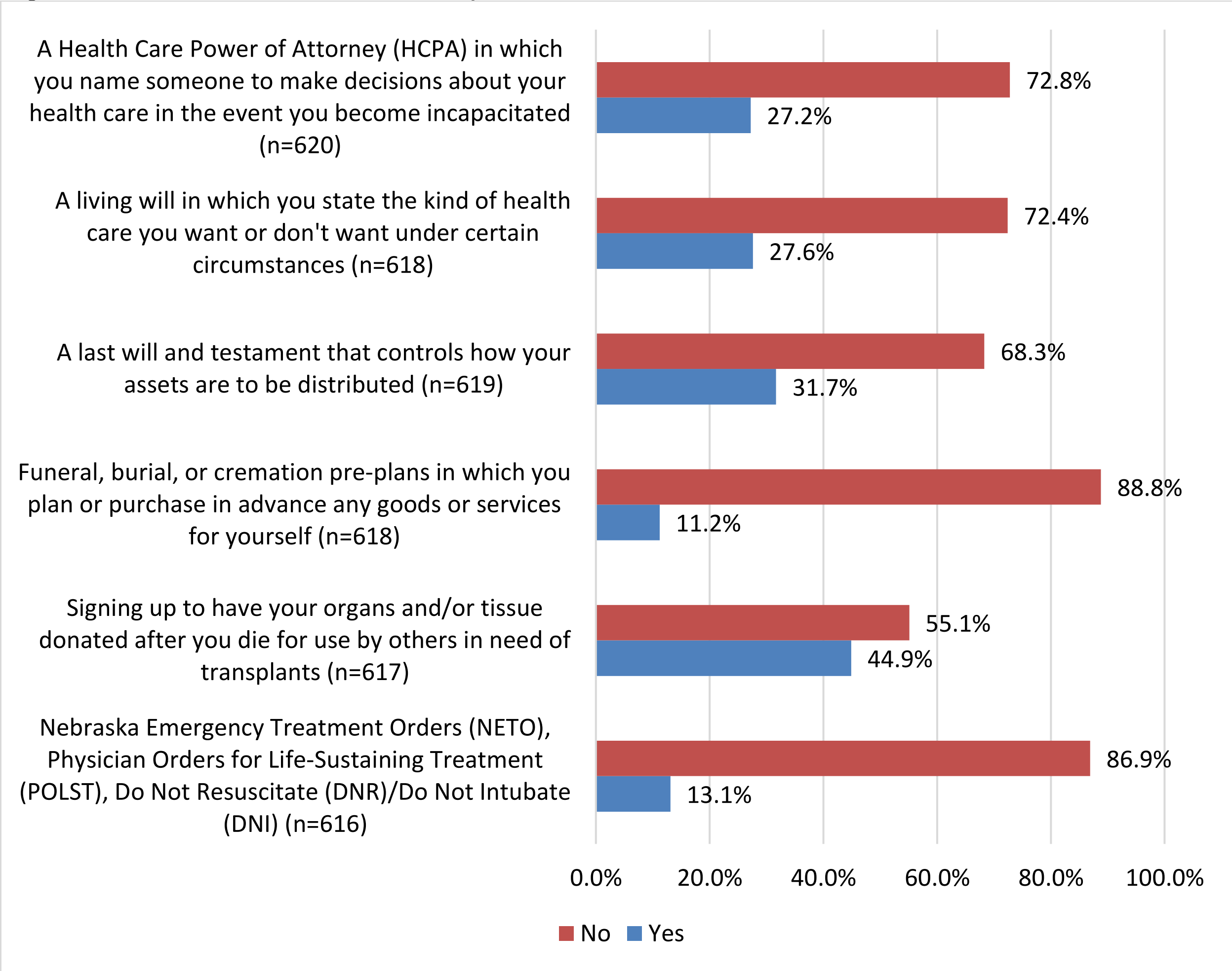
Health Care Power of Attorney (HCPA) have been completed by 32.8% of respondents while more than half (62.3%) of respondents have heard about one but do not have it completed and few (4.9%) have not heard about a HCPA. Similarly, living wills have been completed by 32.4%, known by the majority (66.5%), and unknown by a small (1.1%) number of respondents. Over one-third (37.5%) of respondents have completed a last will and testament while over half (61.9%) have heard of one but not completed it, leaving a small percent (0.7%) without any knowledge. Funeral or burial pre-plans are less common to be completed (11.9%) even though the majority of respondents (846.6%) identified knowing about these plans. Over half (60.8%) of respondents have signed up to be an organ or tissue donor, less than half (37.4%) know about the program but are not signed up, and few (1.8%) have not heard about the program. Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/ Do Not Intubate (DNI) have been completed by 18.0%, over half (69.3% of respondents have heard of these options but have not completed one, and some (12.8%) have not heard about them (Figure 23).

Figure 23: Advance care directives knowledge and action



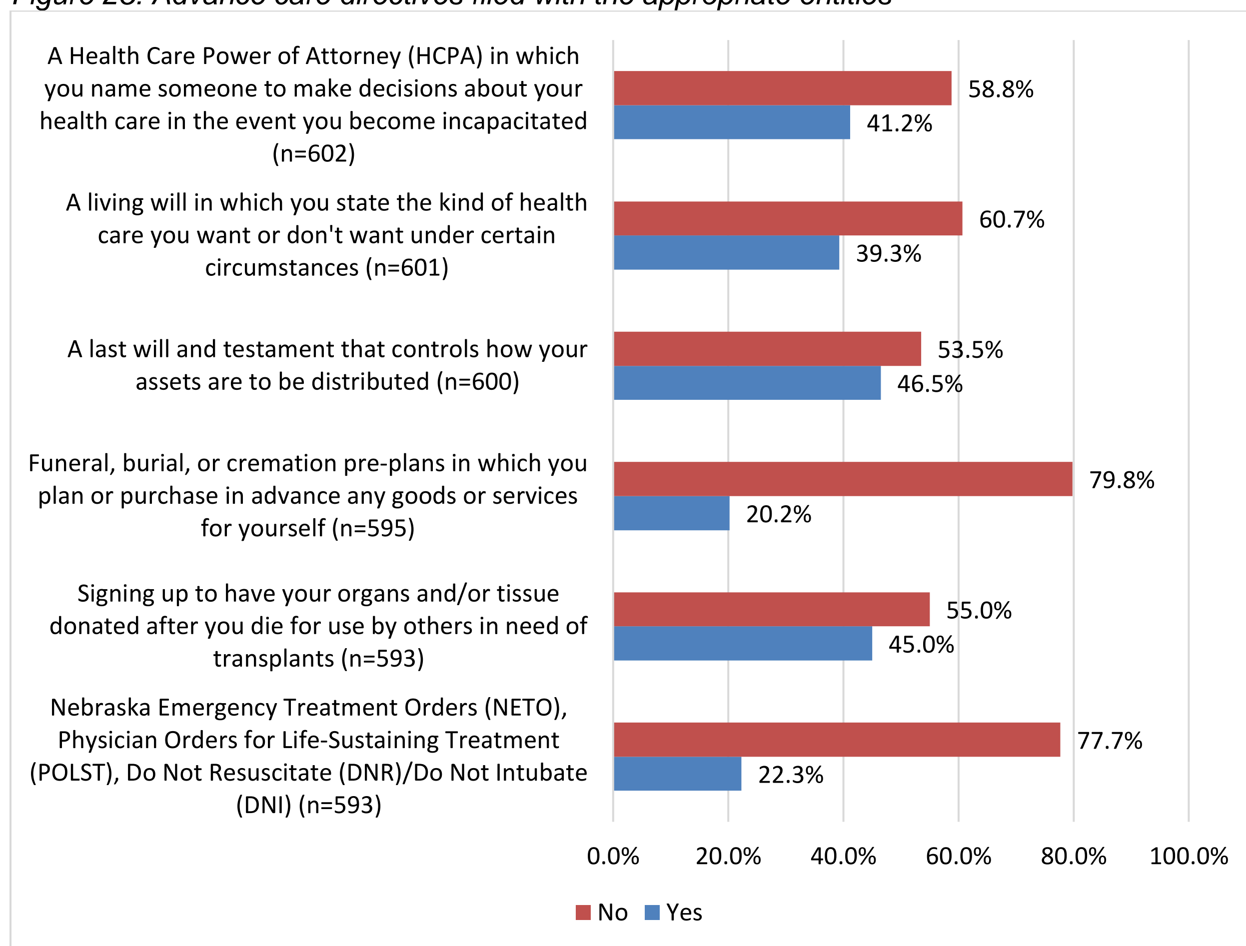
Health Care Power of Attorney (HCPA) have been updated by 27.2% of respondents. Similarly, living wills have been updated by 27.6%, nearly one-third (31.7%) of respondents have updated their last will and testament. Funeral or burial pre-plans are less common to be updated (11.2%). Almost half (44.9%) of respondents have updated their organ or tissue donor status, Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/ Do Not Intubate (DNI) have been updated by 13.1% of respondents (Figure 24).

Figure 24: Advance care directives updated



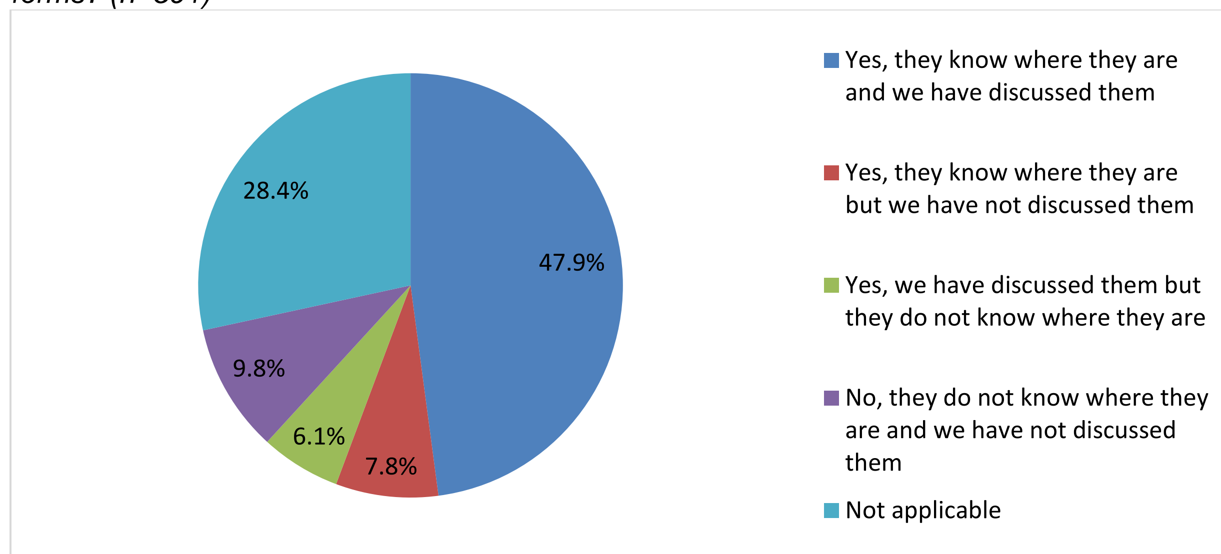
Health Care Power of Attorney (HCPA) have been filed with the appropriate entities by 41.2% of respondents. Similarly, living wills have been filed with the appropriate entities by 39.3% of respondents, 46.5% of respondents have filed their last will and testament appropriately. Funeral or burial pre-plans are less common to be filed appropriately (20.2%), 45.0% of respondents have filed their organ or tissue donor status with an appropriate entity, and Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/ Do Not Intubate (DNI) have been file appropriately by 22.3% of respondents (Figure 25).

Figure 25: Advance care directives filed with the appropriate entities



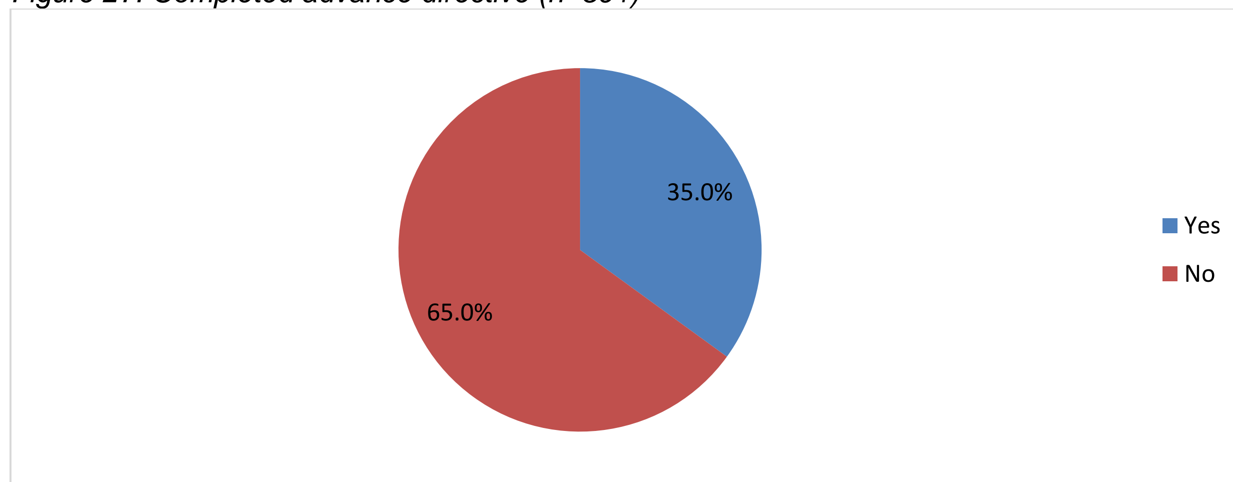
When asked if their intended people have access to the forms they have completed nearly half (47.9%) indicate that their intended person knows where the forms are, and they have discussed them. A smaller rate (7.8%) indicate that their intended person knows where the forms are, but they have not discussed them, 6.1% state they have discussed them, but they do not know where they are, 9.8% report that they do not know where they are, and they have not discussed them. The question was not applicable to 28.4% of respondents (Figure 26).

Figure 26: Of the forms you have completed, do your intended people have access to the forms? (n=591)



When asked if they have completed an advance directive, over one-third (35%) reported that they have, while 65% reported that they have not (Figure 27).

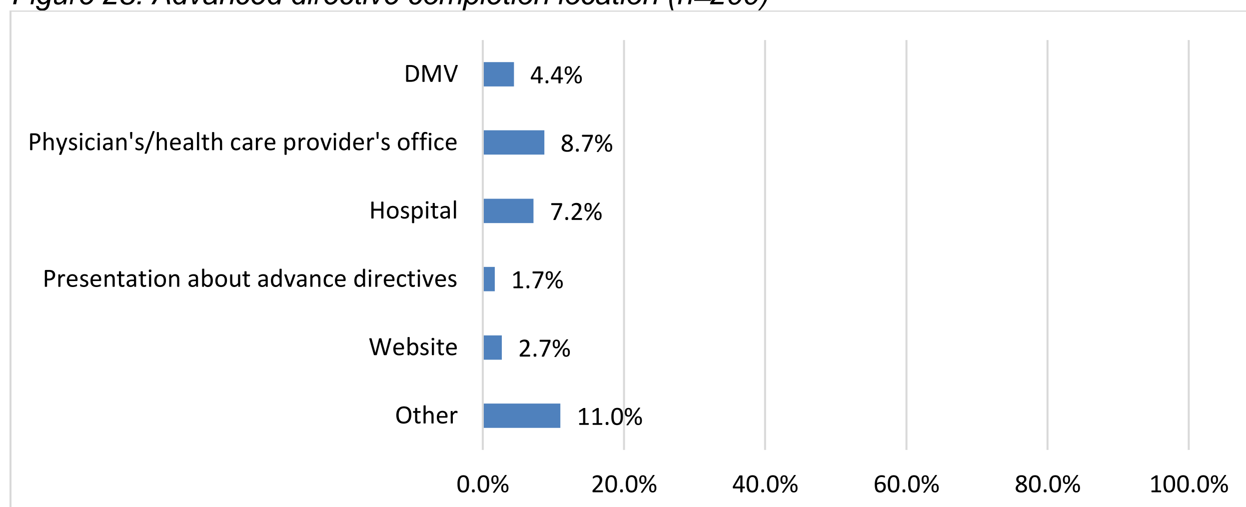
Figure 27: Completed advance directive (n=591)



Of those who had completed an advanced directive, the most common manner (11.0%) was to complete it through a mean not listed in the survey, followed by a physician's office (8.7), a hospital (7.2%), a DMV (4.4%), a website (2.7%), and a presentation (1.7%) (Figure 28).

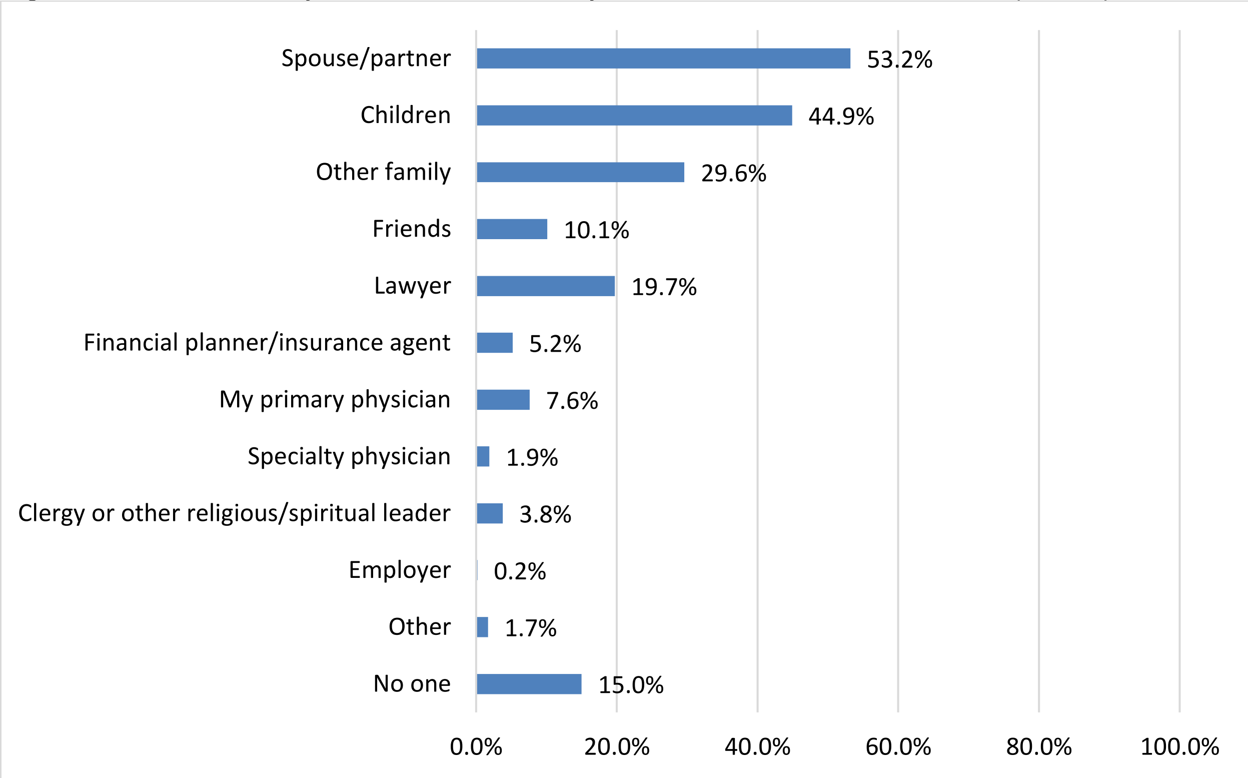
Respondents who completed their advanced directive on a website often did not remember the website information or completed it on a legal website. If respondents selected other, they had the option to specify where they completed their advanced directive. The overwhelming majority completed it at an attorney's office (Figure 28).

Figure 28: Advanced directive completion location (n=200)



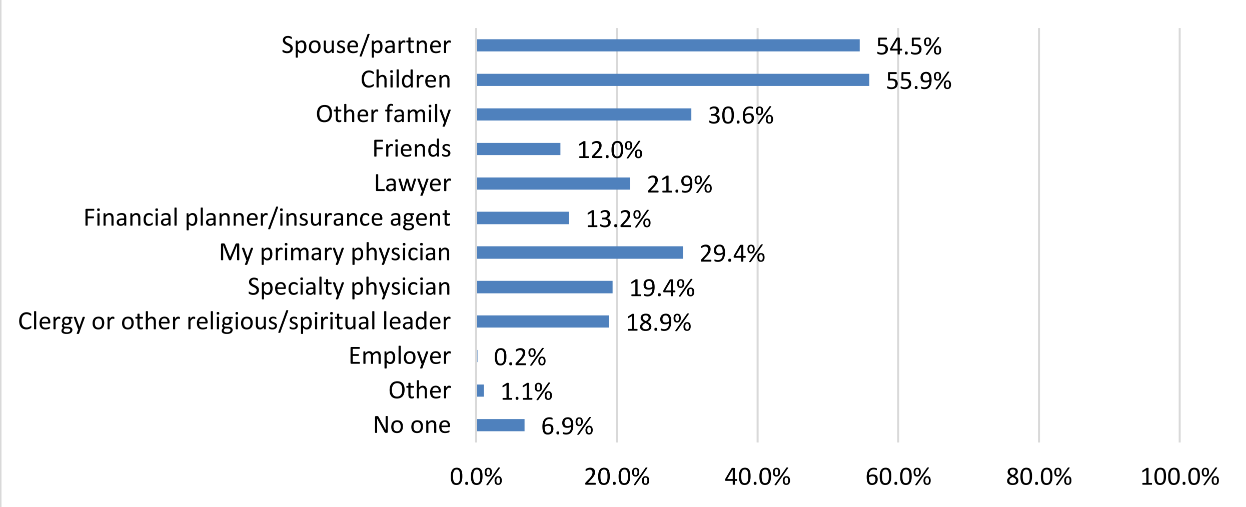
Most respondents (53.2%) have talked with their spouse/partner, about their wishes for their care at the end of their life, followed by their children (44.9%), and other family (29.6%). Some identified talking with lawyers (19.7%), No one (15.0%), friends (10.1%), their primary physician (7.6%), or financial planner/insurance agent (5.2%). Fewer respondents (3.8%) identified talking with a clergy or other religious/spiritual leader such as a priest, minister, or rabbi, a specialty physician such as a cancer doctor or heart doctor (1.9%), others (1.7%), or their employer (0.2%) (Figure 29). Of the respondents who selected other, the majority specified a family member or friend.

Figure 29: Whom have you talked with about your wishes for end of life care? (n=607)



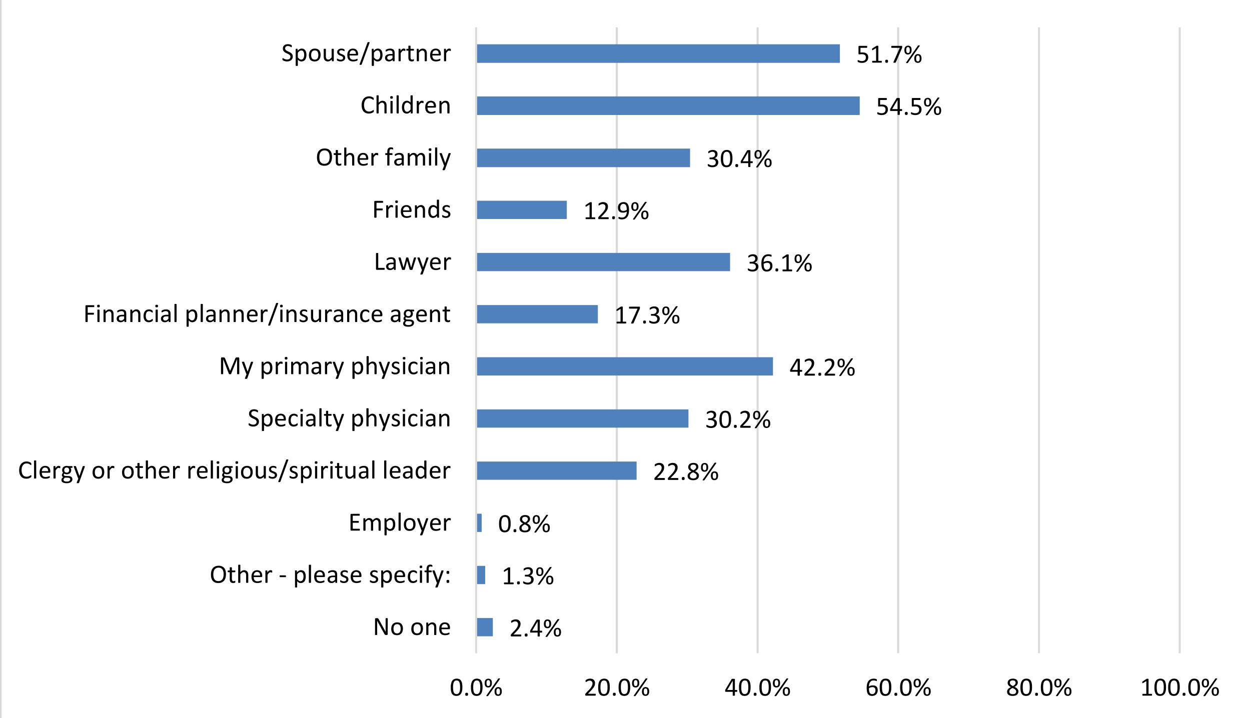
Respondents were asked whom they would like to talk with about their wishes for end of life care. Over half (55.9%) of respondents indicated that they would like to talk with their children, and their spouse/partner (54.5%). Others desire talking with other family (30.6%), followed by their primary physician (29.4%), a lawyer (21.9%), a specialty physician (19.4%), a financial planner/insurance agent (13.2%), or their friends (12.0%). Fewer respondents (6.9%) reported wishing to speak with no one, other (1.1%), or an employer (0.2%) (Figure 30). Of the respondents who indicated other, some specified the individual they would like to initiate this conversation, others stated that this conversation has already taken place.

Figure 30: Whom would you like to talk with about your wishes for end of life care? (n=597)



Respondents identified that children (54.5%) are the most trusted providers of information on end-of-life issues followed by their spouse/partner (51.7%), their primary physician (42.2%), a lawyer (31.1%), other family (30.4%), specialty physicians (30.2%), clergy or other religious/spiritual leaders (22.8%), a financial planner/insurance agent (17.3%), friends (12.9%), no one (2.4%), other (1.3%), and an employer (0.8%). Other sources of information indicated by respondents were family members and professionals such as health care providers or social service workers (Figure 31).

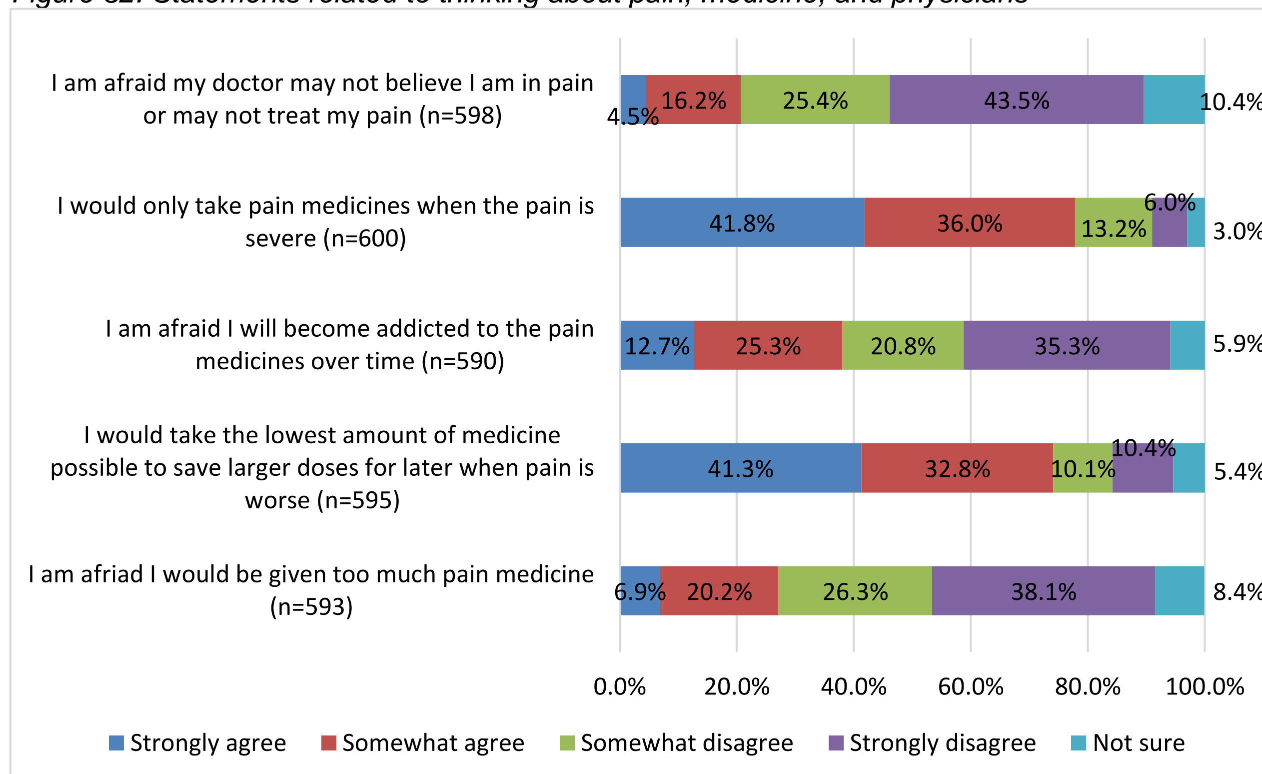
Figure 31: Trusted providers of end of life issues (n=601)



Section 5: Thinking about Pain

Most respondents (68.9%) are not concerned about their future doctor's perception and treatment of their pain levels, while a smaller percent (10.4%) are unsure. Using pain medication only when pain is severe is the indicated plan for most (77.8%) respondents. Over one-third of respondents (38.0%) are concerned about addiction to pain medication and nearly three-fourths (74.1%) plan to take the lowest amount of medicine, but the majority (64.4%) are not concerned about being given too much pain medicine by their physician (Figure 32).

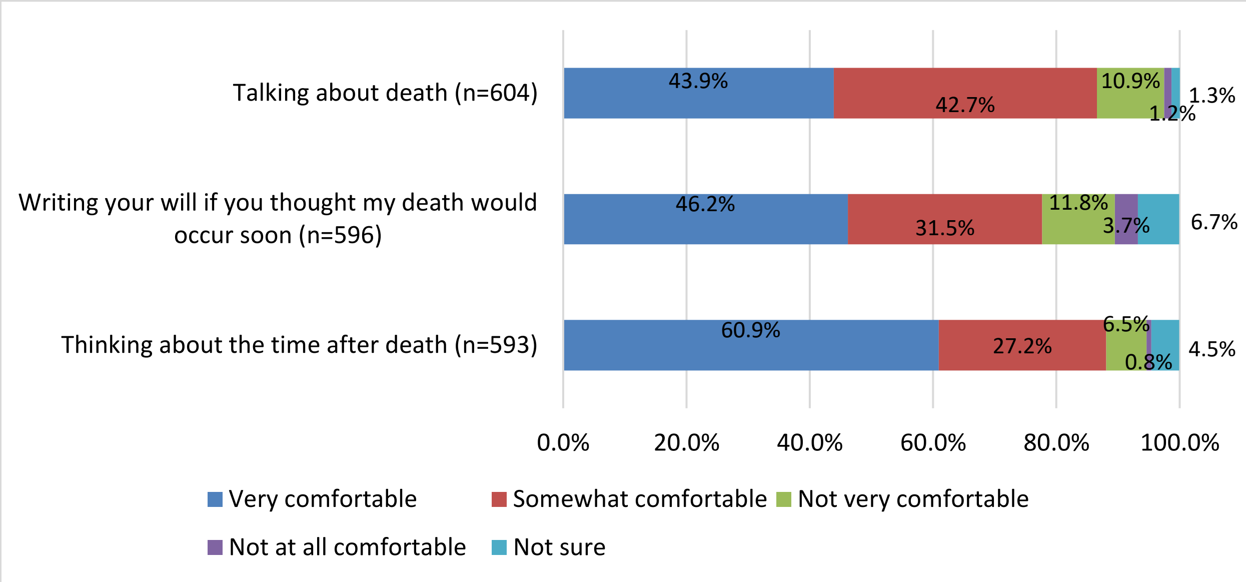
Figure 32: Statements related to thinking about pain, medicine, and physicians



Section 6: Thoughts on Death

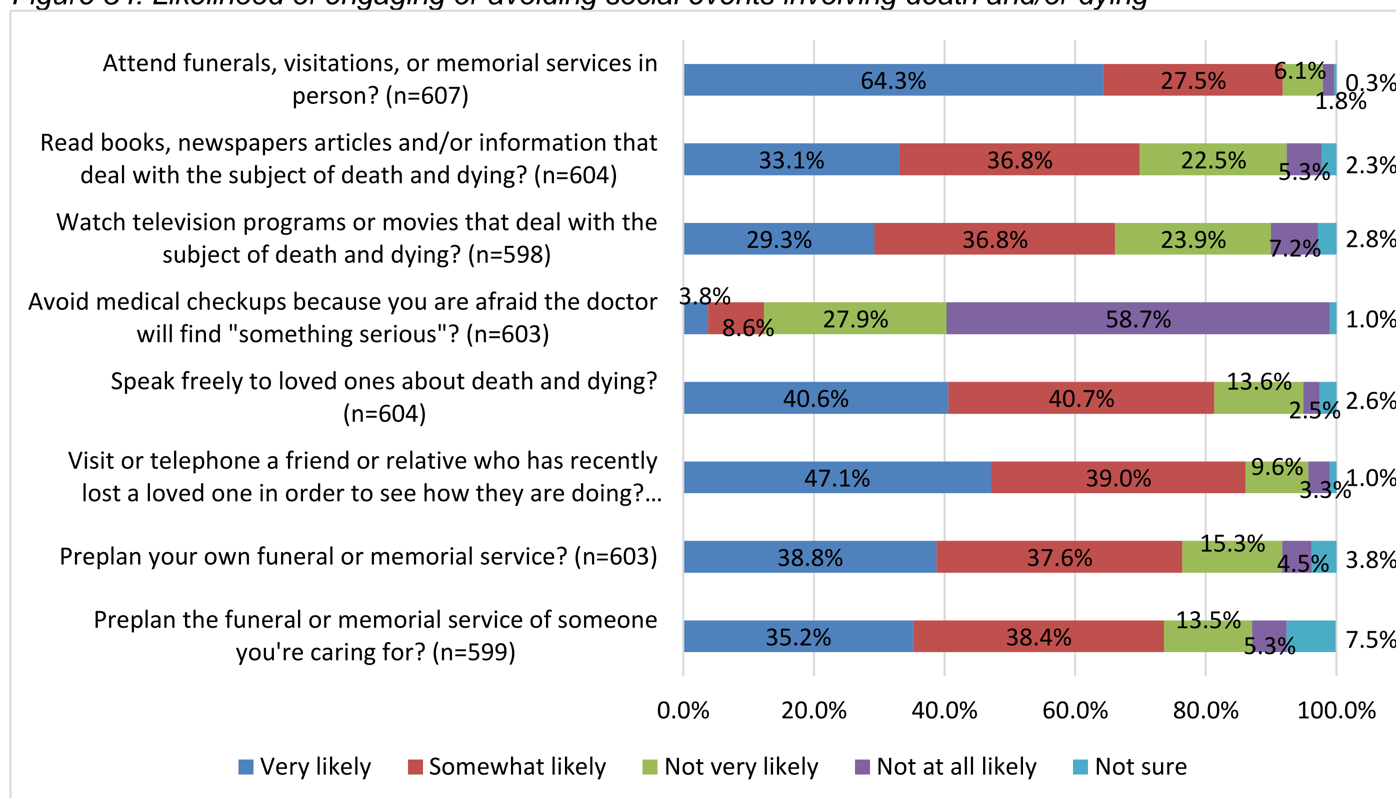
When talking about death, the largest group of respondents identified that they were very comfortable talking about death (43.9%), followed by somewhat comfortable (42.7%), not very comfortable (10.9%), not at all comfortable (1.2%), and not sure (1.3%). The overwhelming majority (77.7%) would be very comfortable or somewhat comfortable writing their will if they thought that their death would occur soon. Similarly, most (88.1%) were comfortable thinking about life after death (Figure 33).

Figure 33: Comfortability with death



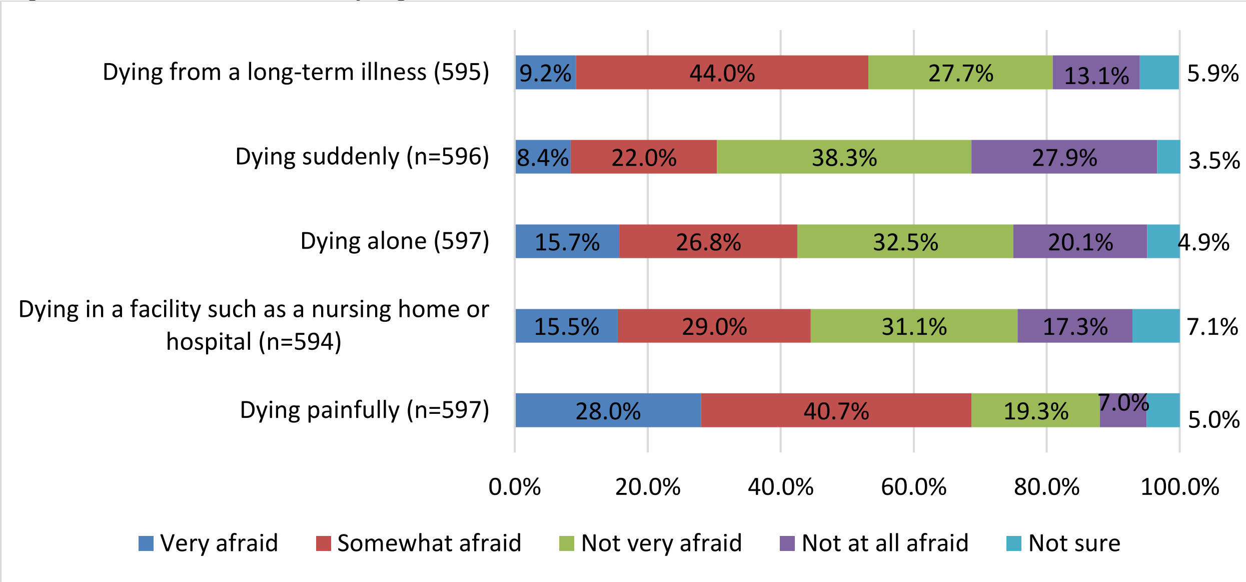
Respondents are very or somewhat likely (91.8%) to attend funerals, visitations, or memorial services, read information related to death and dying (69.9%), watch television programs or movies that have death and dying (66.1%), speak to loved ones about death freely (81.3%), as well as visit or call someone who recently had a loved one pass away (86.1%). Additionally, they are very likely or somewhat likely to pre-plan their own funeral service (76.4%) and pre-plan the funeral service of someone in their care (73.6%). However, they are unlikely (86.1%) to avoid going to a medical checkup out of fear that a physician may find something seriously wrong (Figure 34).

Figure 34: Likelihood of engaging or avoiding social events involving death and/or dying



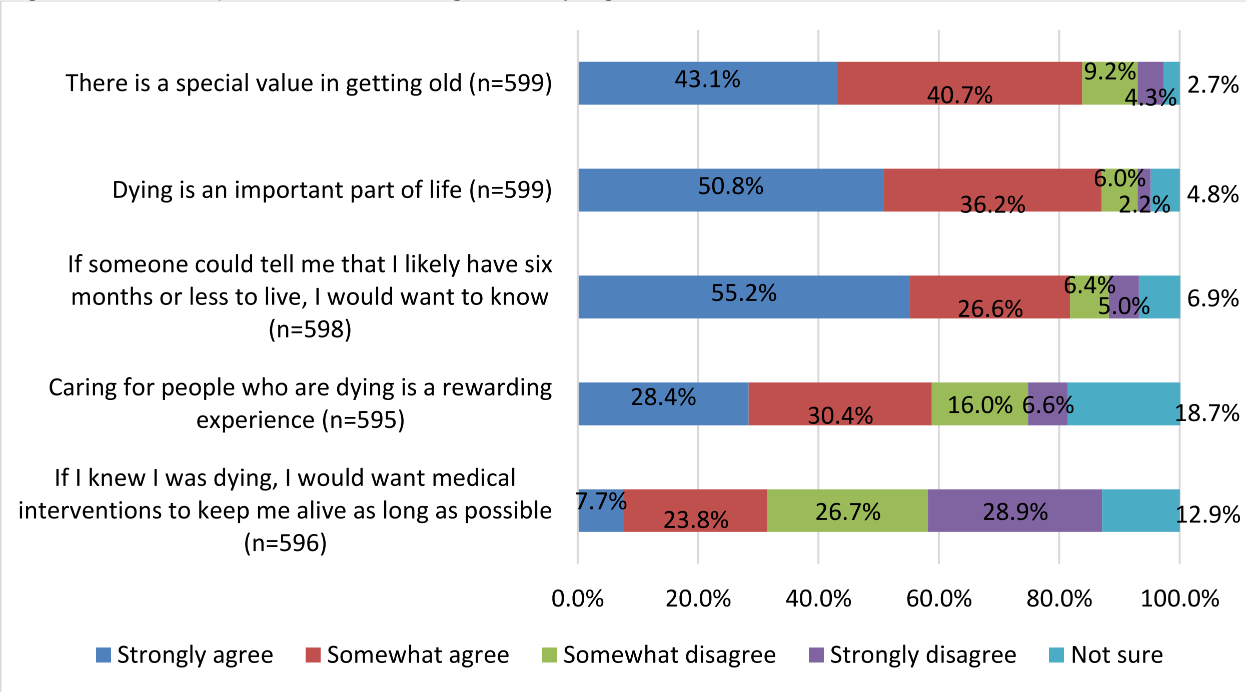
Many respondents have a fear associated with dying. Over half (53.2%) are either very afraid or somewhat afraid of dying from a long-term illness. Nearly one-third (30.4%) are afraid of dying suddenly, nearly half (42.5%) are afraid they will die alone. Similarly, (44.5%) are either very afraid or somewhat afraid of dying in a facility such as a nursing home or hospital, and the majority (68.7%) are either very afraid or somewhat afraid of dying painfully (Figure 35).

Figure 35: Fear related to dying



Overall, respondents have a positive perspective on old age and dying shown through the large percent (83.8%) that think there is a special value in getting older, agreeing that dying is an important part of life (87.0%), and agreeing caring for people who are dying is a rewarding experience (58.8%). Only about one-third (31.5%) want medical interventions to keep them alive for as long as possible. However, most (81.8%) would want to know if they had six months or less to live (Figure 36).

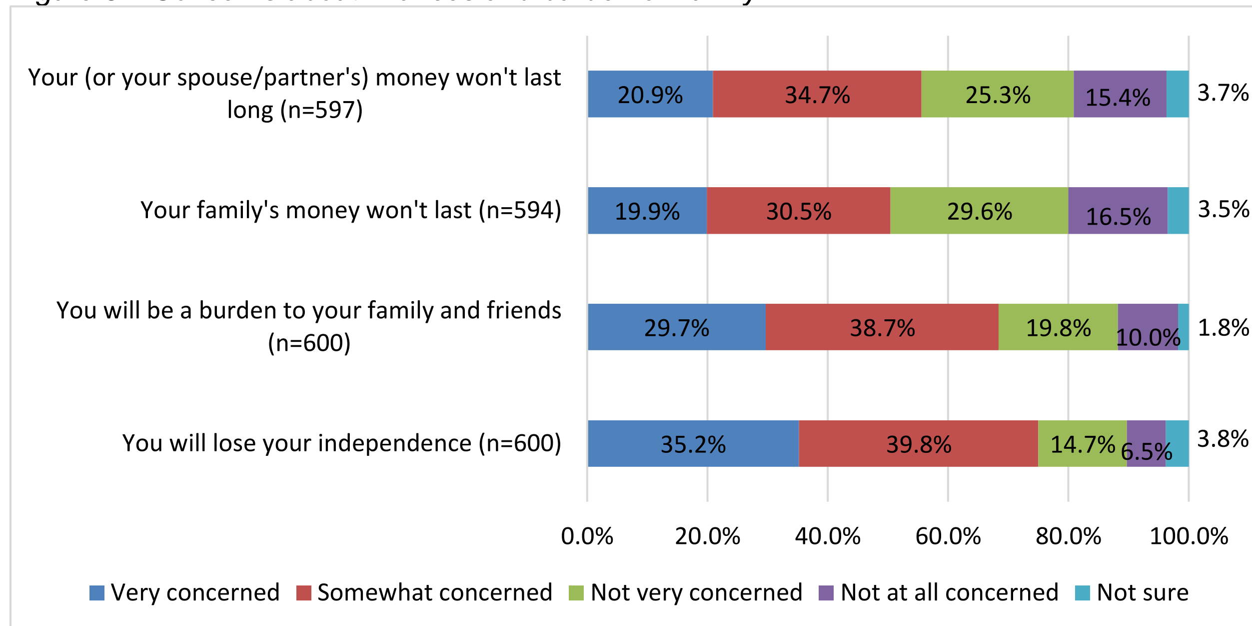
Figure 36: Perceptions about old age and dying



Concerns about financial longevity and burden on family can be a source of unease for people when thinking of aging and dying. Over half of respondents (55.6%) identified that they are

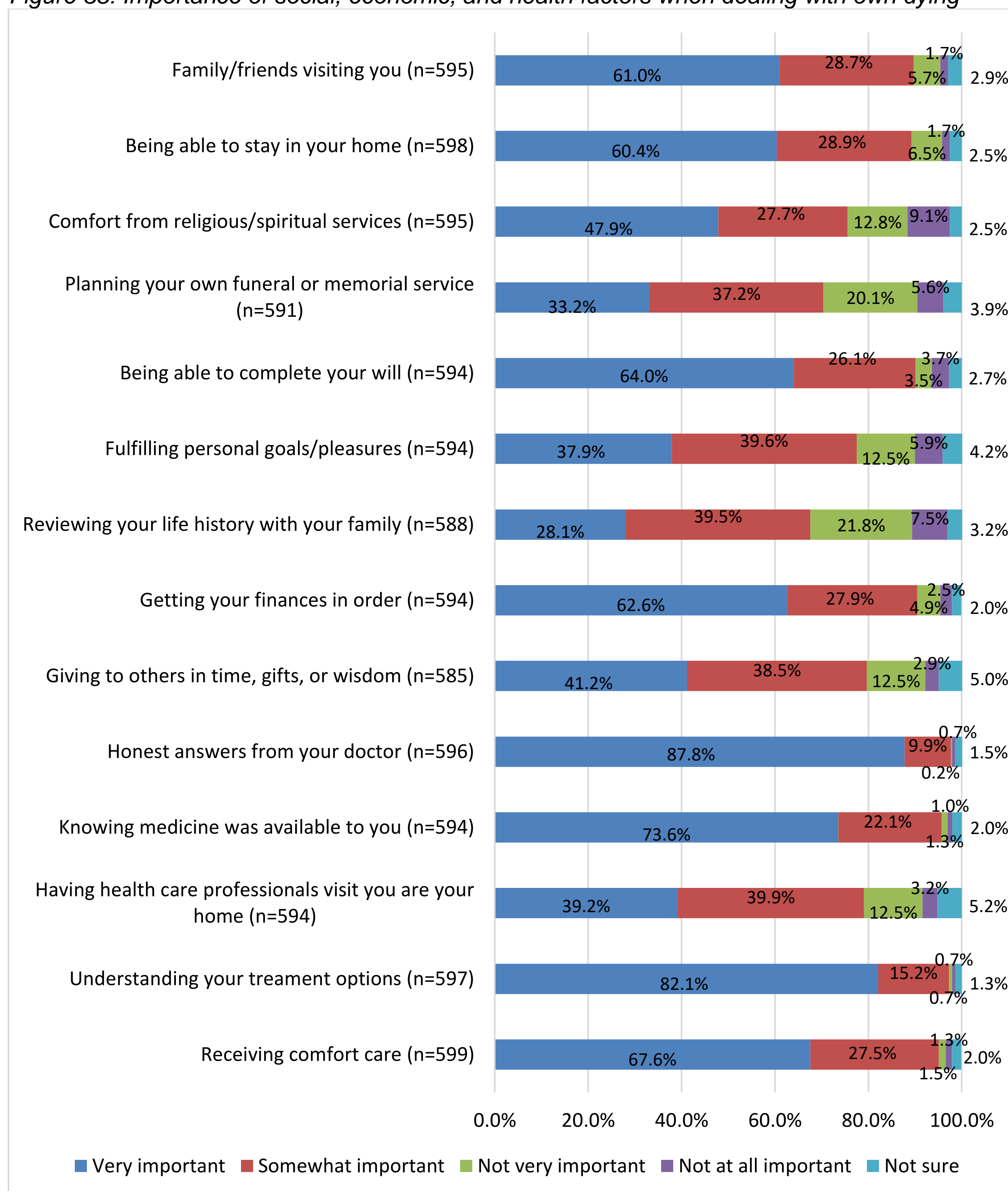
concerned that their money or their spouse's money will not last. Similarly, just over half (50.4%) are concerned that their family's money will not last. Along these lines, over two-thirds (68.4%) express concern that they will be a burden on their friends or family, and three-fourths (75%) are concerned they will lose their independence (Figure 37).

Figure 37: Concerns about finances and burden on family



Respondents answered a myriad of factors in relation to social, economic, and health factors when dealing with their own deaths. Social factors that respondents identified as very important were visits from friends and family (89.7%), giving to others (79.7%), and comfort from religious/spiritual services (75.6%). Economic factors that respondents identified as very important include completing your will (64.0%), getting your finances in order (62.6%), and being able to stay in your home (60.4%). Health factors that respondents identified as important were honest answers from doctors (87.8%), understanding your treatment options (82.1%), knowing what medicine was available to you (73.6%), and receiving comfort care (67.6%) Figure (38).

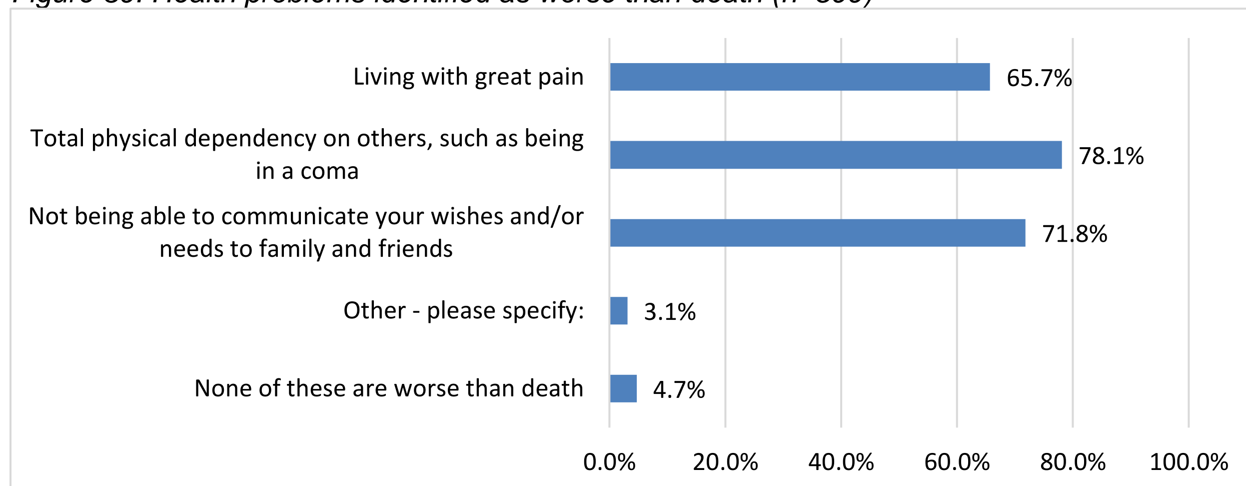
Figure 38: Importance of social, economic, and health factors when dealing with own dying



In a comparison of death and severe health conditions, respondents identified health conditions that they felt would be worse than dying. Over three-fourths (78.1%) of respondents felt that total physical dependency on another would be worse than death, followed by not being able to communicate their wishes and/or needs (71.8%), and living with great pain (65.7%). Only 4.7%

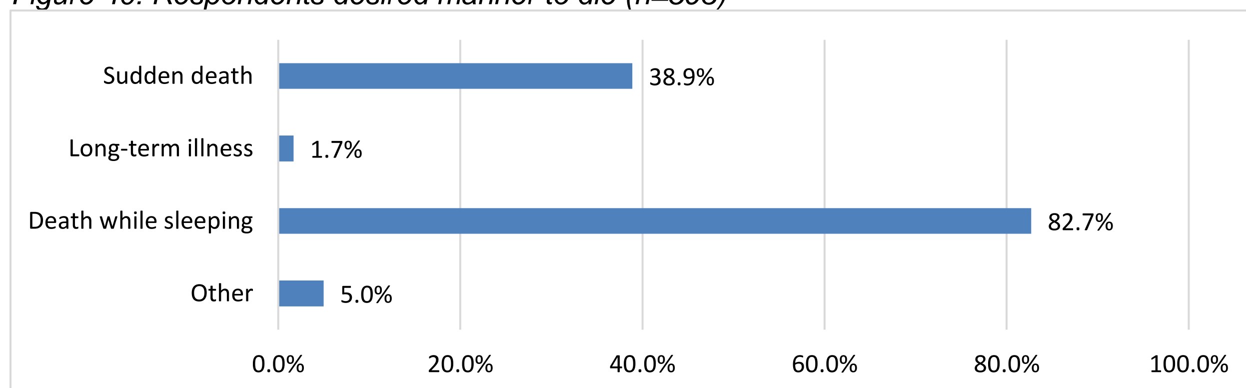
of respondents identified that none of these health problems would be worse than death while some (3.1%) selected other. Among those who chose other, several mentioned Dementia or Alzheimer's, while some chose loneliness and a poor quality of life (Figure 39).

Figure 39: Health problems identified as worse than death (n=599)



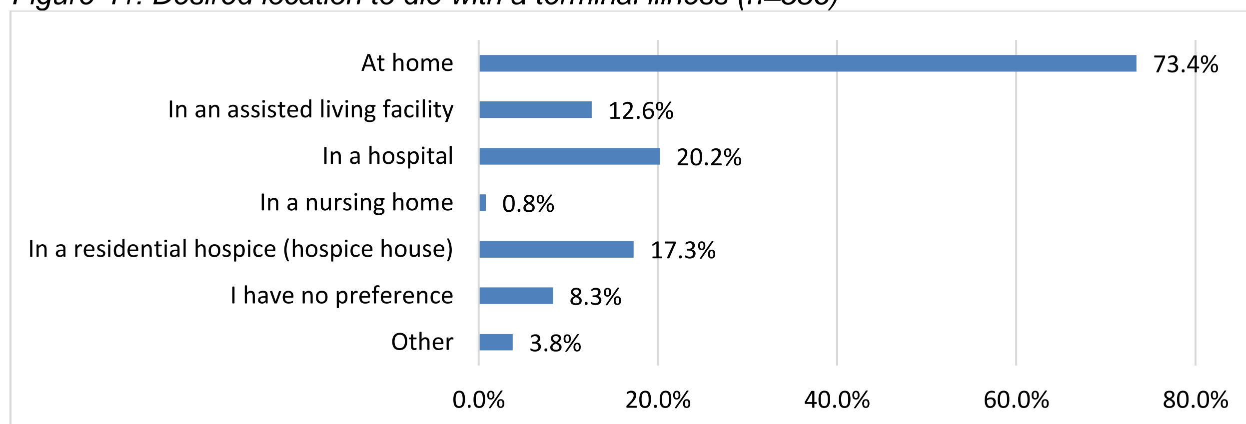
When asked their preference on a manner in which to die, most respondents (82.7%) reported that they would like to die in their sleep. Less than half (38.9%) of respondents choose sudden death, while fewer chose other (5.0%), or long-term illness (1.7%) (Figure 40). Of those who stated they would prefer to die in another manner, most stated that they were unsure, while others mentioned surrounded by loved ones, or however God intends.

Figure 40: Respondents desired manner to die (n=593)



Overall, respondents selected that they would prefer to die in their homes (73.4%) followed by in a hospice (20.2%), in a residential hospice (17.3%), and in an assisted living facility (12.6%). Fewer respondents selected I have no preference (8.3%), other (3.8%), and in a nursing home (0.8%). Other common locations people chose were with nature, with loved ones nearby, and depends on the circumstances (Figure 41).

Figure 41: Desired location to die with a terminal illness (n=586)



Section 7: Religion and Spirituality

Respondents largely (93.1%) identified as being religious or spiritual with nearly one-third (32.7%) being very religious/spiritual and nearly half (48.0%) classifying as somewhat religious/spiritual (Figure 42). To that end, most (91.4%) who identified as religious attend religious or spiritual services with nearly half (45.6%) attending regularly (Figure 43). Overall, nearly all (90.6%) of those who are religious/spiritual have found some strength from their beliefs, with several (42.8%) finding strength daily (Figure 44). When thinking about end of life desires for religious/spiritual support, about one-third (34.9%) of respondents would like support a few times a week with a small percent (6.3%) not wanting religious/spiritual support (Figure 45).

Figure 42: Respondent level of religiosity/spirituality (n=596)

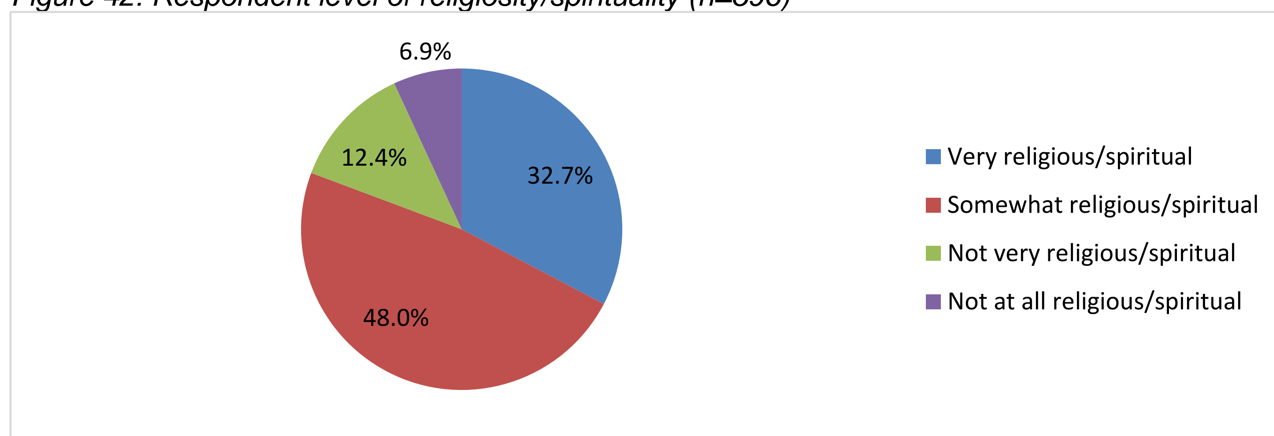


Figure 43: Respondent attendance at religious/spiritual services (n=553)

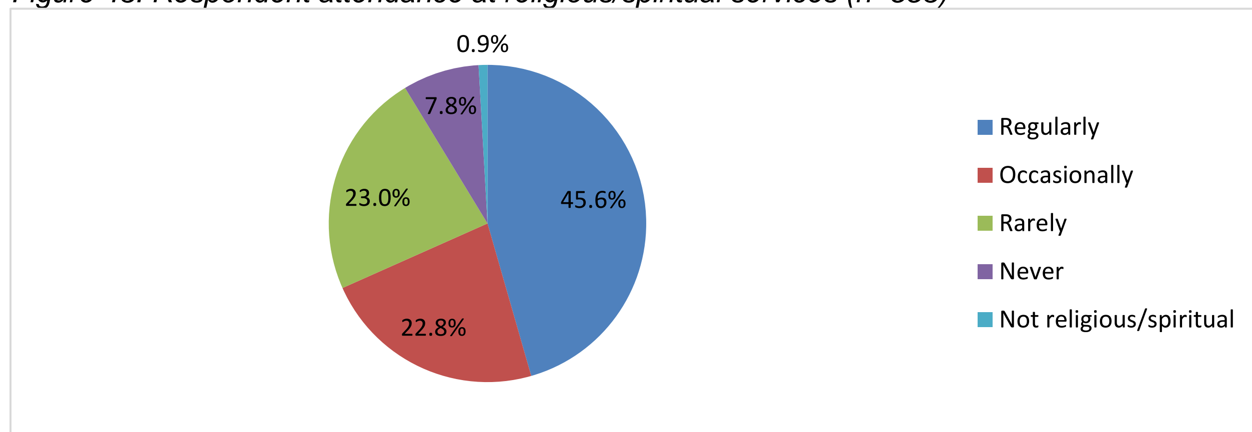


Figure 44: Frequency of finding strength in religion or spirituality (n=549)

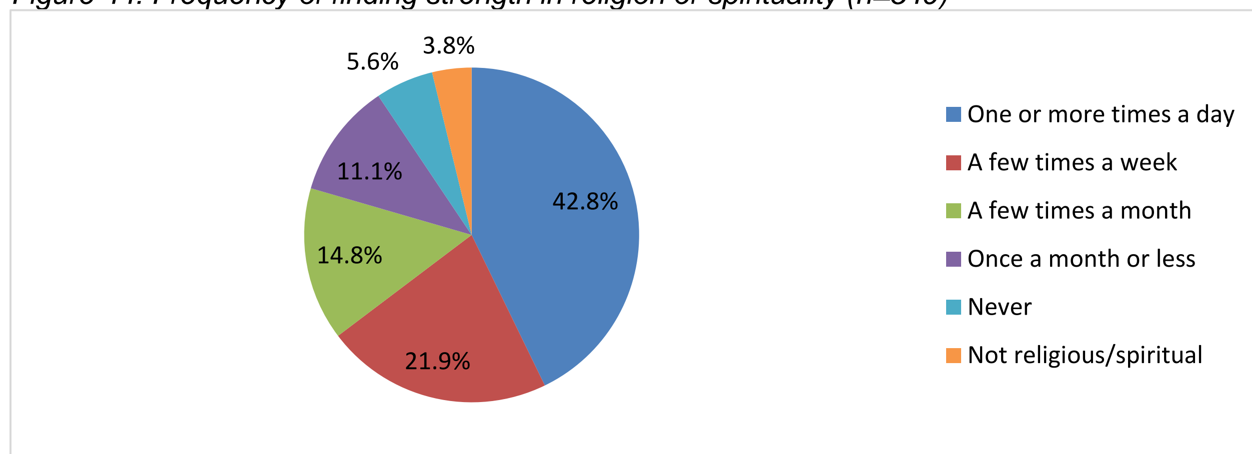
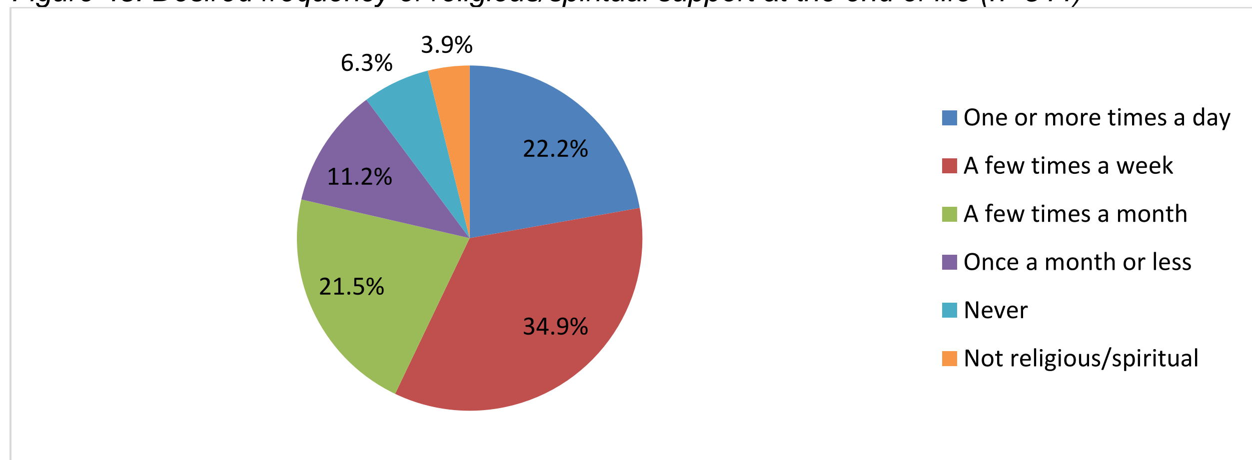


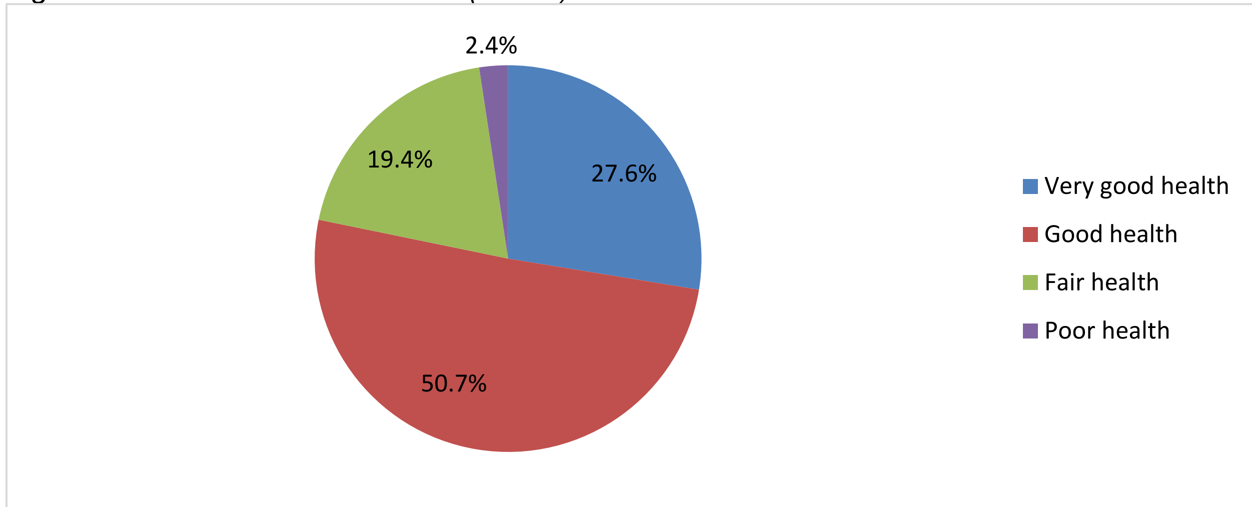
Figure 45: Desired frequency of religious/spiritual support at the end of life (n=544)



Section 8: Demographic Information

Self-rated health was high overall for respondents. Most stated that they have very good (27.6%) or good (50.7%) health while a small percent (2.4%) identified having poor overall health (Figure 46).

Figure 46: Overall self-rated health (n=594)



Nearly one half (49.5%) of respondents were caregivers (Figure 47). The majority (81.6%) Cared for persons between the age of 65-101, followed by ages 35-64 (14.4%), 19-34 (2.2%), <19 (1.1%), and only 0.7% 102+ (Figure 48).

Figure 47: Is the respondent a caregiver? (n=592)

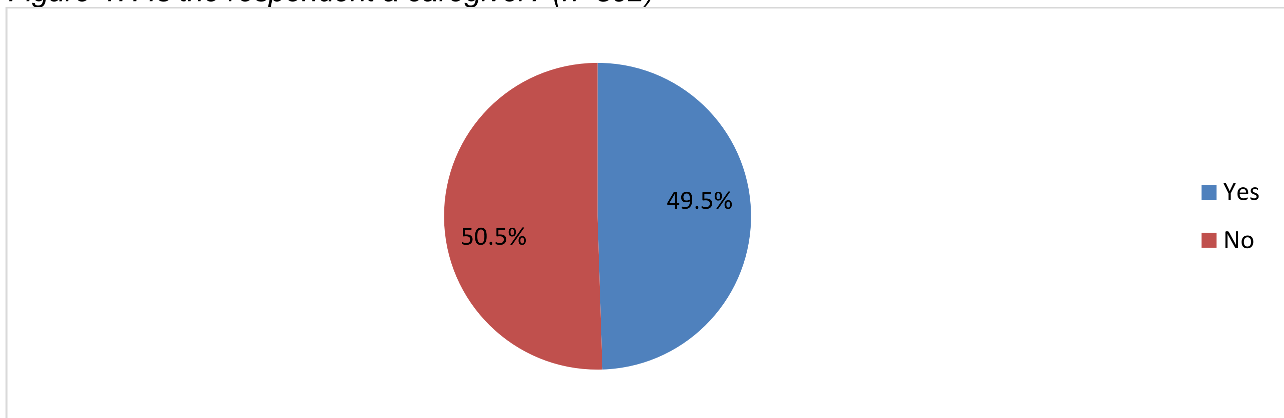
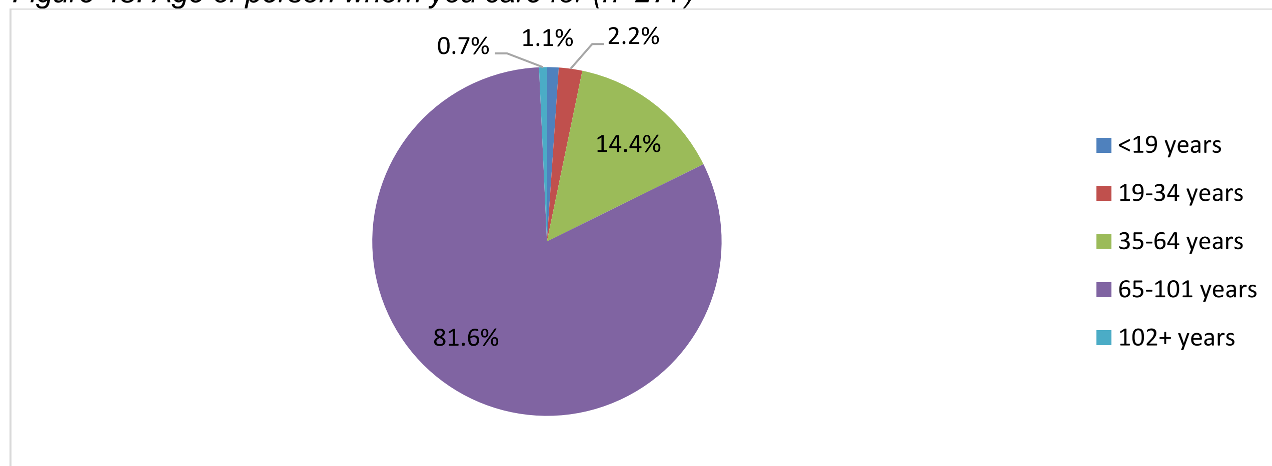


Figure 48: Age of person whom you care for (n=277)



Some (20.0%) respondents had serious chronic illnesses (Figure 49). Among these respondents, several had other conditions (8.8%), followed by heart disease (7.6%), lung disease (3.5%), and cancer (3.3%). Fewer respondents selected stroke (1.6%), followed by COVID-19 (0.9%), and Alzheimer's (0.3%) (Figure 50). Other common conditions for respondent's serious illnesses were diabetes, kidney disease, and a cardiovascular condition.

Figure 49: Respondent chronic illness (n=595)

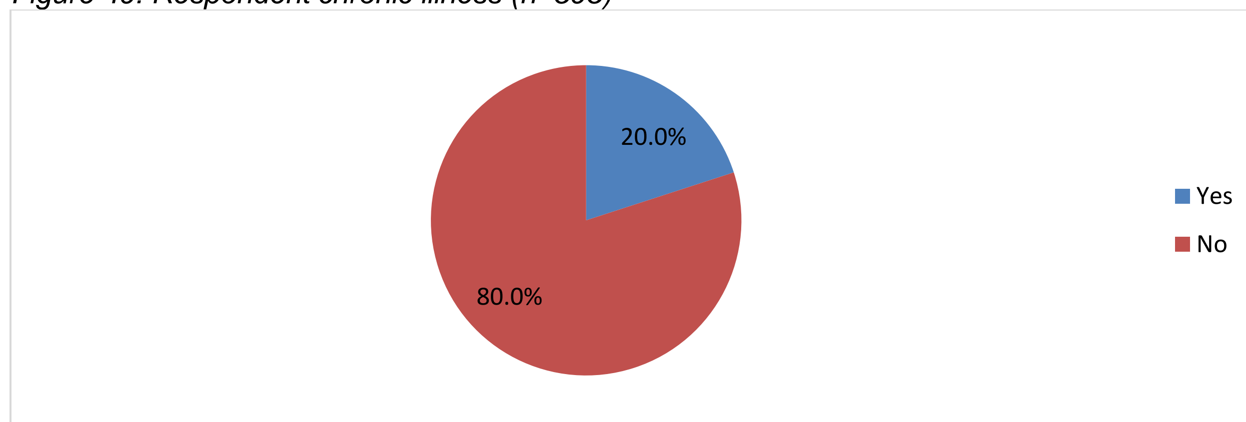
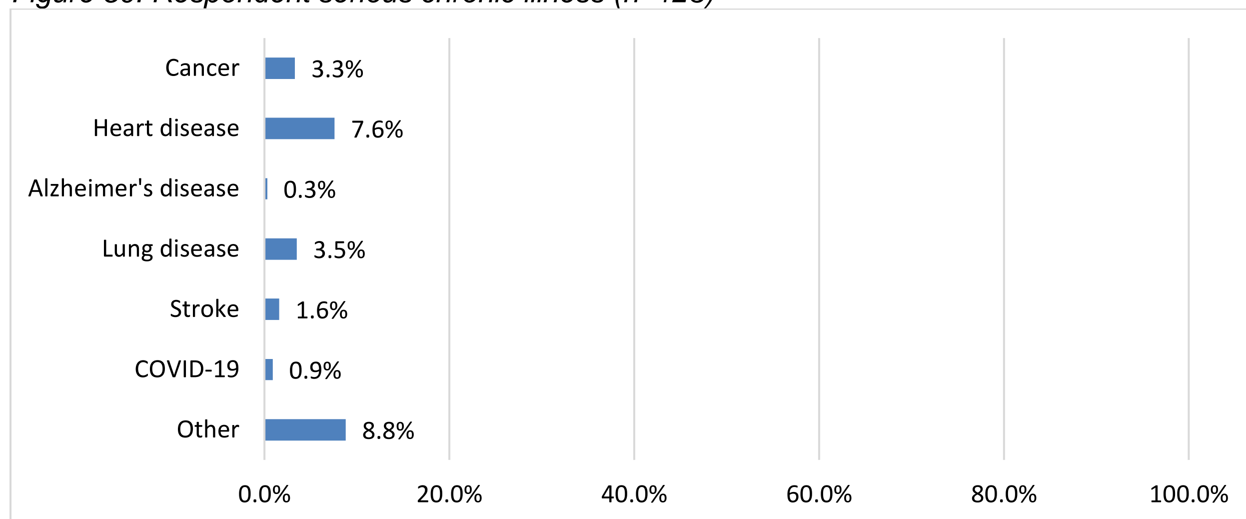


Figure 50: Respondent serious chronic illness (n=123)



For some respondents (14.9%), a member of their household has a chronic illness (Figure 51). The most common chronic illnesses for someone in their household was heart disease (9.0%), followed by cancer (6.9%), other conditions (6.8%), stroke (4.4%), lung disease (4.1%), Alzheimer's disease (4.1%), and COVID-19 (1.4%) (Figure 52).

Other common conditions for respondent's serious illnesses were diabetes and Parkinson's.

Figure 51: Member of household chronic illness (n=591)

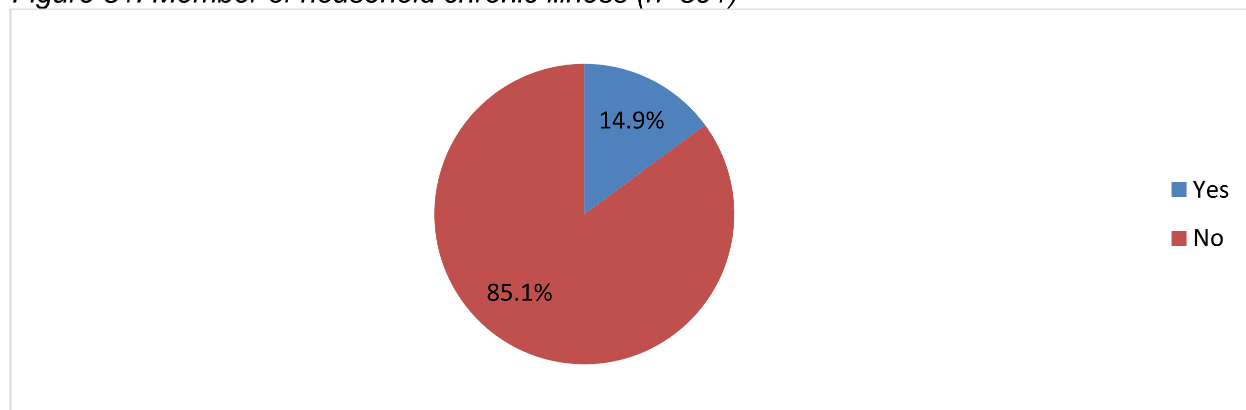
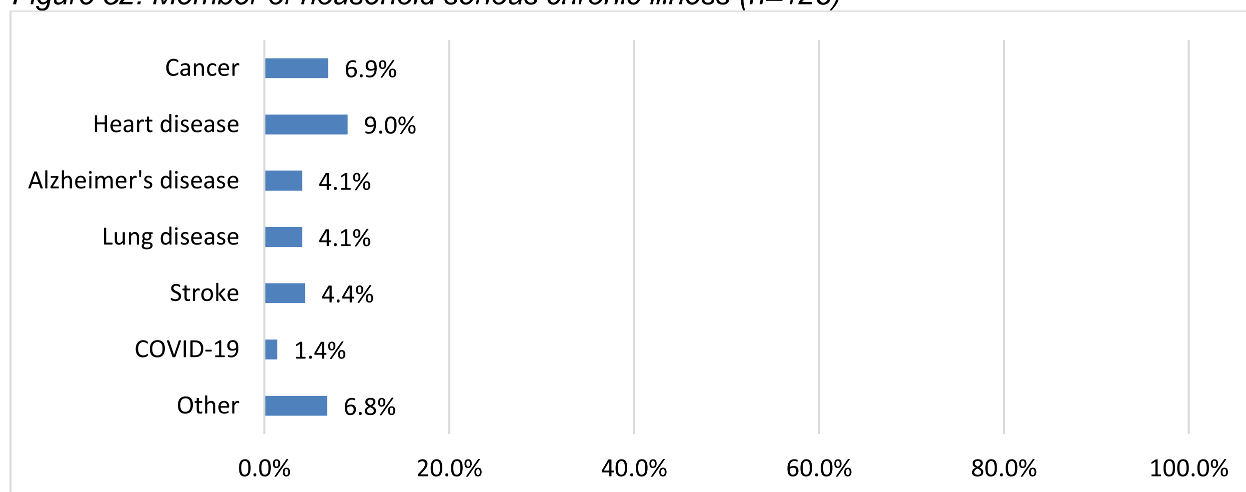
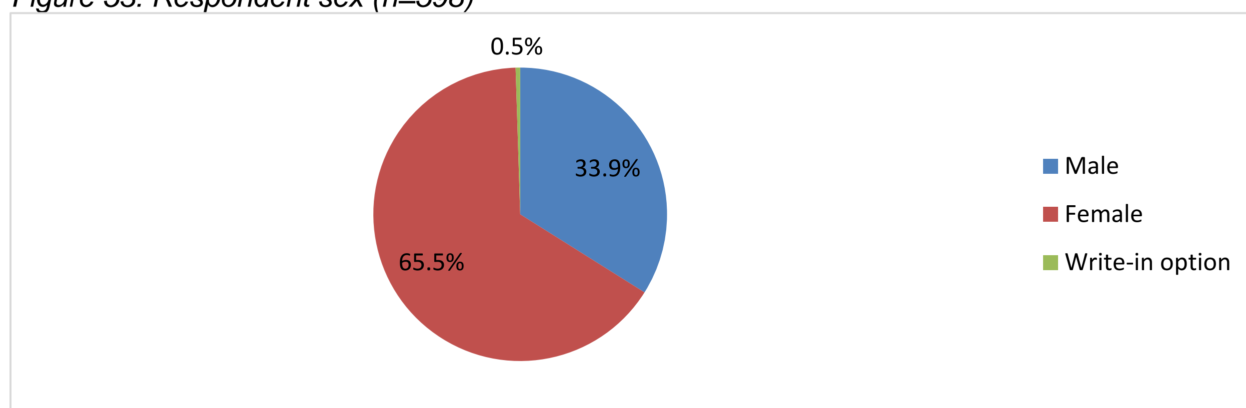


Figure 52: Member of household serious chronic illness (n=126)



Two-thirds (65.5%) of respondents were female (Figure 53).

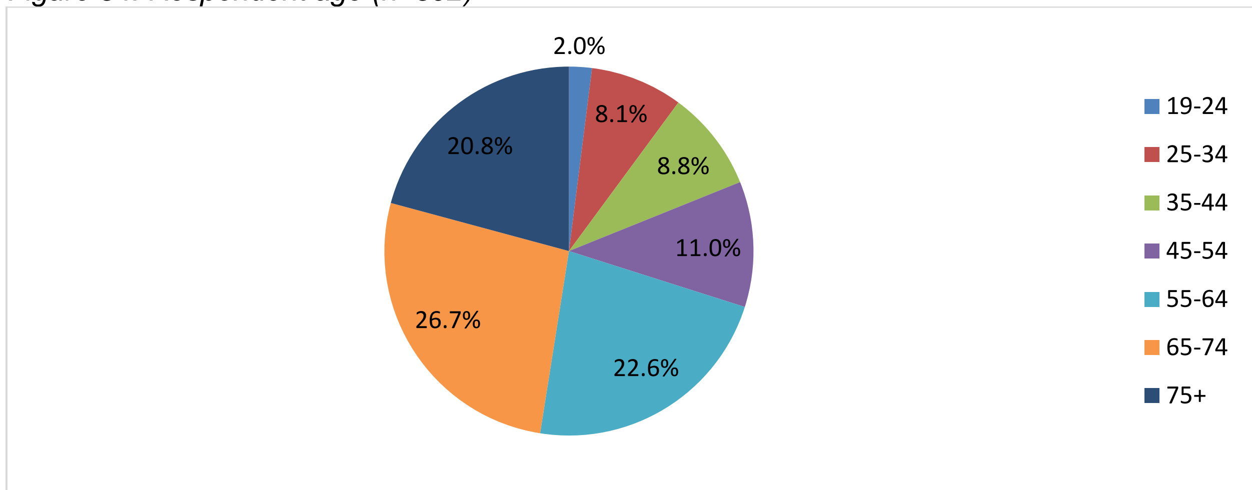
Figure 53: Respondent sex (n=598)[3]



Age of respondents ranged from 19 to 75 and older with the largest percent of respondents (26.7%) being 65-74 years old (Figure 54).

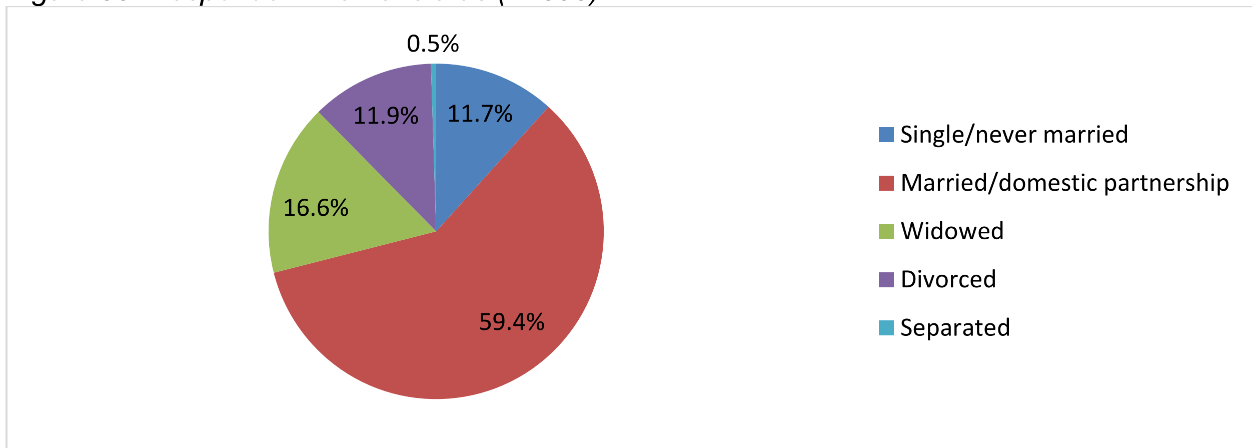
[3] Since poststratification weights were applied based on age and gender, these two variables are presented in unweighted form here.

Figure 54: Respondent age (n=592)[4]



The majority of respondents (59.4%), are married or in a domestic partnership with a smaller number (16.6%) of people who are widowed, followed by divorced (11.9%), single/never married (11.7%), and separated (0.5%) (Figure 55).

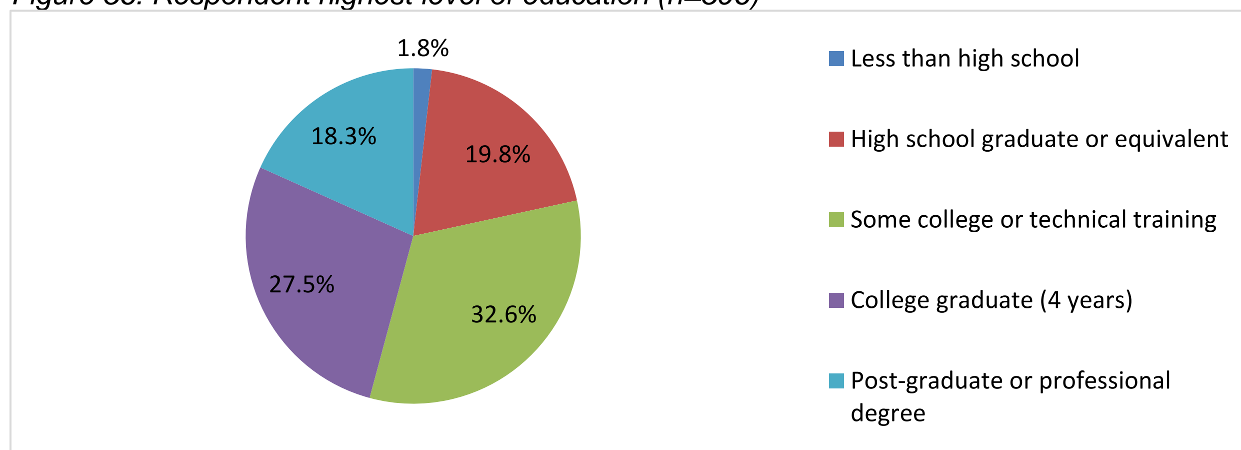
Figure 55: Respondent marital status (n=598)



The educational attainment of respondents ranges from a small percent (1.8%) not completing high school, 19.8% completing high school, and the remaining majority (78.4%) attending and/or graduating from college (Figure 56).

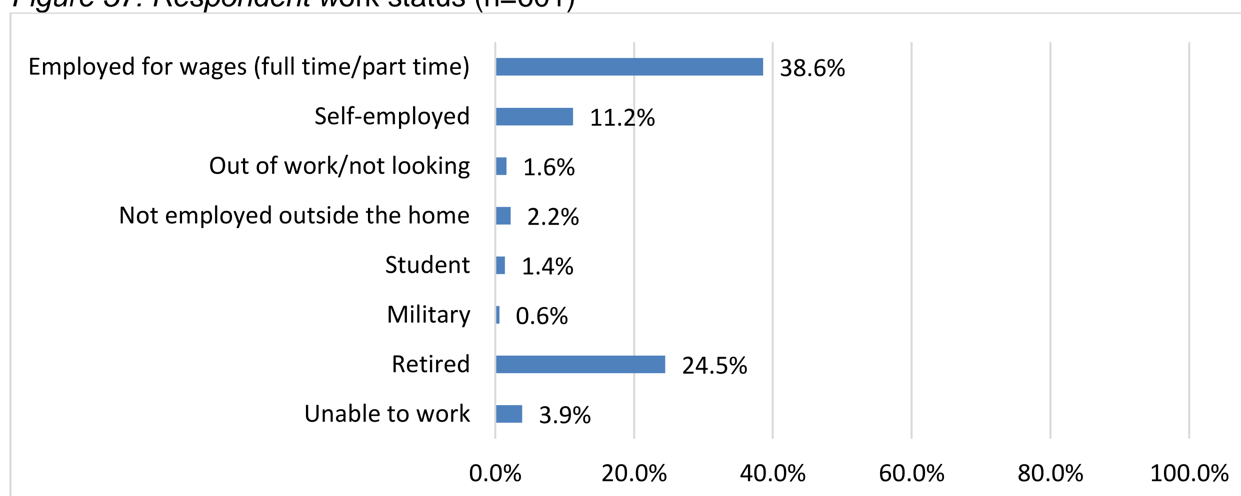
[4] Since poststratification weights were applied based on age and gender, these two variables are presented in unweighted form here.

Figure 56: Respondent highest level of education (n=596)



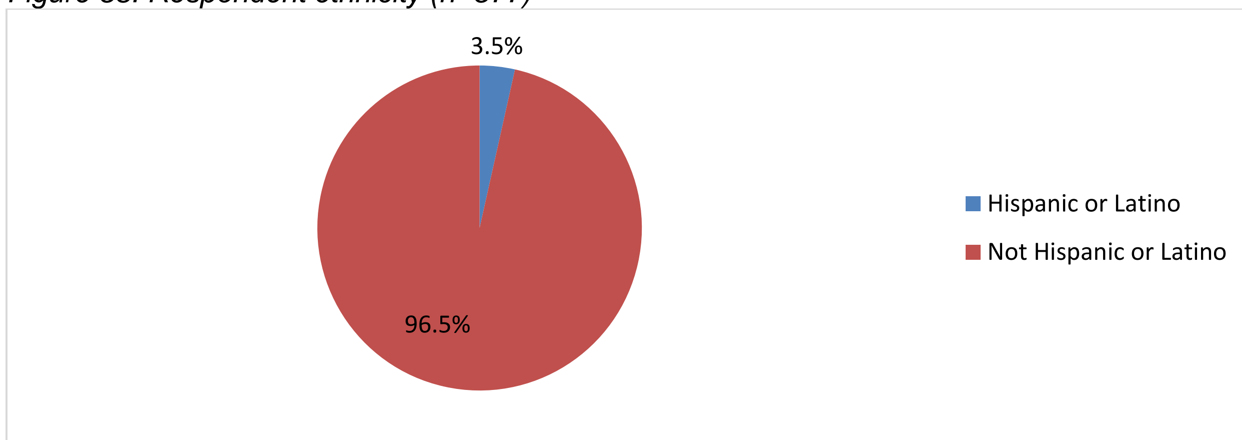
Nearly four-fifths of respondents (38.6%) are employed either full or part time, followed by people who have retired (24.5%), and the remainder are self-employed (11.2%), unable to work (3.9%), not employed outside the home (2.2%), out of work/not looking (1.6%) are students (1.4%) or are in the military (0.6%) (Figure 57).

*Figure 57: Respondent w*ork status (n=601)



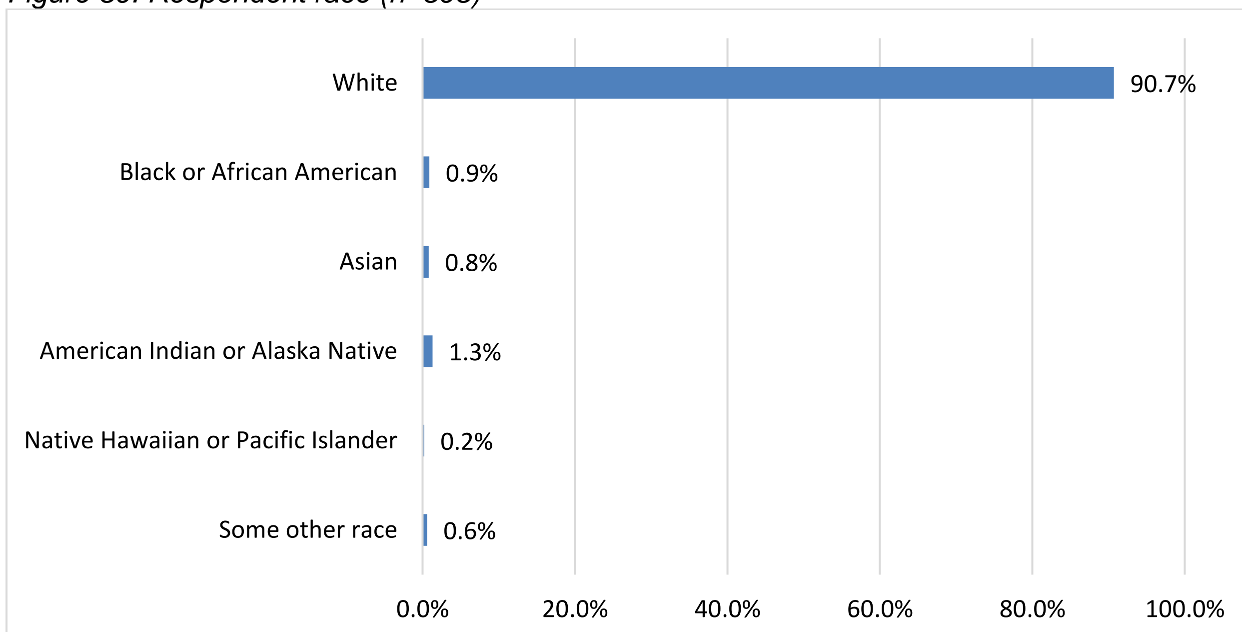
A small percent (3.5%) of respondents identify as Hispanic or Latino (Figure 58).

Figure 58: Respondent ethnicity (n=577)



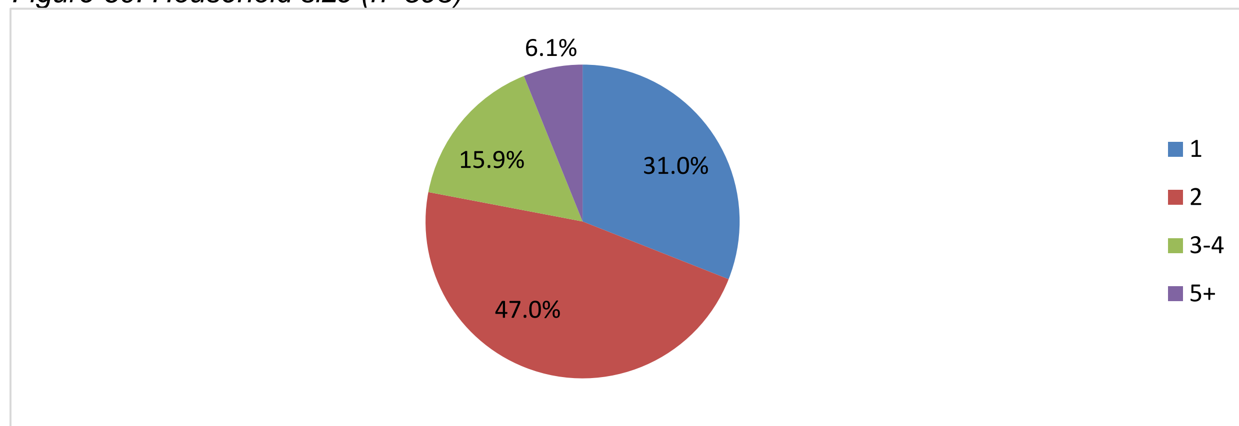
Most respondents (90.7%) were white with the largest racial minority (1.3%) being American Indian or Alaska Native (Figure 59).

Figure 59: Respondent race (n=595)



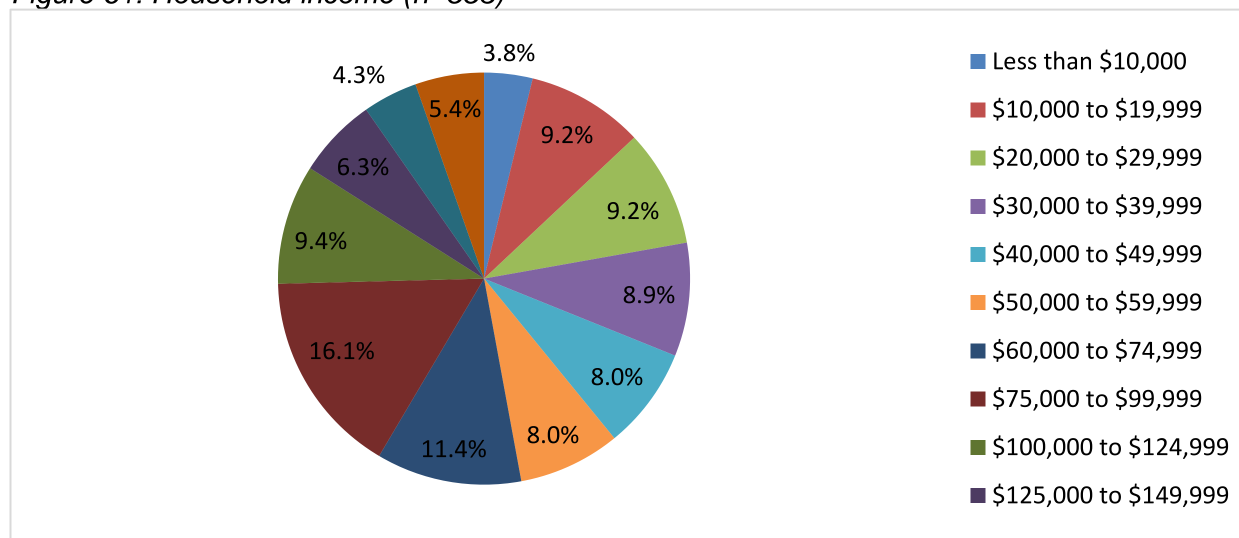
Household size varied as nearly half (47.0%) were two people, 31.0% were one person, 15.9% were three or four people, and 6.1% were households of five or more people (Figure 60).

Figure 60: Household size (n=593)



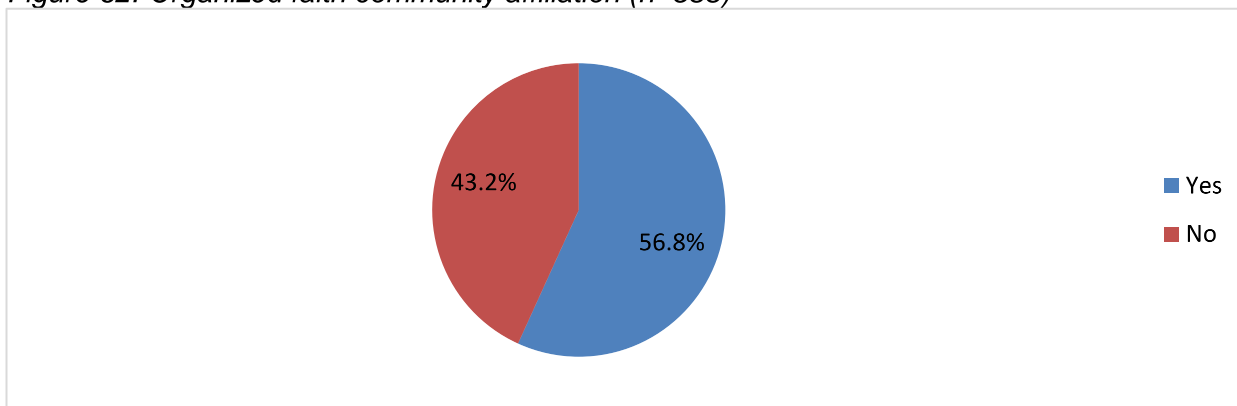
Household income ranged from less than $10,000 per year to $75,000 or more per year. The largest (16.1%) income bracket was $75,000 with a small percent (3.8%) having a household income less than $10,000 per year (Figure 61).

Figure 61: Household income (n=553)



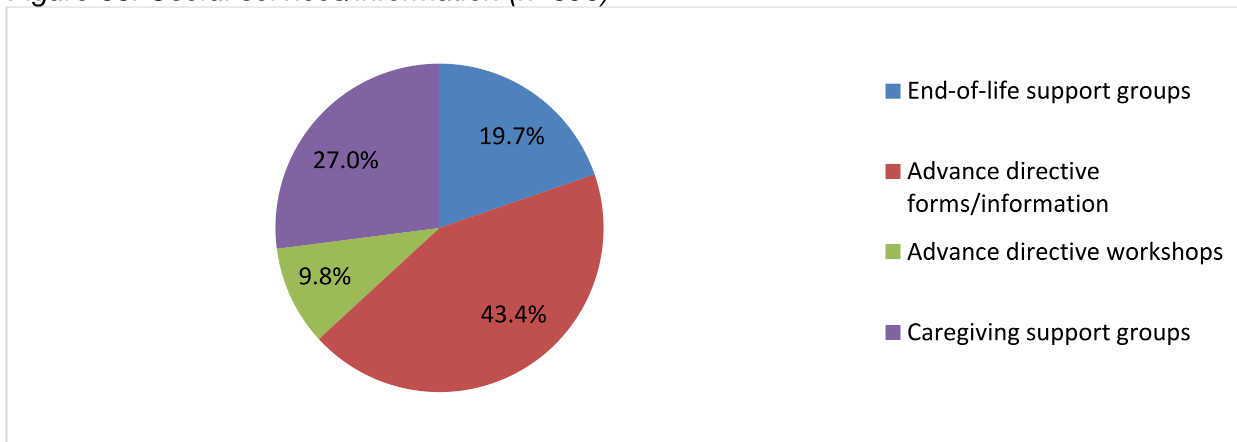
Slightly more than half (56.8%) of respondents had an affiliation with an organized faith community (Figure 62). Many of these respondents stated that they are Protestant, while several stated that they are Catholic.

Figure 62: Organized faith community affiliation (n=588)



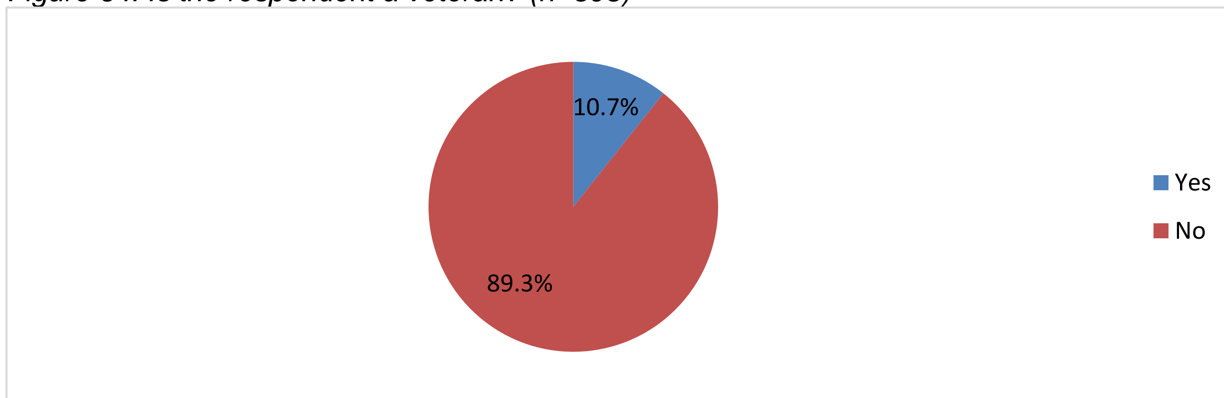
43.4% of respondents selected advance directive forms/information as the most useful services/information, followed by caregiving support groups (27.0%), End of life support groups (19.7%), and advance directive workshops (9.8%) (Figure 63).

Figure 63: Useful services/information (n=396)



10.7% of respondents are veterans (Figure 64).

Figure 64: Is the respondent a veteran? (n=598)



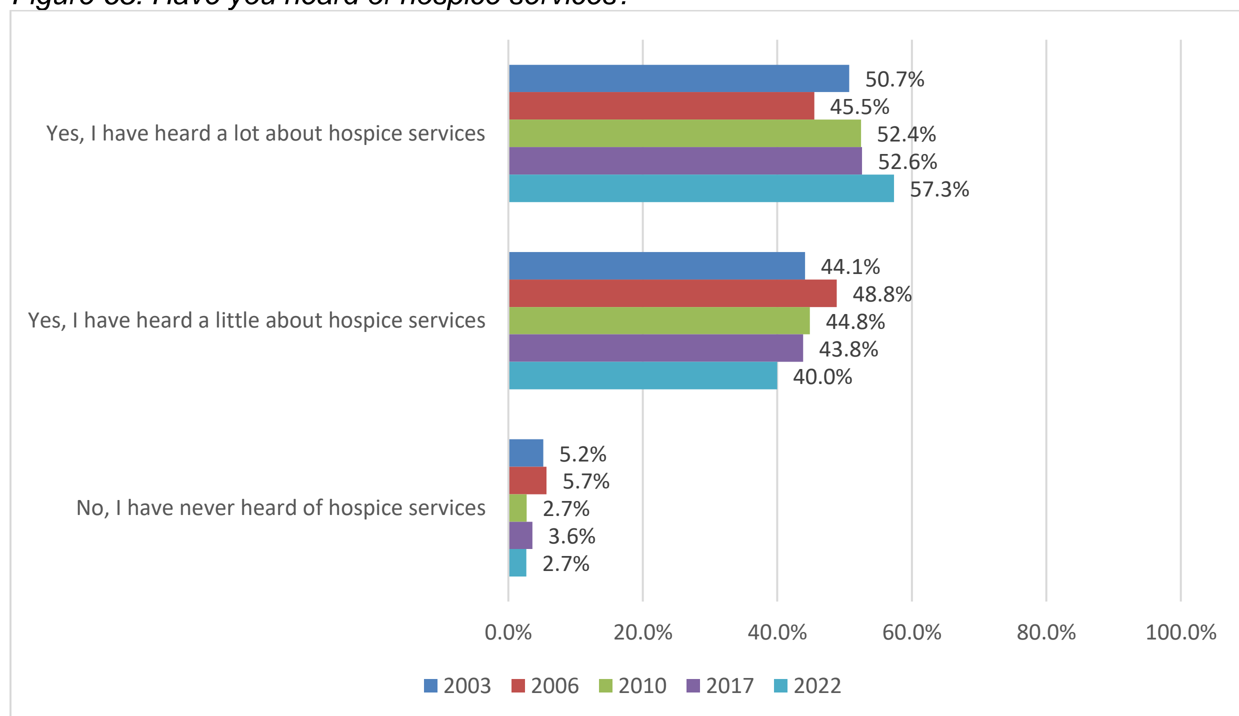
Trends 2003-2022

In August of 2003, NHPCA conducted the first randomly sampled statewide end-of-life survey in the United States. This survey was then repeated by NHPCA in August of 2006 and August of 2010. 300 respondents completed the survey in 2003, 315 in 2006, 862 in 2010, 1,128 in 2017, and 635 in 2022. Chi-square tests were conducted in order to access if the changes over time were statistically significant. Differences are reported for responses that were significant (indicated by * if $p < 0.05$, ** if $p < 0.01$, *** if $p < 0.001$).

Section 1: Hospice Services

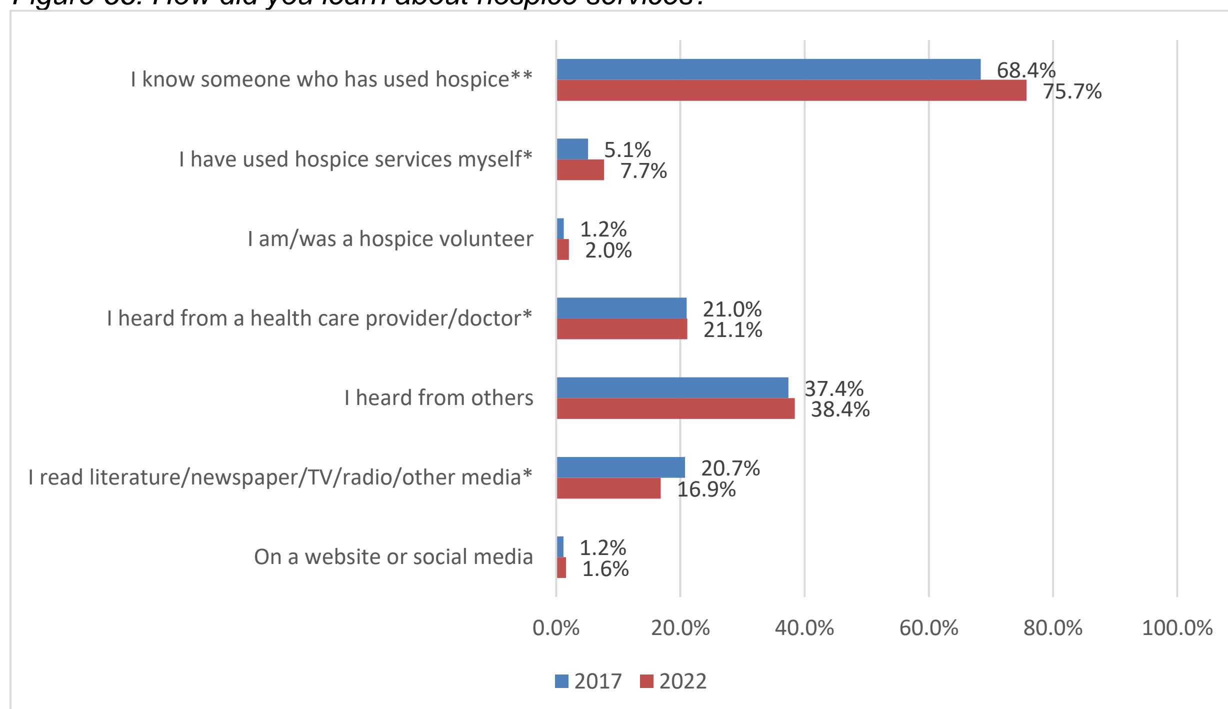
As seen in Figure 65, the percentage of respondents who report having heard a lot about hospice services dropped from 2003 (50.7%) to 2006 (45.5%) and has been increasing since. Additionally, those who report having heard a little about hospice services grew from 2003 (44.1%) to 2006 (48.8%), then dropped in 2017 (43.8%) and 2022 (40.0%).

*Figure 65: Have you heard of hospice services?**



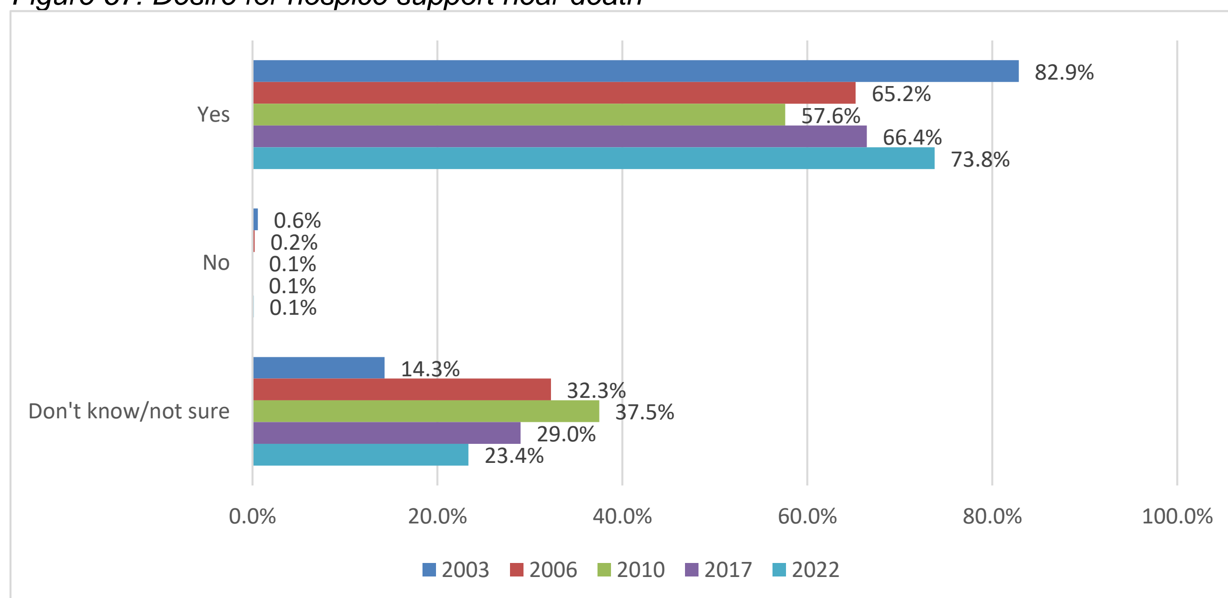
Since 2003, the NHPCA asked participants how they learned about hospice services (Figure 66). Due to the different question wording on the 2017 and 2022 administrations, the results cannot be compared to generate reliable statistics. Therefore, data points obtained prior to the 2017 were omitted.

Figure 66: How did you learn about hospice services?



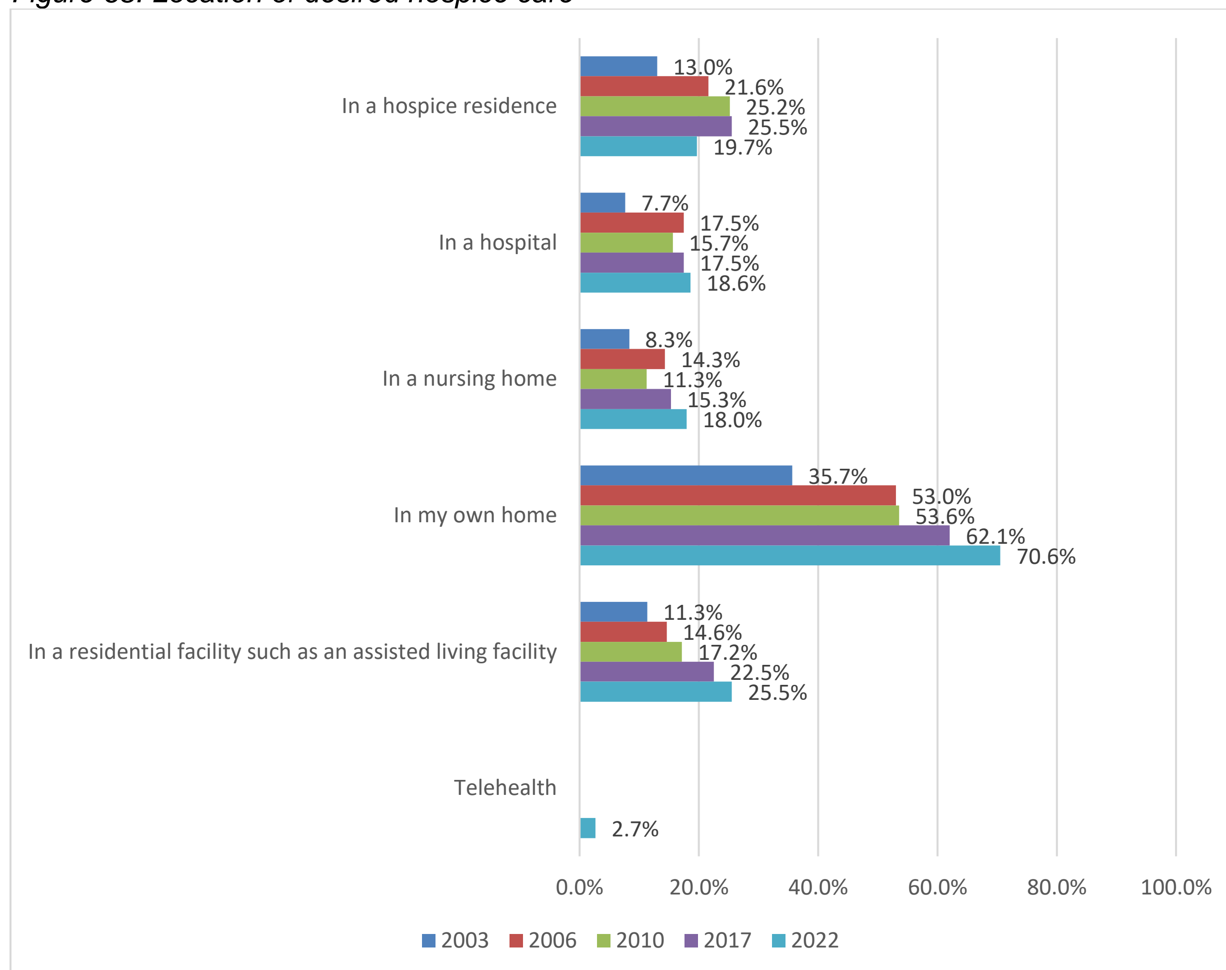
When respondents were asked if they would want hospice support if needed (Figure 67), the percentage of 2022 respondents who reported yes (73.8%) was higher than 2017 (66.4%), but much lower than it was in 2003 (82.9%).

*Figure 67: Desire for hospice support near death****



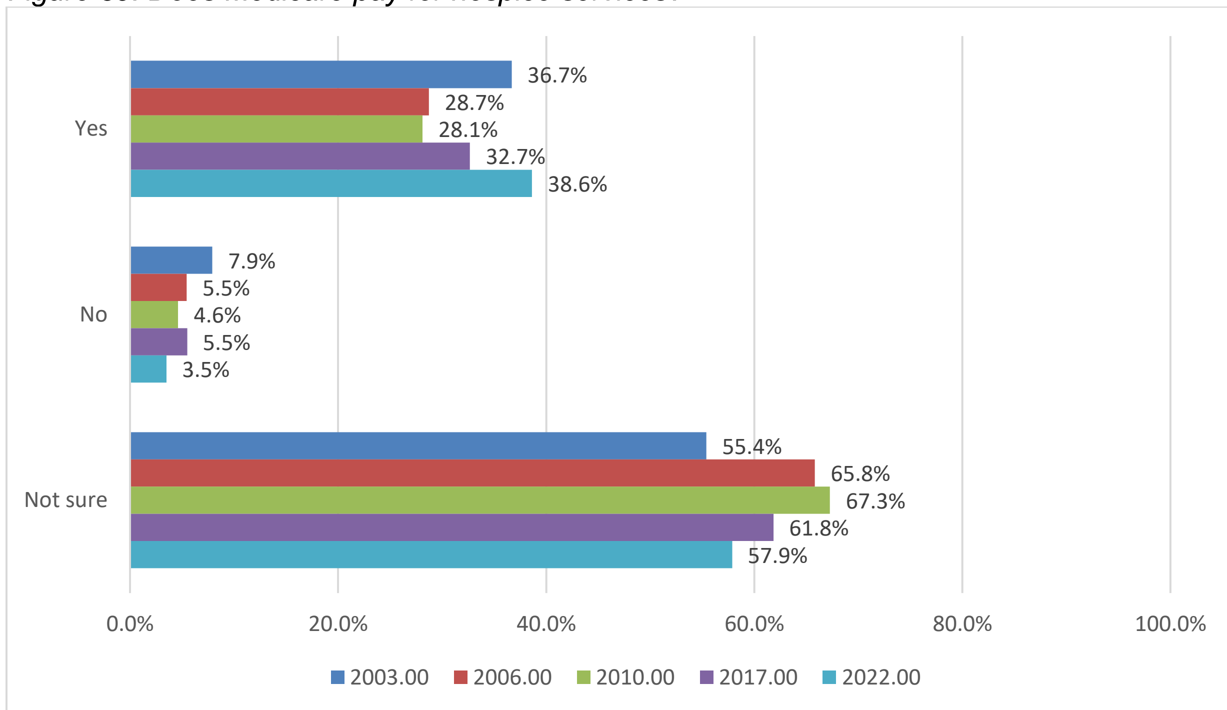
Respondents were asked how they would want to receive hospice services (Figure 68). However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable.

Figure 68: Location of desired hospice care



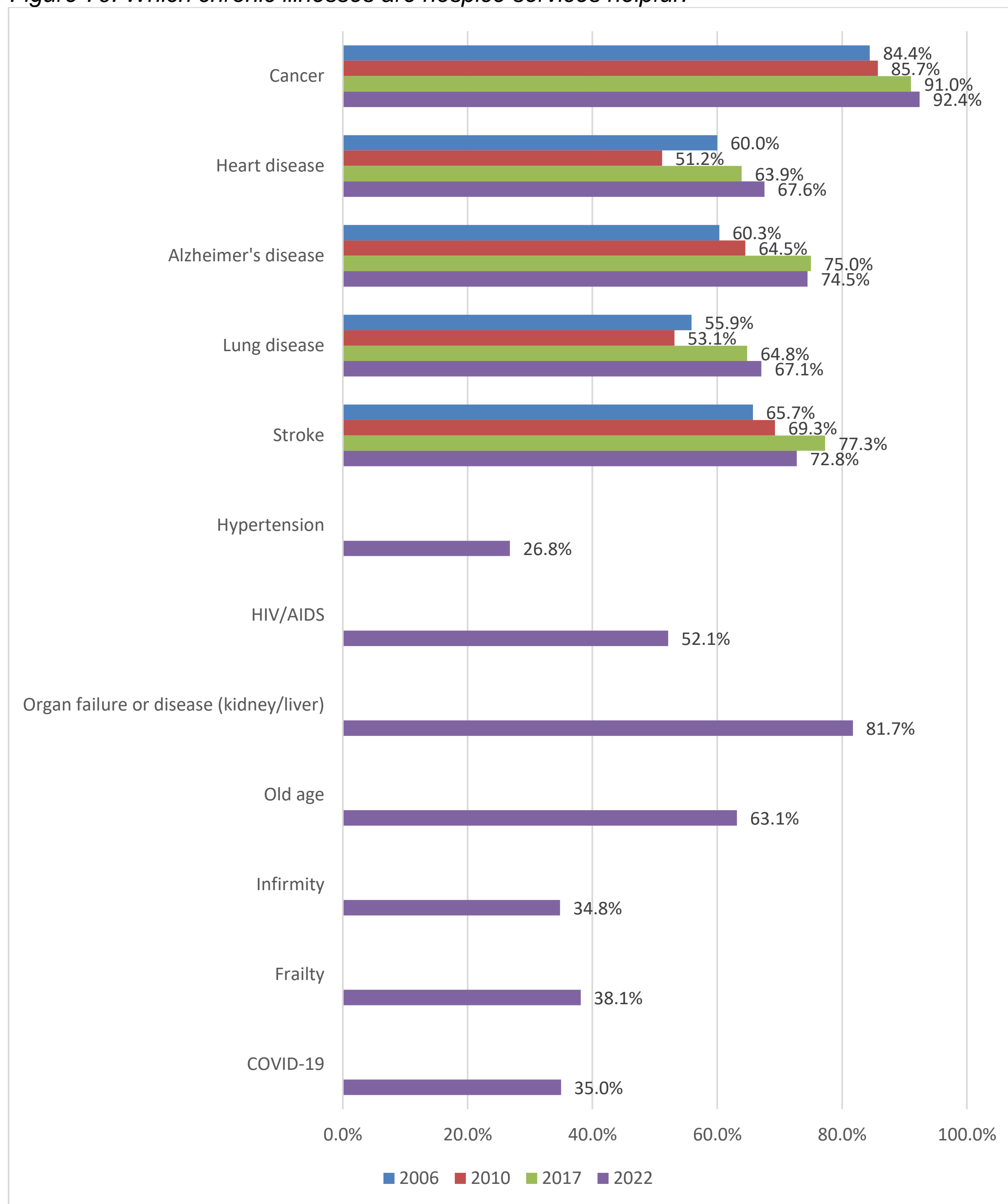
As shown in Figure 69, the biggest shift responses to the question "To the best of your knowledge, does Medicare or other insurance pay for hospice services?" appeared in 2006, where 28.7% reported yes, 5.5% reported no, and 65.8% reported not sure. In 2003 these rates were 36.7%, 7.9% and 55.4% respectively.

*Figure 69: Does Medicare pay for hospice services?****



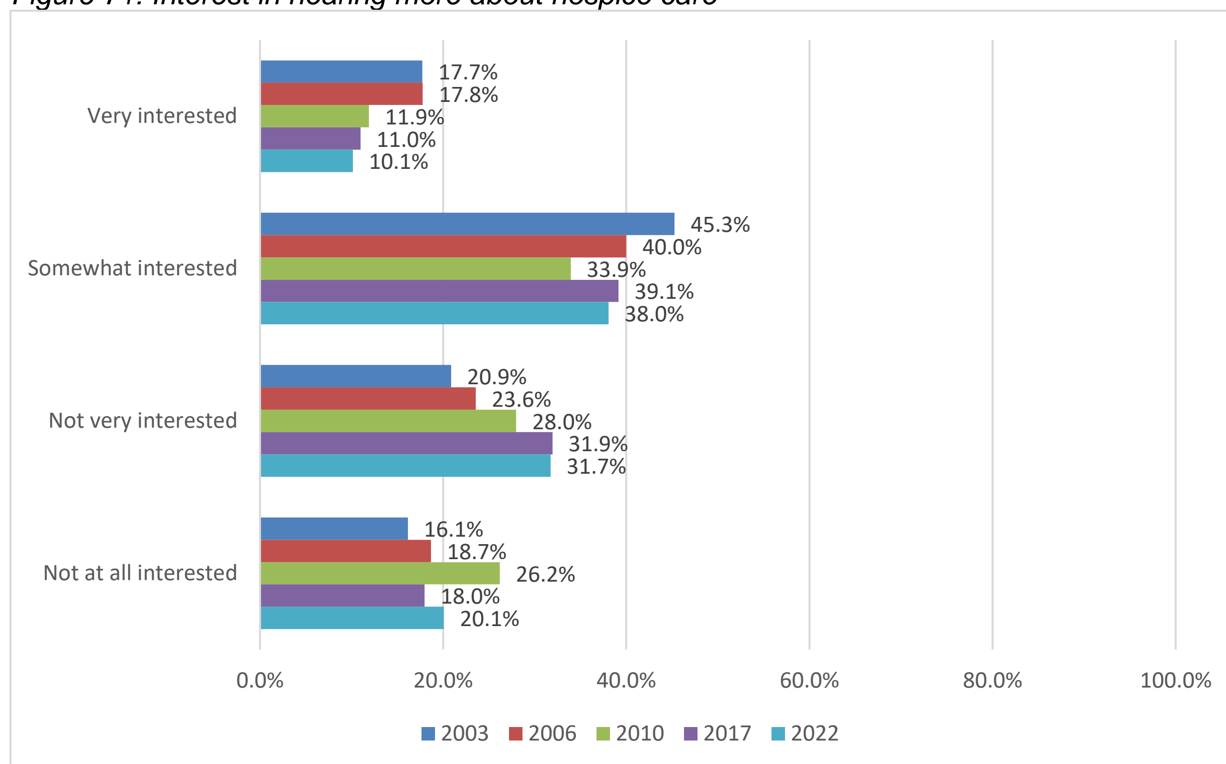
Since 2003, the NHPCA asked participants for which chronic illnesses are hospice services helpful. However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable (Figure 70).

Figure 70: Which chronic illnesses are hospice services helpful?



As shown in Figure 71, participants' reported level of interest in hearing more about hospice services went from the majority (63.0% combined) indicating they were interested in 2003, to 48.2% combined in 2022. However, those who reported their interested level as somewhat interested have consistently made up the highest percentage rate.

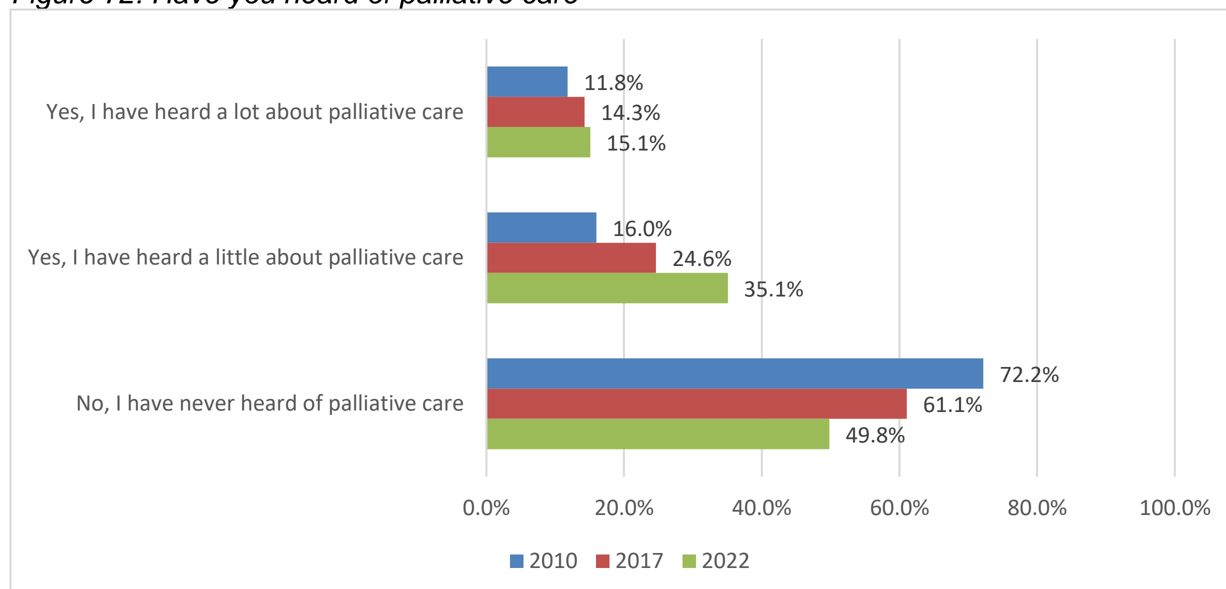
*Figure 71: Interest in hearing more about hospice care****



Section 2: Palliative Care

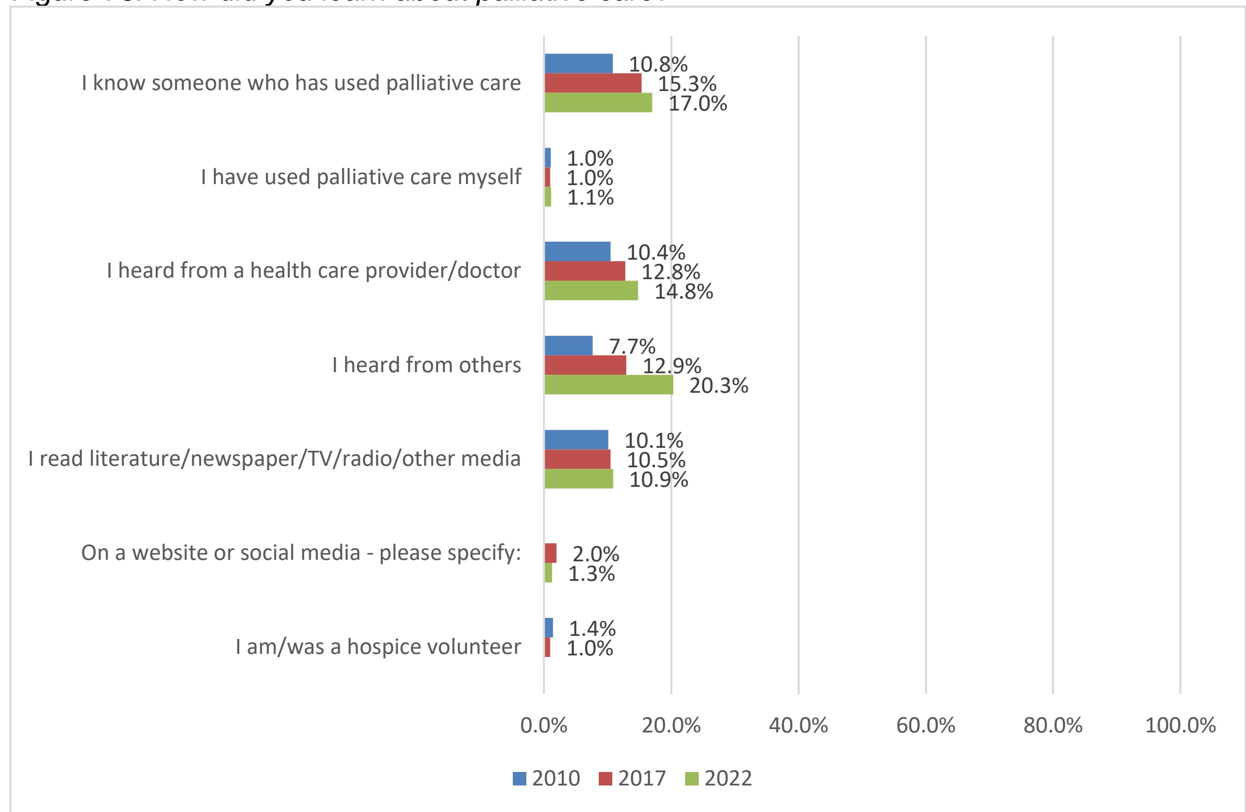
Questions on palliative care were added to the survey in 2010. Although nearly half (49.8%) of 2022 respondents have never heard of palliative care, those who have heard of palliative care has significantly increased from 2010 (27.8% combined) to 2022 (50.2%) (Figure 72).

*Figure 72: Have you heard of palliative care****



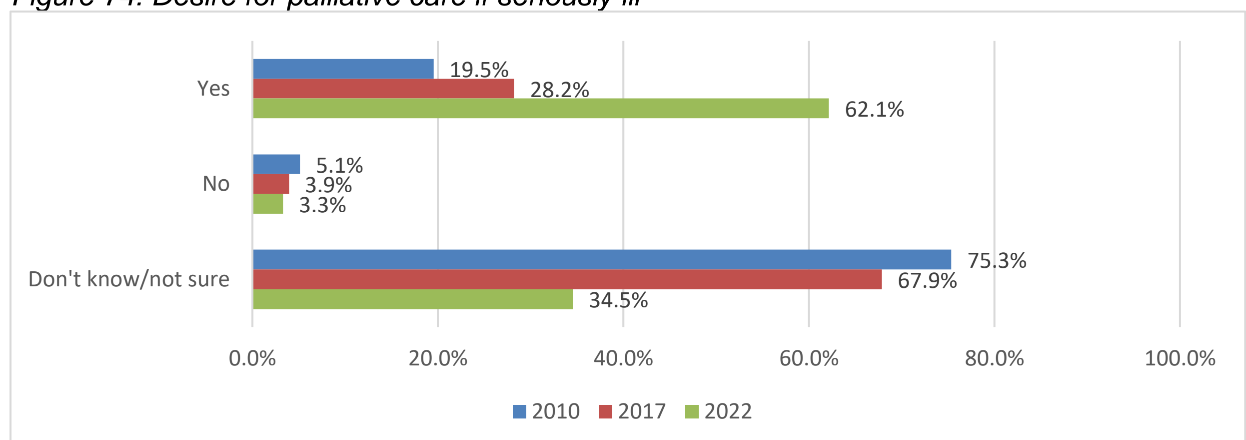
Since 2010, the NHPCA asked participants how they had heard about palliative care (Figure 73). However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable.

Figure 73: How did you learn about palliative care?



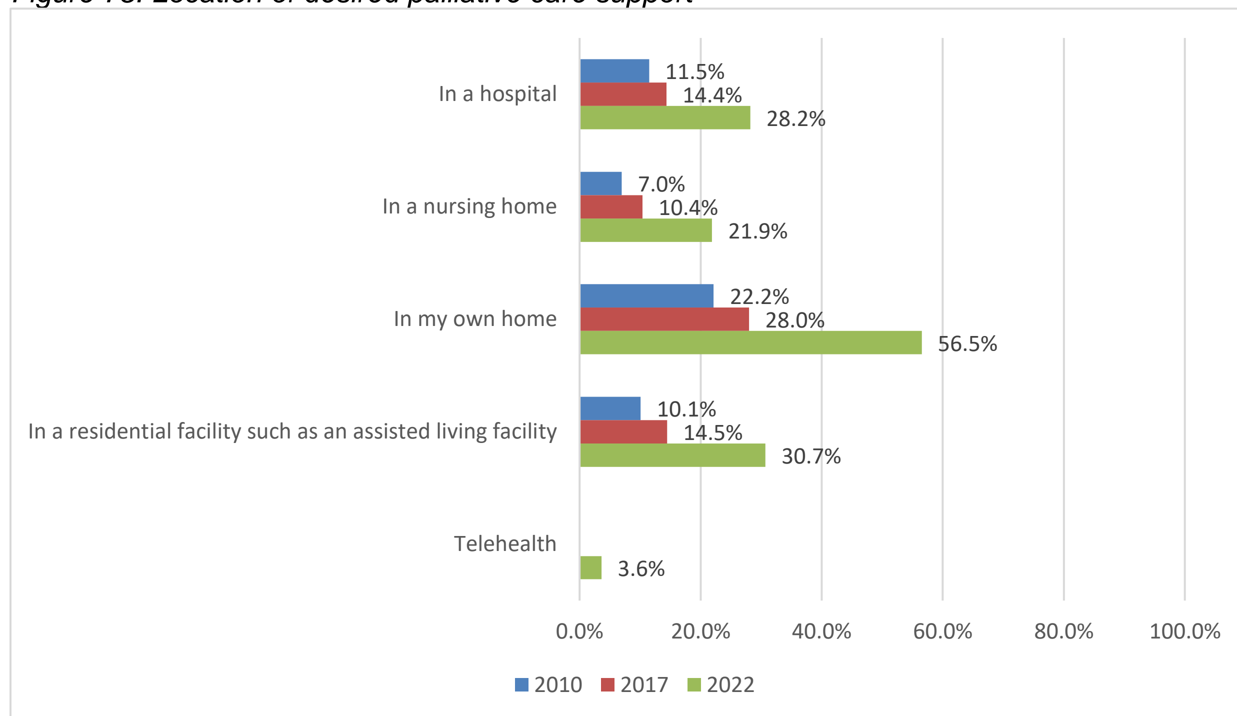
Those who responded they would like to receive palliative care if needed significantly increased between 2017 (28.2%) and 2022 (62.1%) (Figure 74). Although many were still unsure (34.5% in 2022).

*Figure 74: Desire for palliative care if seriously ill****



Since 2010, the NHPCA asked participants how where they would like to receive palliative care (Figure 75). However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable.

Figure 75: Location of desired palliative care support



As with prior years, when participants were asked, to the best of your knowledge, does Medicare or other insurance pay for palliative care, the majority of 2022 (76.8%) were not sure. However, this is lower than it has been in past years (Figure 76).

Figure 76: Does Medicare pay for palliative care?

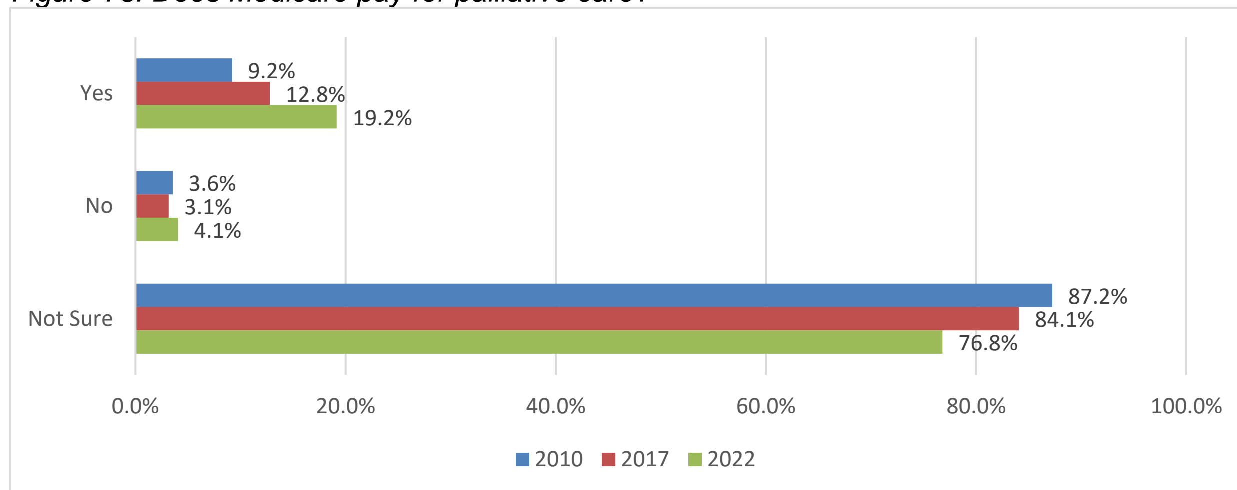
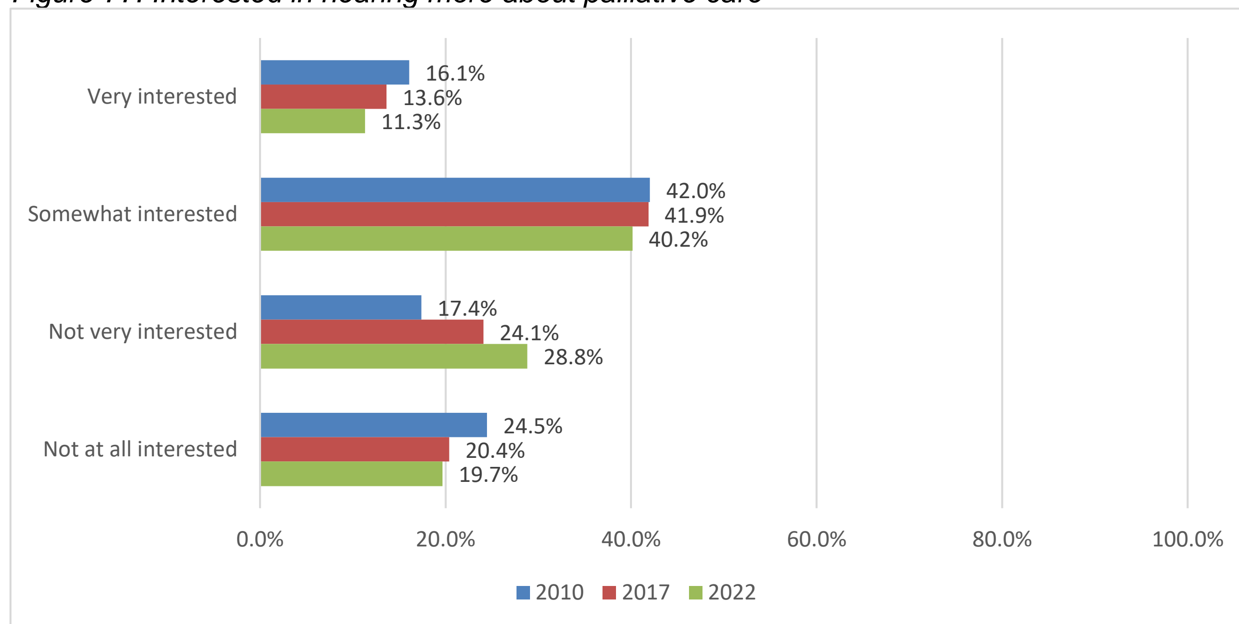


Figure 77 shows the level of interest in hearing more about palliative care participants. In 2022, respondents were nearly split in half between those who were very or somewhat interested (51.5% combined) and those who were not very or not at all interested (48.5%).

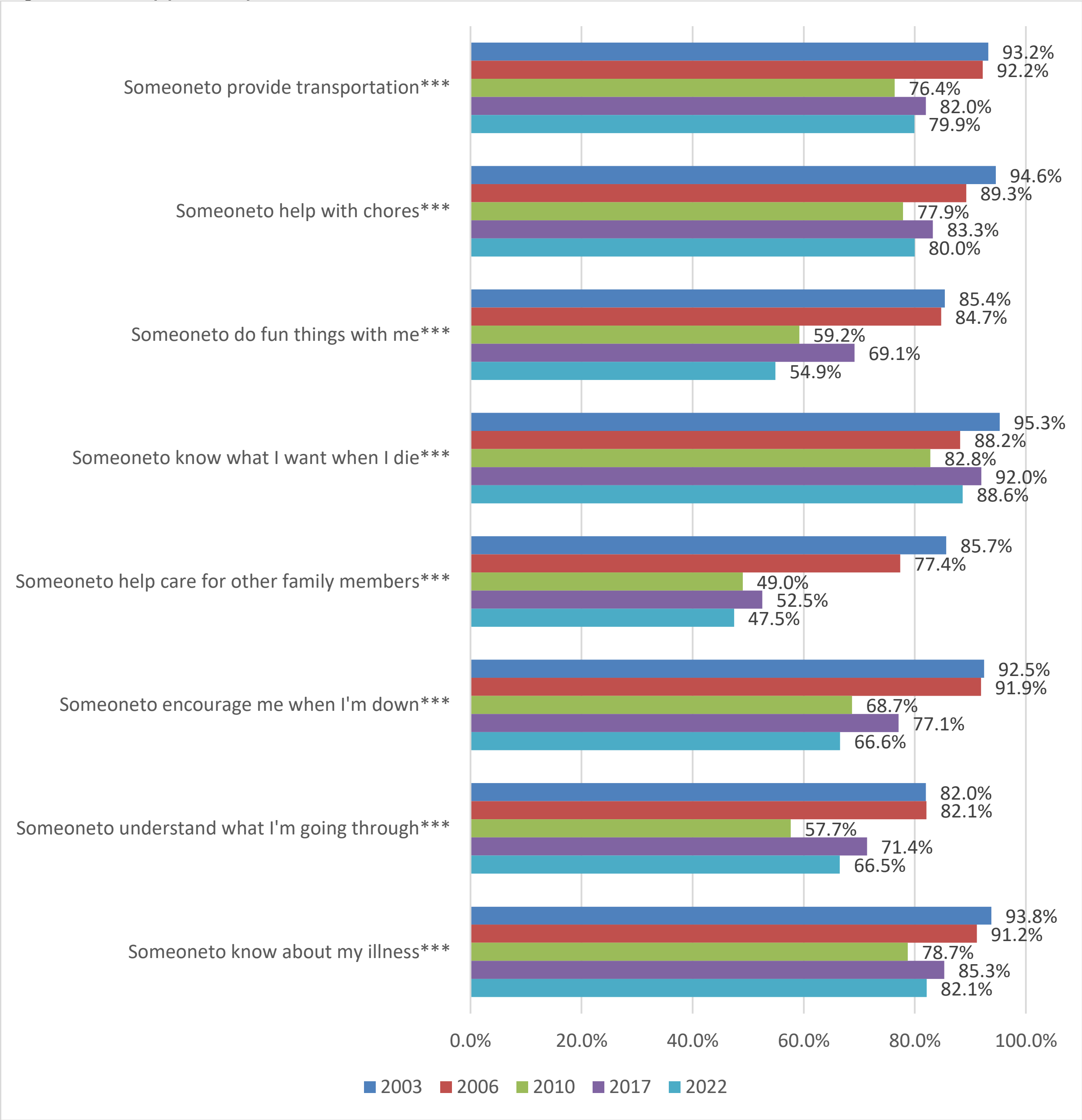
*Figure 77: Interested in hearing more about palliative care****



Section 3: Support near the End of Life

Participants were asked about the types of support they expect to need near the end of their life and whom they expect to provide each type of support. As seen in Figure 78, all eight categories of support have presented a similar pattern from 2003 to 2017. Following a declining trend, most of the categories underwent a drastic drop in 2010. However, all eight categories rose in 2017, and dropped once again in 2022.

Figure 78: Support expectations from others needed at the end of life



Since 2003, the NHPCA asked participants who should provide this type of service, for each of the services addressed in Figure 78 above (Figures 79-86). However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable.

Figure 79: I expect to need someone to provide transportation

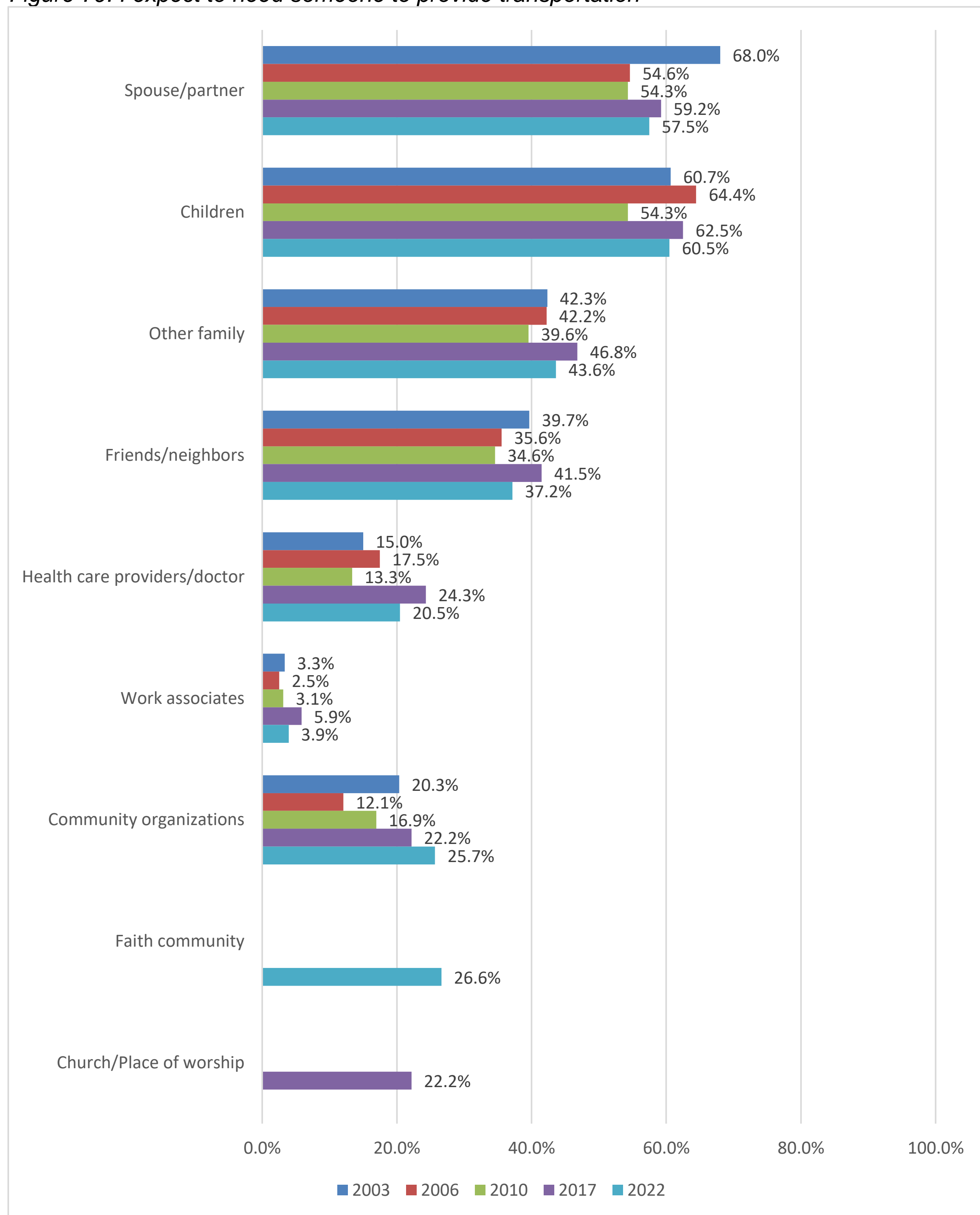


Figure 80: I expect to need someone to help with chores

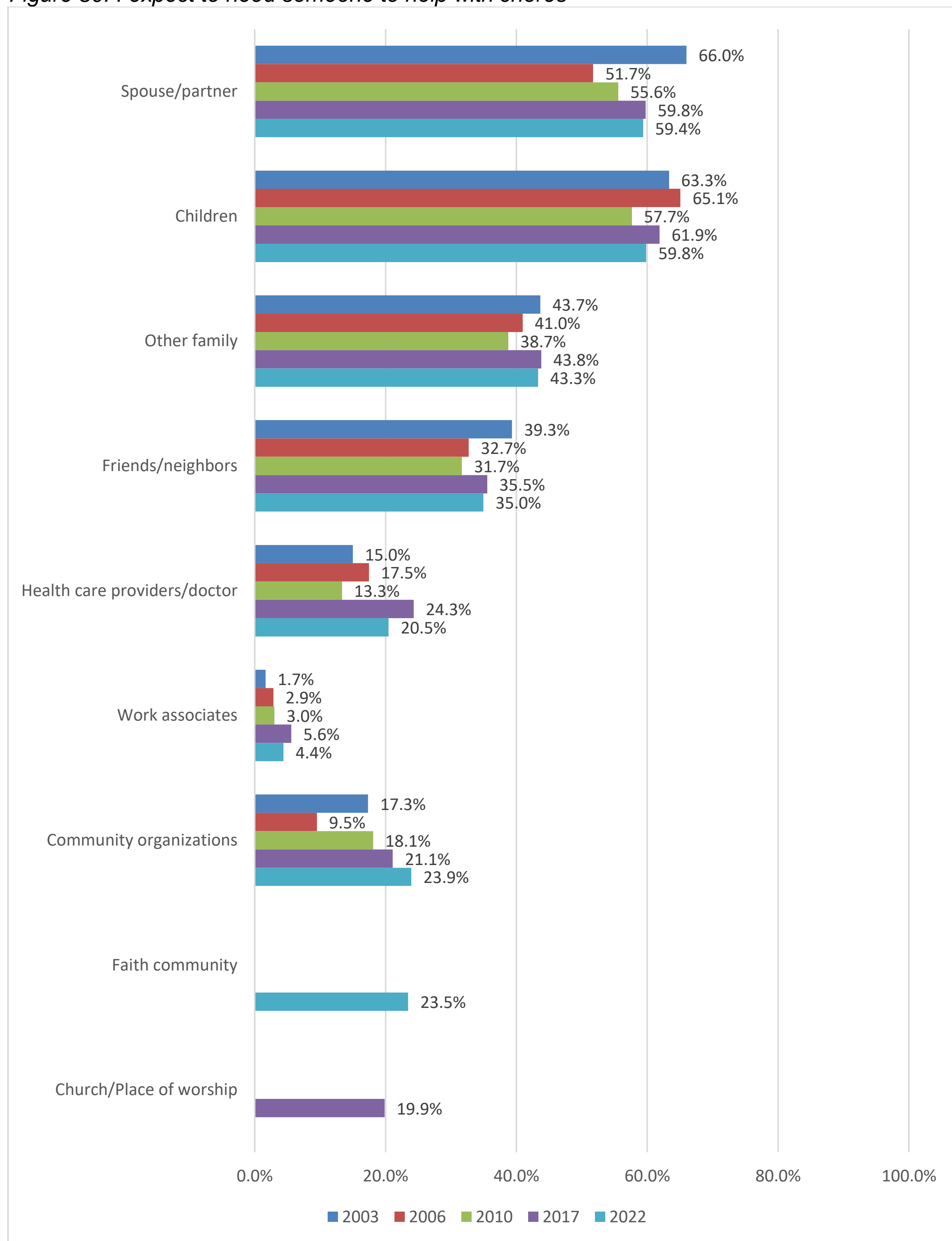


Figure 81: I expect to need someone to do fun things with me

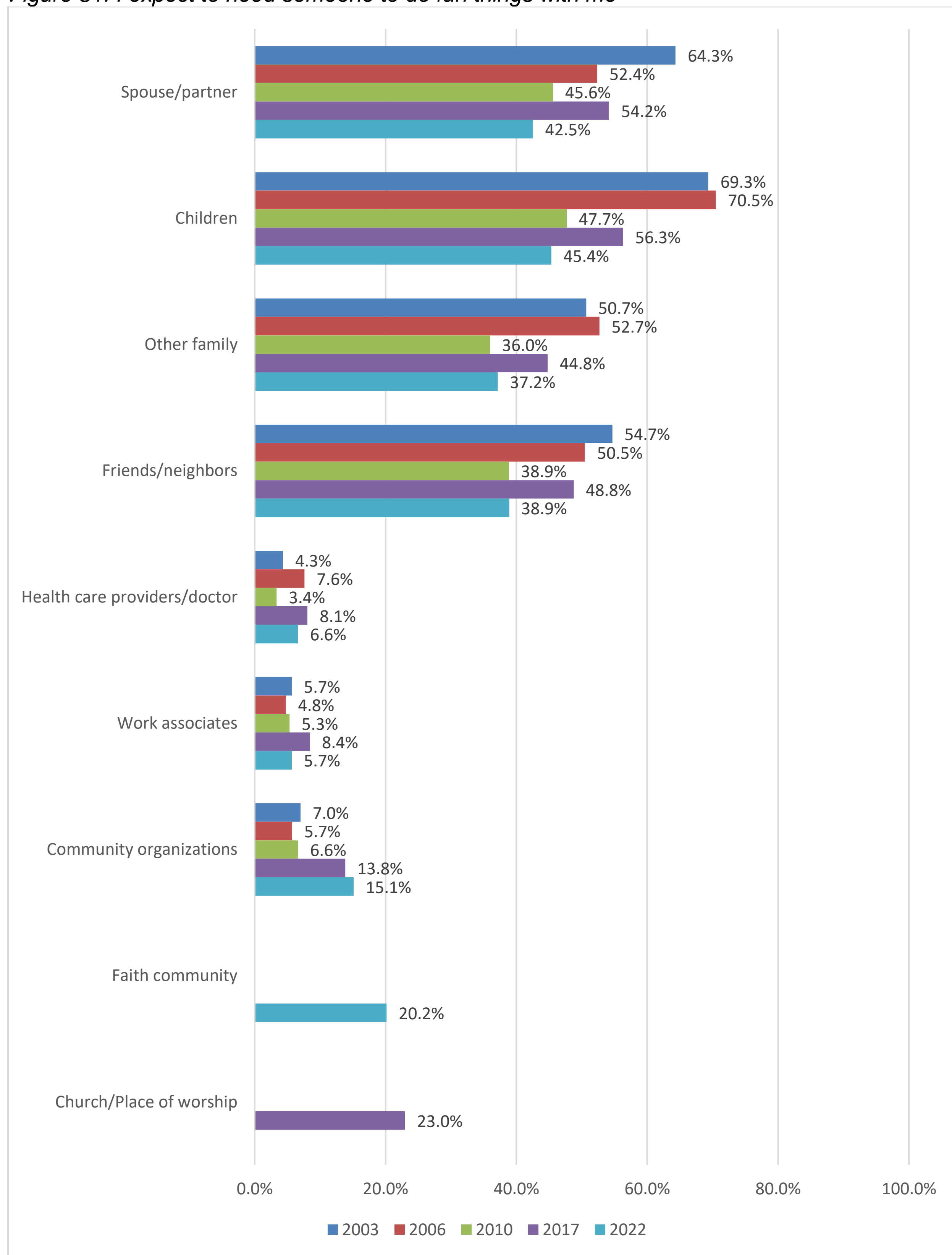


Figure 82: I expect to need someone to know what I want when I die

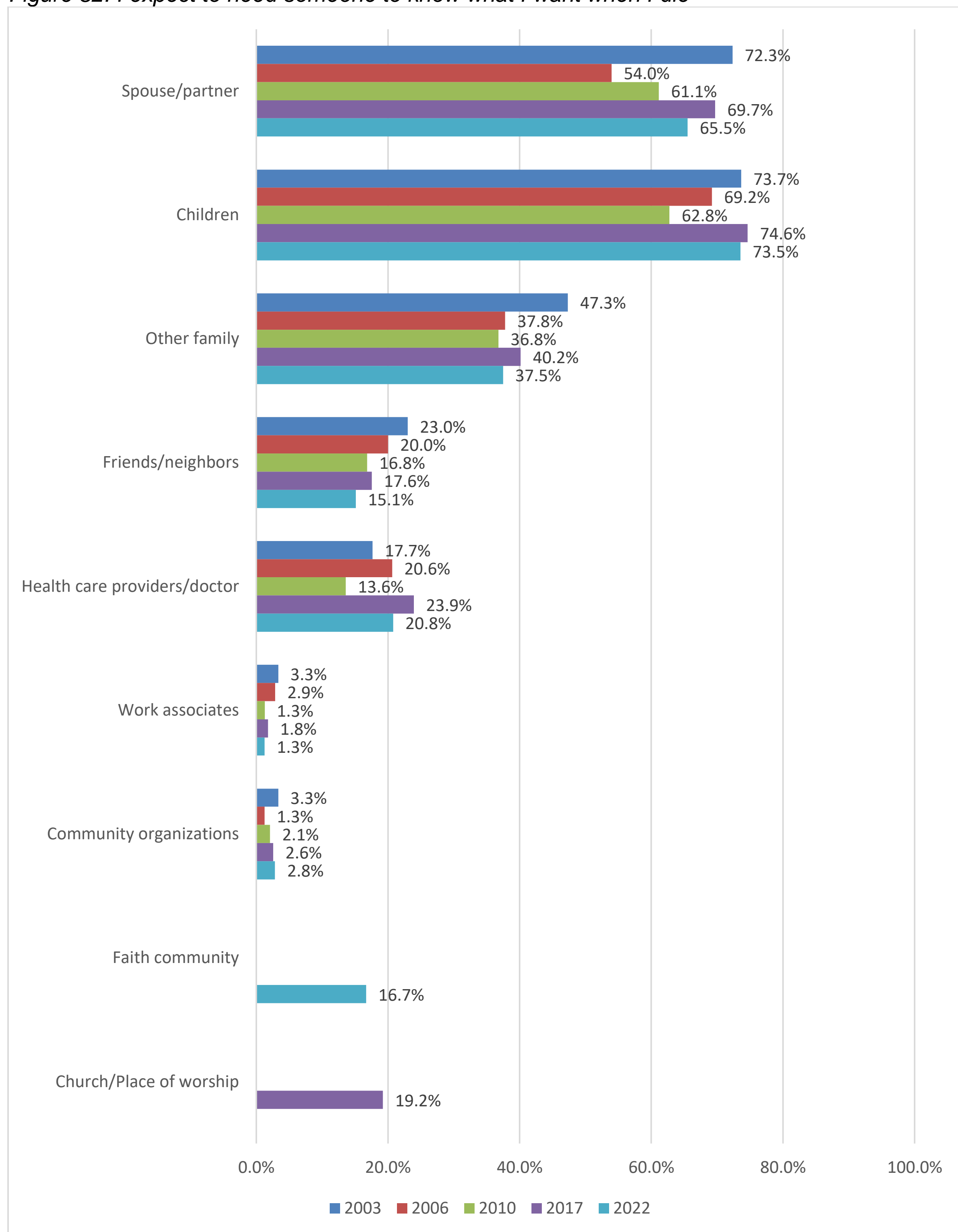


Figure 83: I expect to need someone to help care for other family members

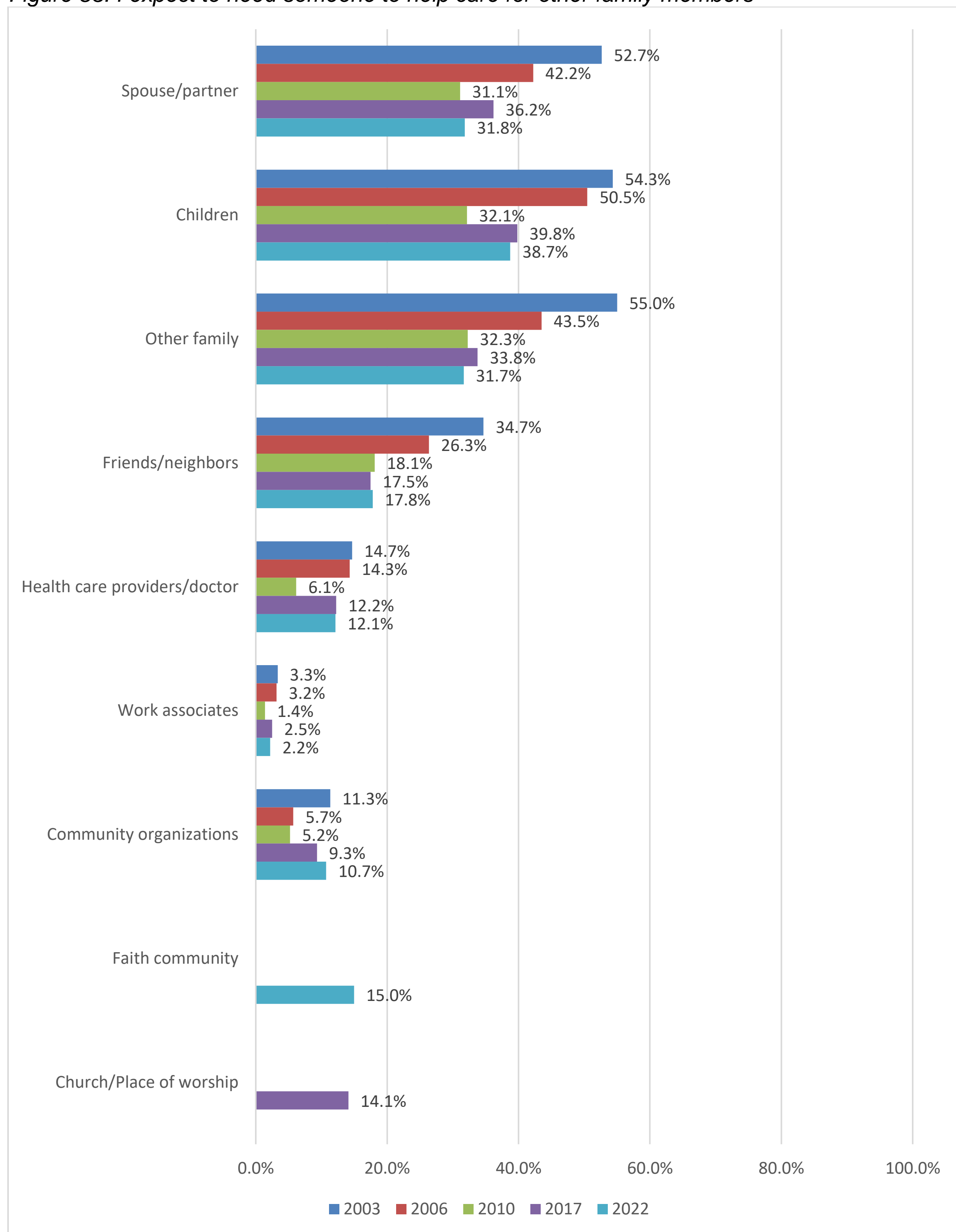


Figure 84: I expect to need someone to encourage me when I'm down

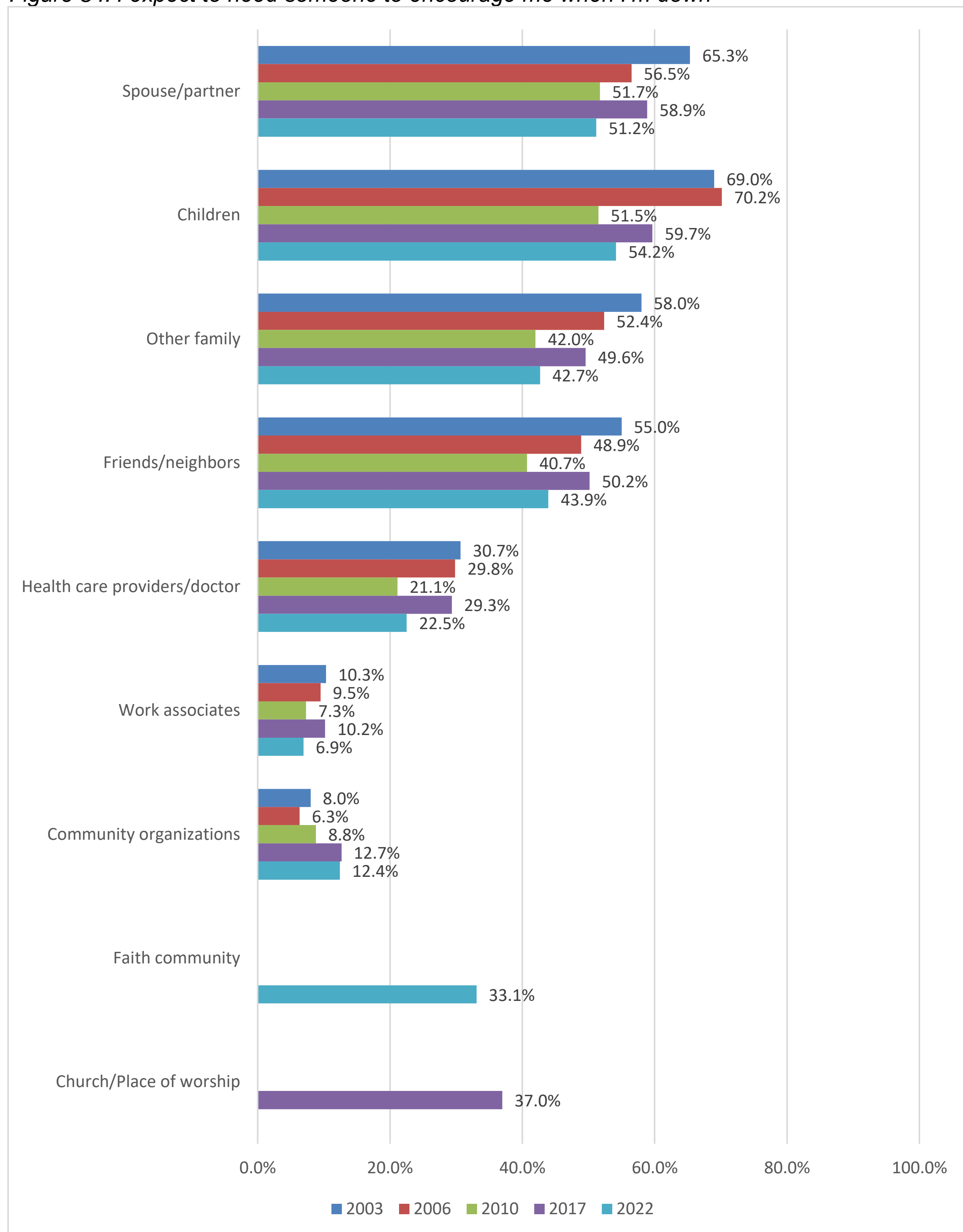


Figure 85: I expect to need someone to understand what I'm going through

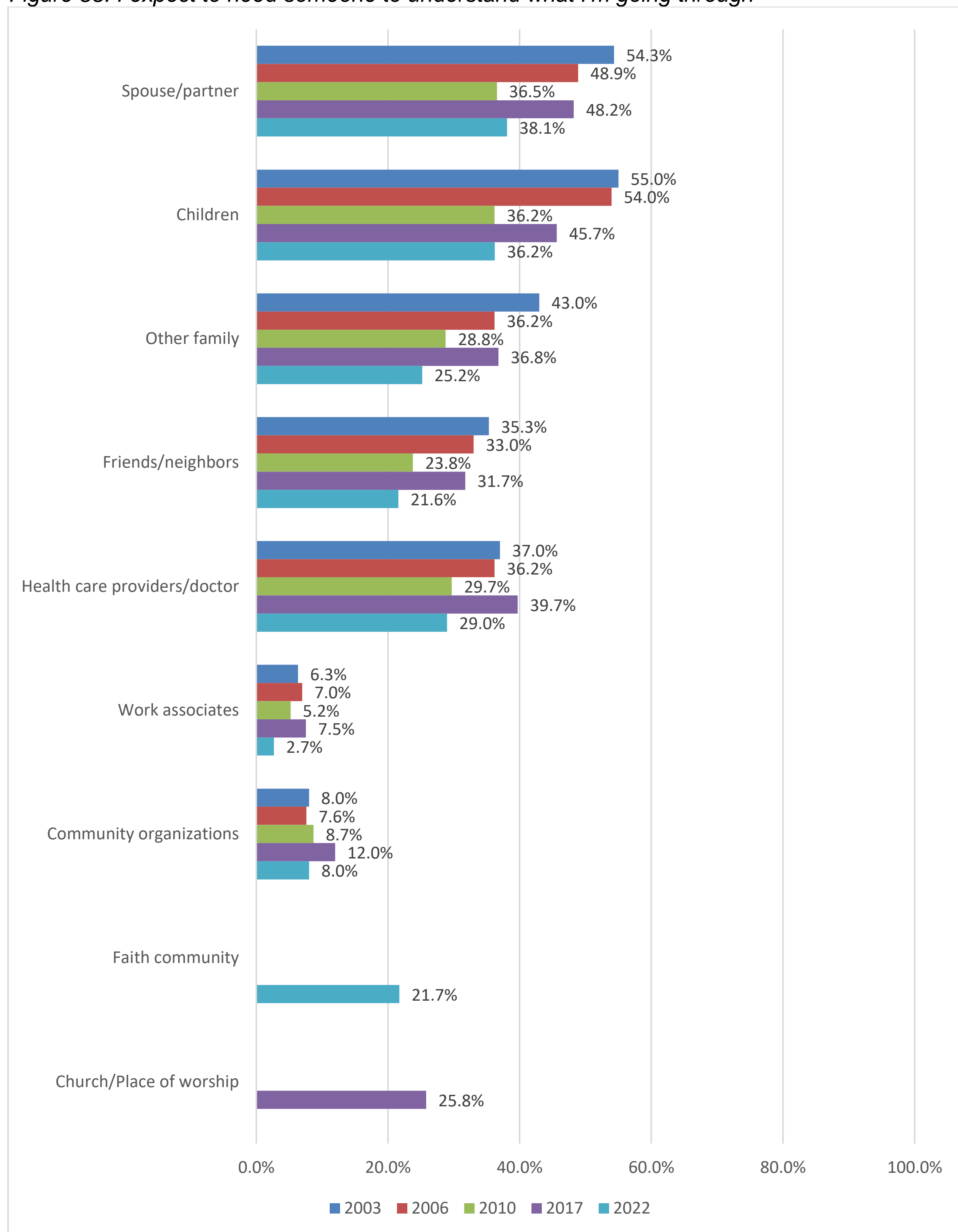
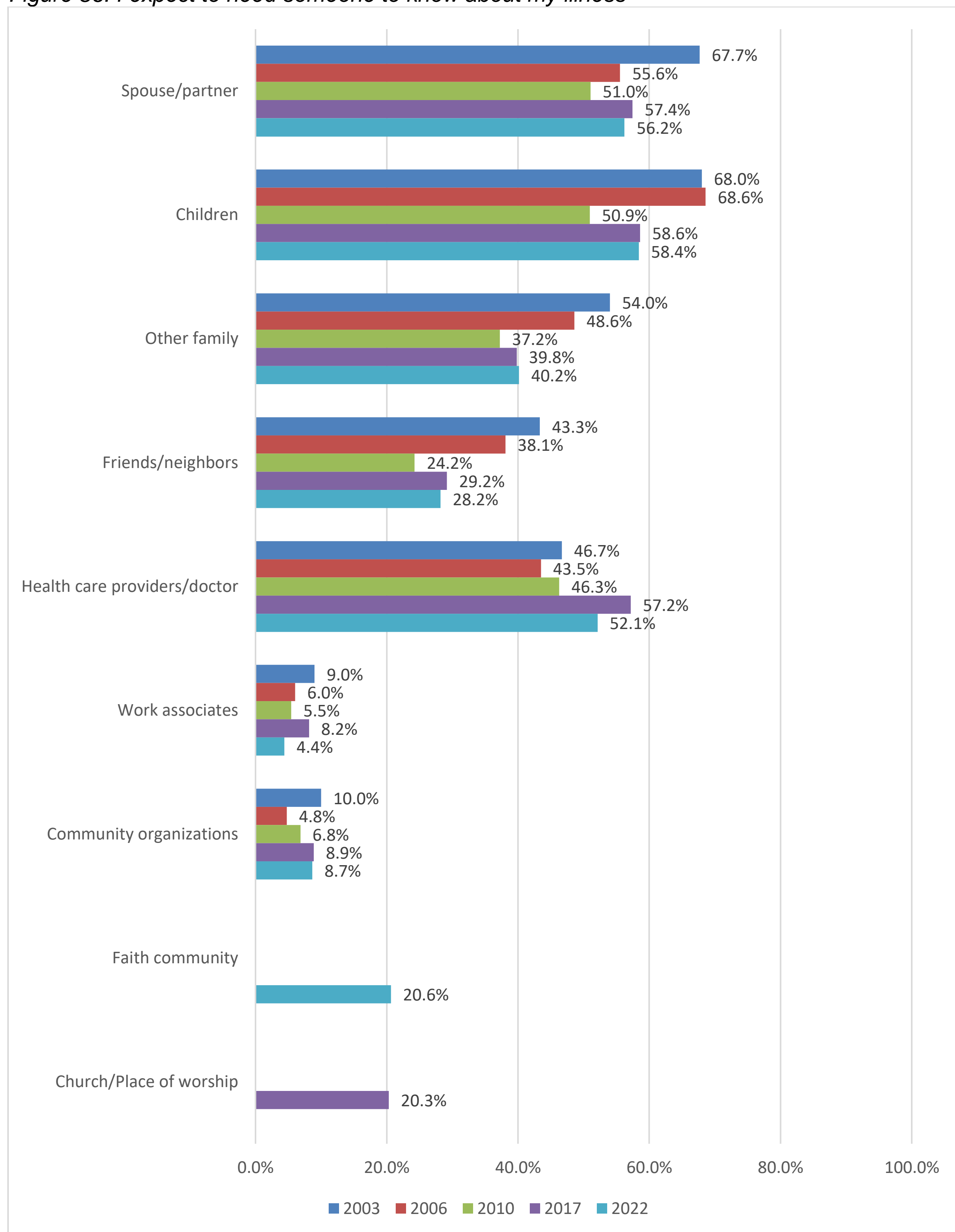


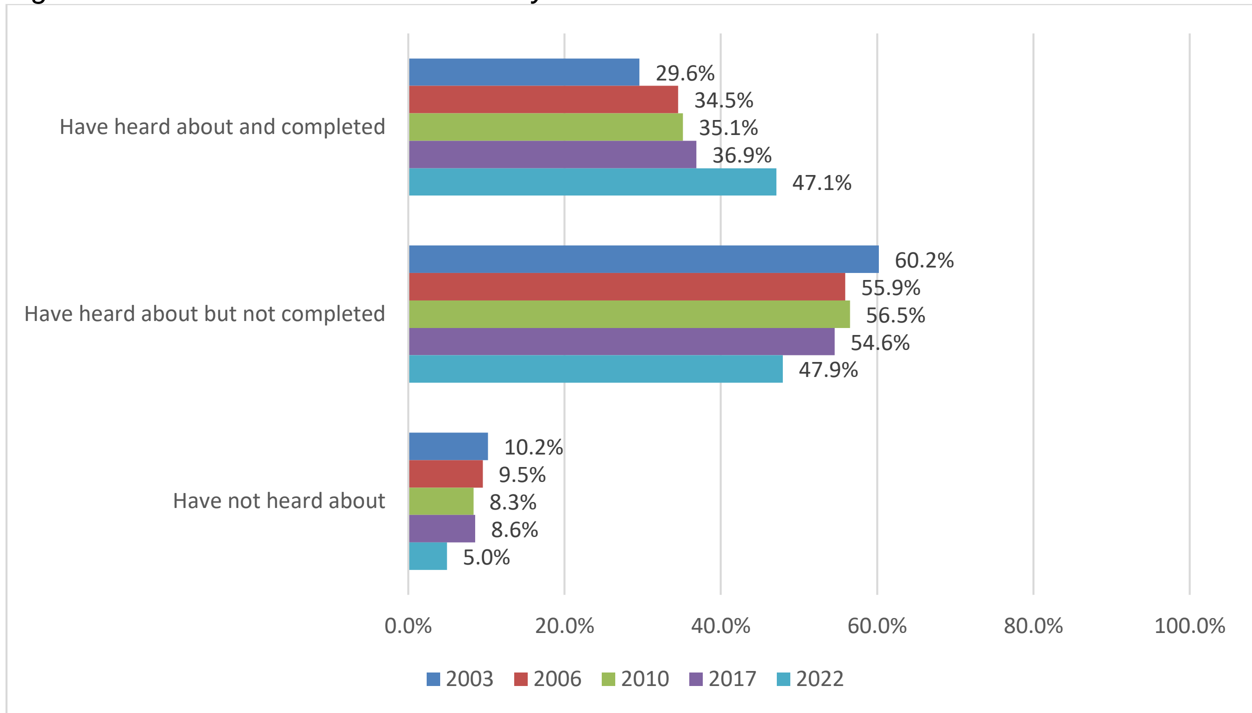
Figure 86: I expect to need someone to know about my illness



Section 4: Advance Directives

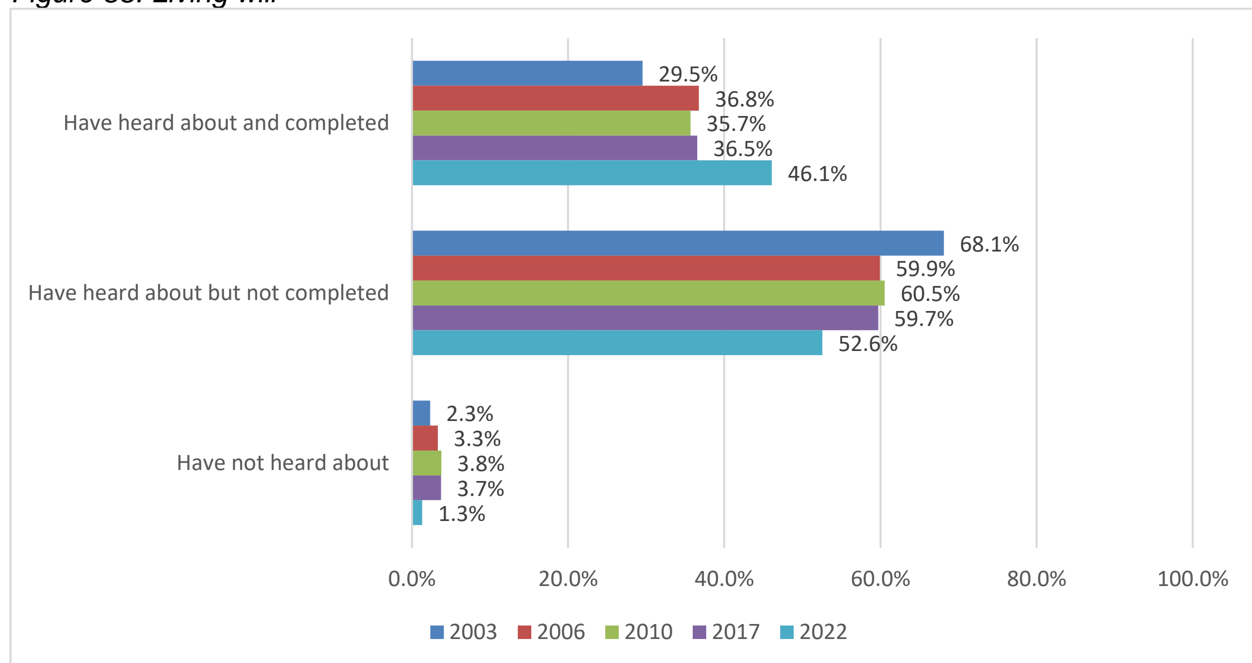
Figure 87 shows that the number of respondents who have heard about a Health Care Power of Attorney (HCPA) and completed one has been increasing over the years, with the highest percentage occurring in 2022 (47.1%).

*Figure 87: Health Care Power of Attorney****



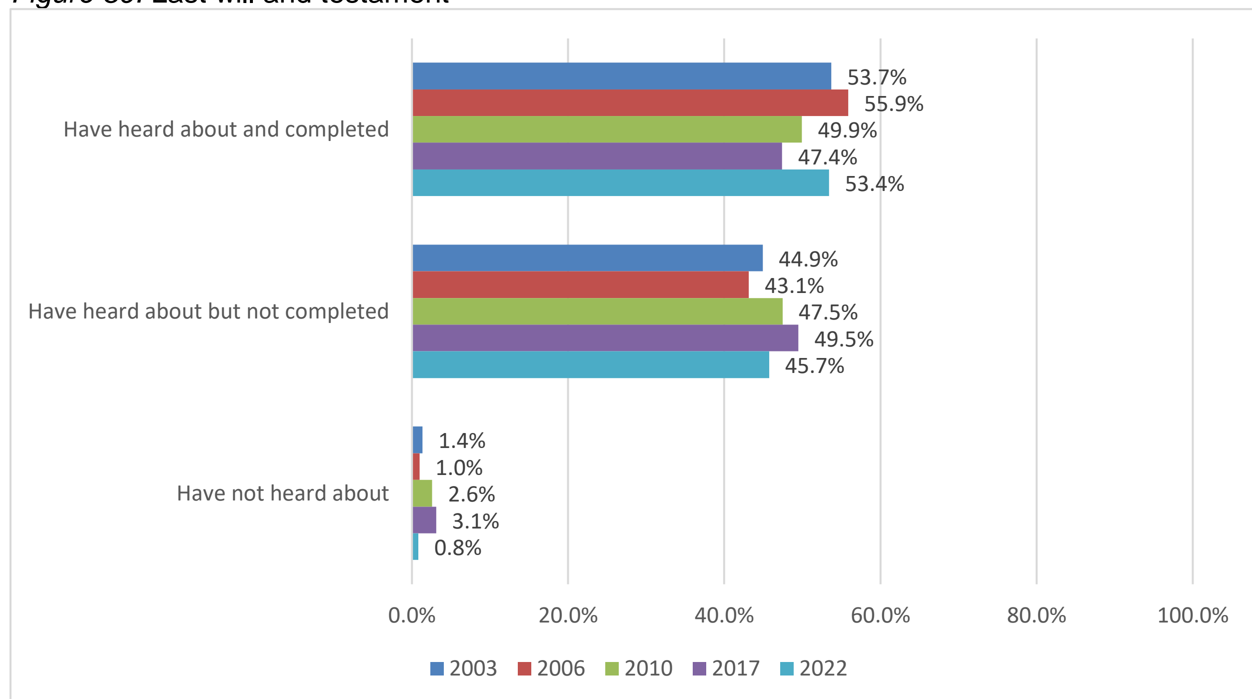
As with past years, almost all 2022 respondents have heard about completing a living will (98.7%), and the percentage of respondents who have completed one was at its highest in 2022 (46.1%) (Figure 88).

*Figure 88: Living will****



As shown in Figure 89, the majority of respondents have heard about a last will and testament, (99.2% in 2022), though the number of respondents who have completed one has fluctuated over the years.

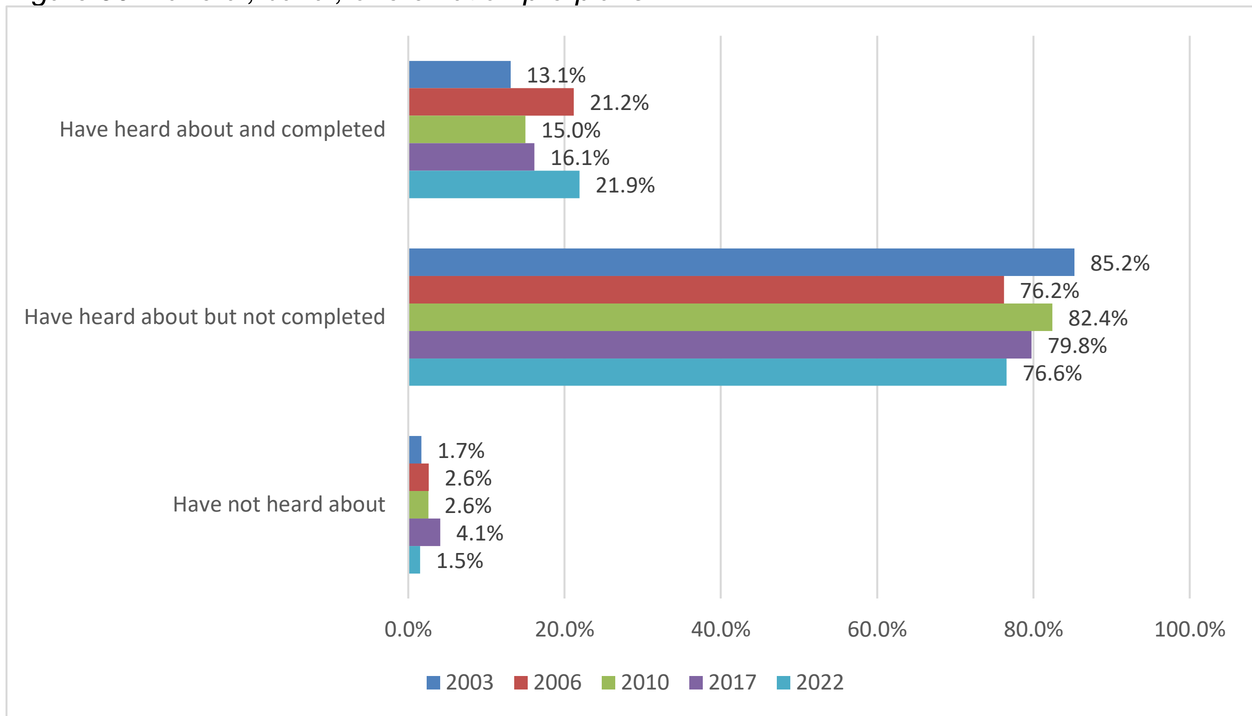
Figure 89: Last will and testament**



As with past years, the majority of 2022 participants have heard of funeral, burial, or cremation pre-plans (98.5%) but not completed one (76.6%). The percentage of respondents who have

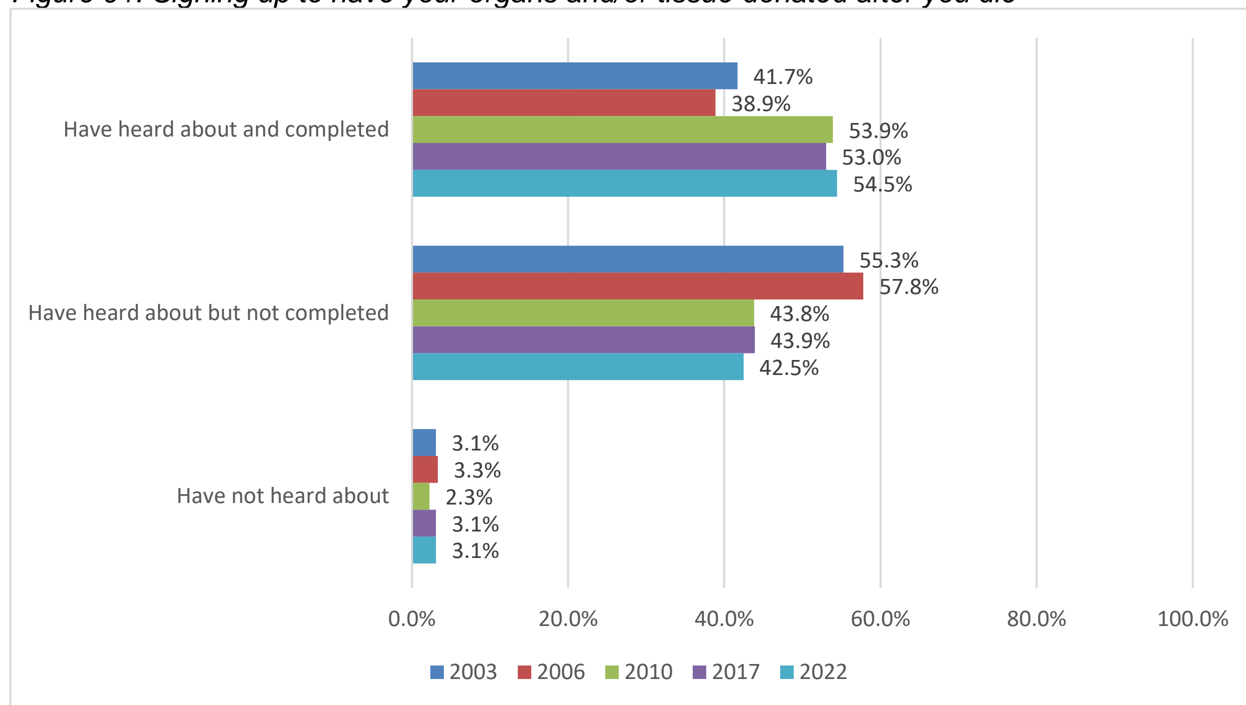
not heard about funeral, burial, or cremation pre-plans was at its highest in 2017 (4.1%) (Figure 90).

*Figure 90: Funeral, burial, or cremation pre-plans****



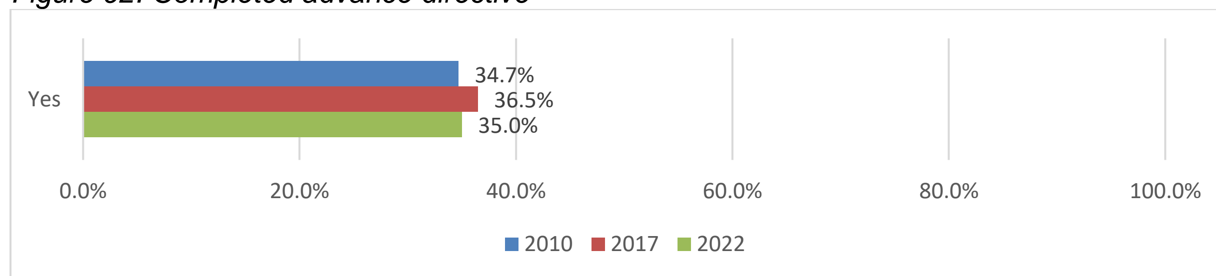
As seen in Figure 91, the majority of 2022 participants (54.5%) have signed up to donate organs and/or tissue after death, as demonstrated by a sharp rise from 2006 (38.9%) to 2010 (53.9%).

*Figure 91: Signing up to have your organs and/or tissue donated after you die****



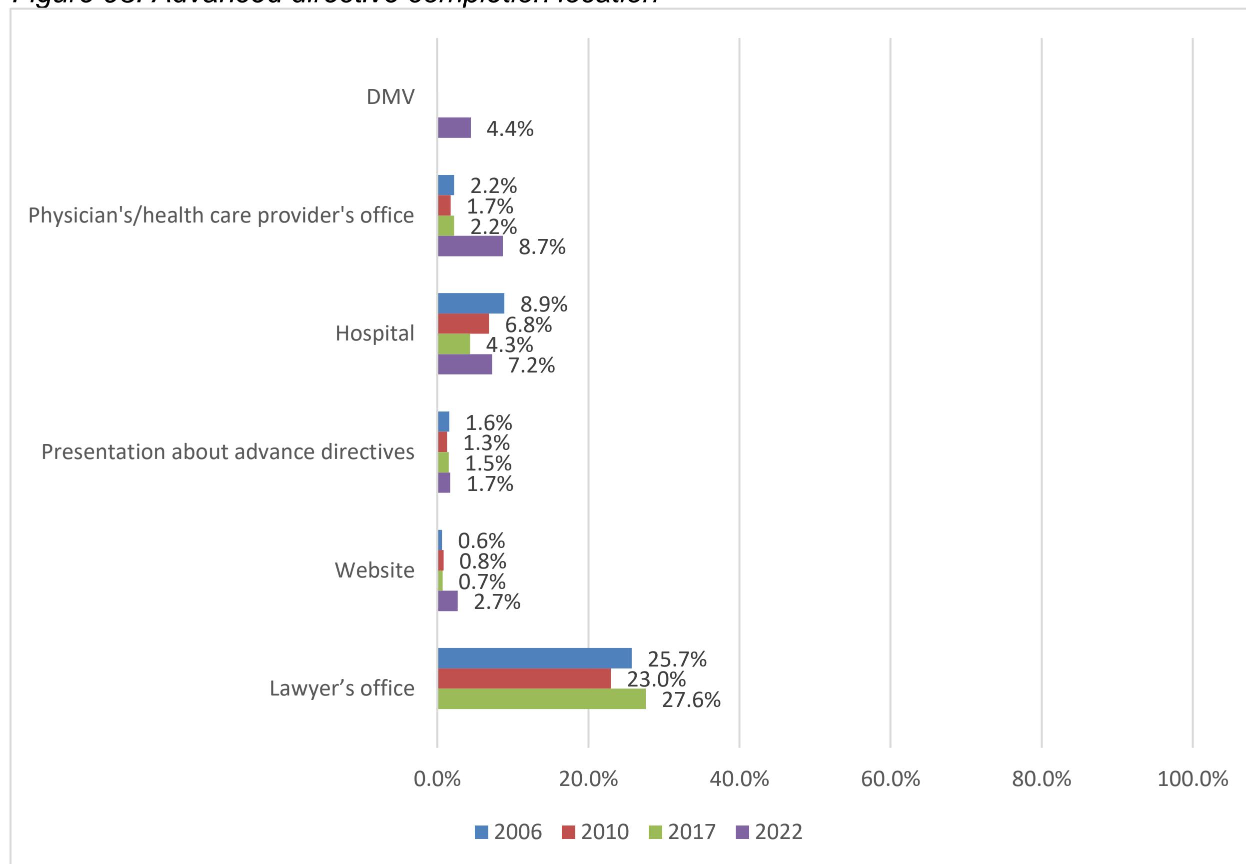
Participants were first asked if they have completed an advance directive in 2010. The percentage of participants who indicated they have completed an advanced directive has remained consistent throughout the years (Figure 92).

Figure 92: Completed advance directive



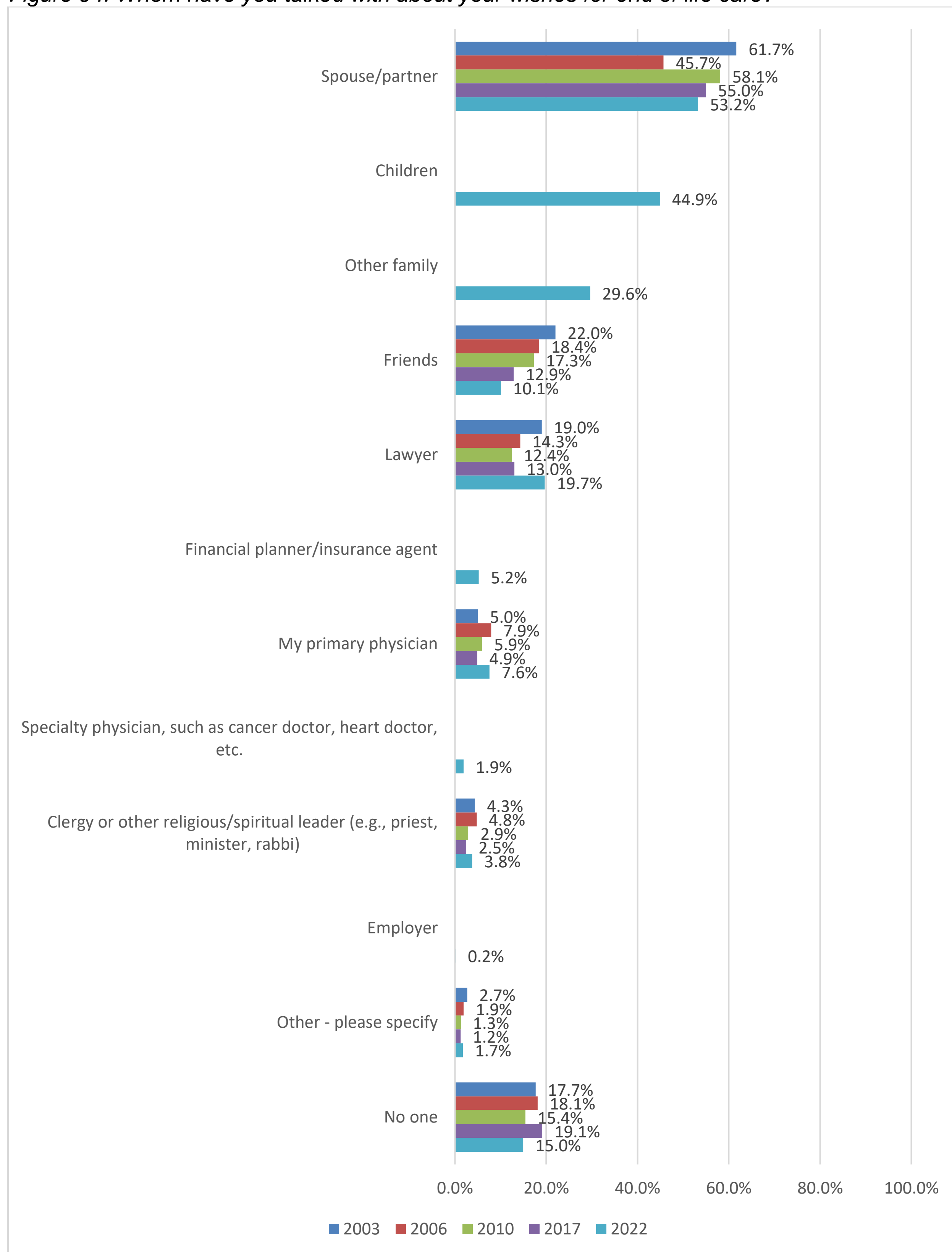
Where participants obtained the advance directive form has varied throughout the years (Figure 93). However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable.

Figure 93: Advanced directive completion location



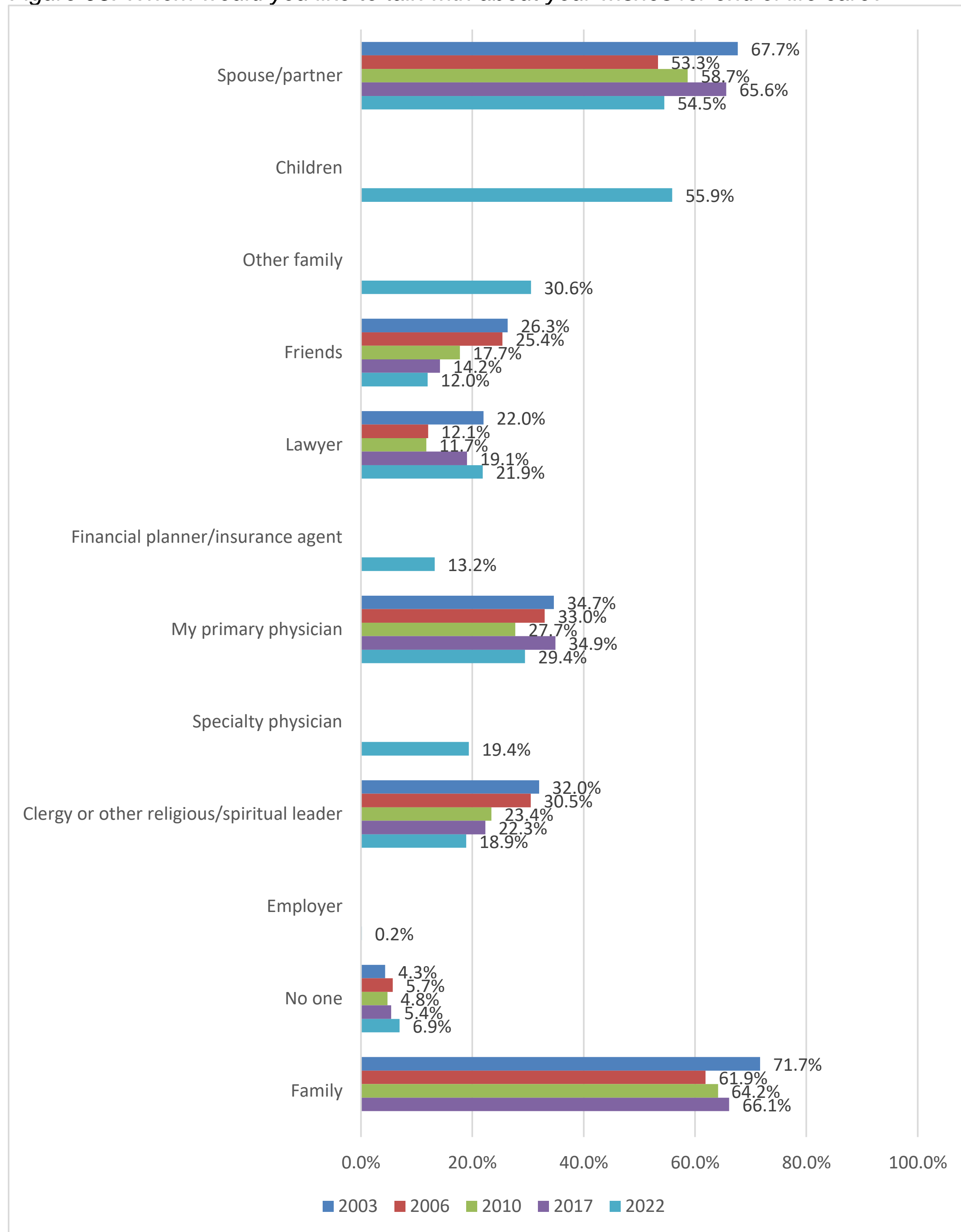
With whom participants have talked about their wishes for end-of-life care varied throughout the years. However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable (Figure 94).

Figure 94. Whom have you talked with about your wishes for end of life care?



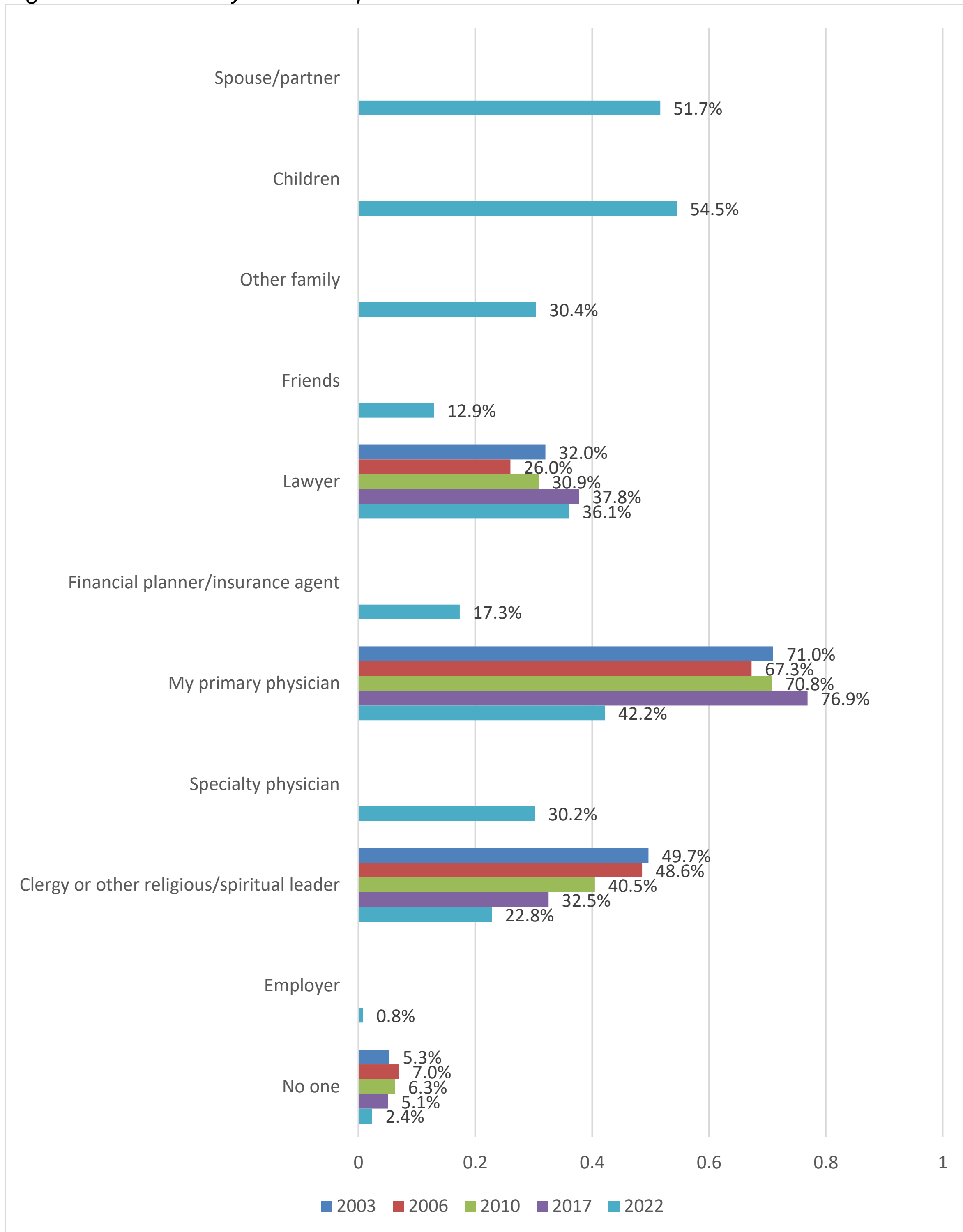
Whom participants would like to talk with about their wishes for end of life care has varied throughout the years. However, because the category options changed on later surveys, the data points obtain prior to the 2022 administration are no longer comparable (Figure 95.)

Figure 95: Whom would you like to talk with about your wishes for end of life care?



Whom participants would trust to provide information on end-of-life issues varied throughout the years. However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable (Figure 96).

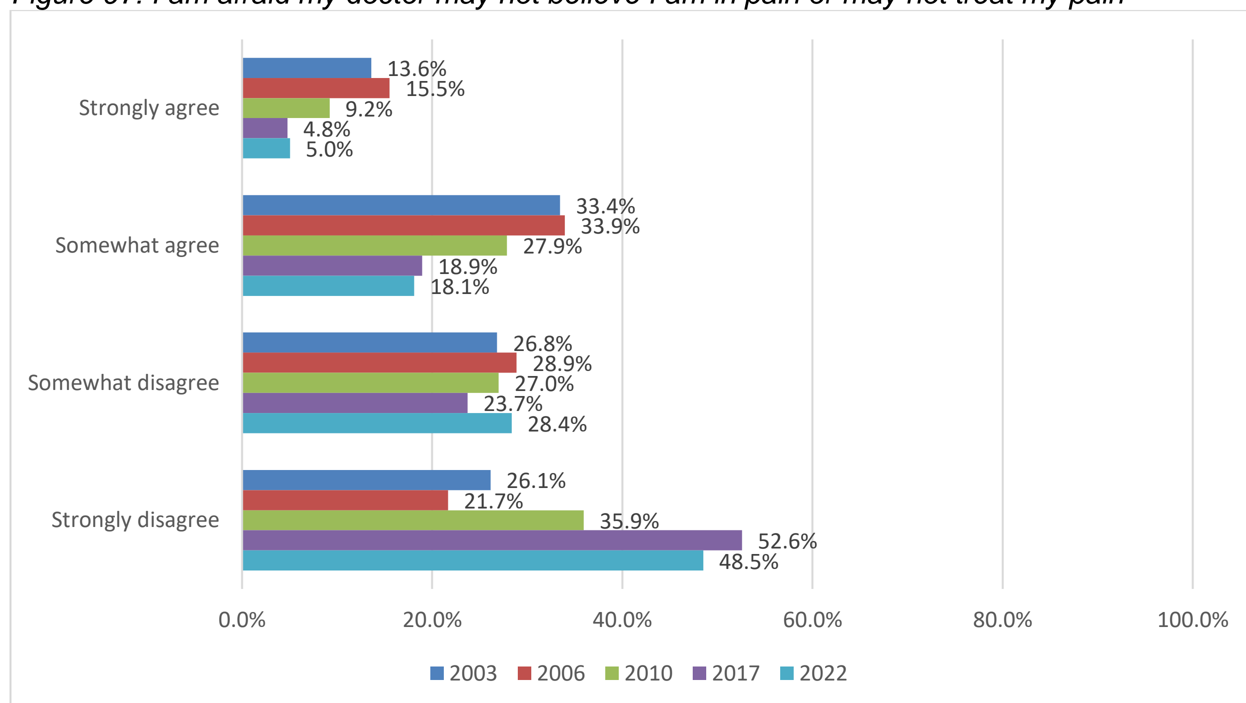
Figure 96: Whom do you trust to provide information on end-of-life issues



Section 5: Thinking about Pain

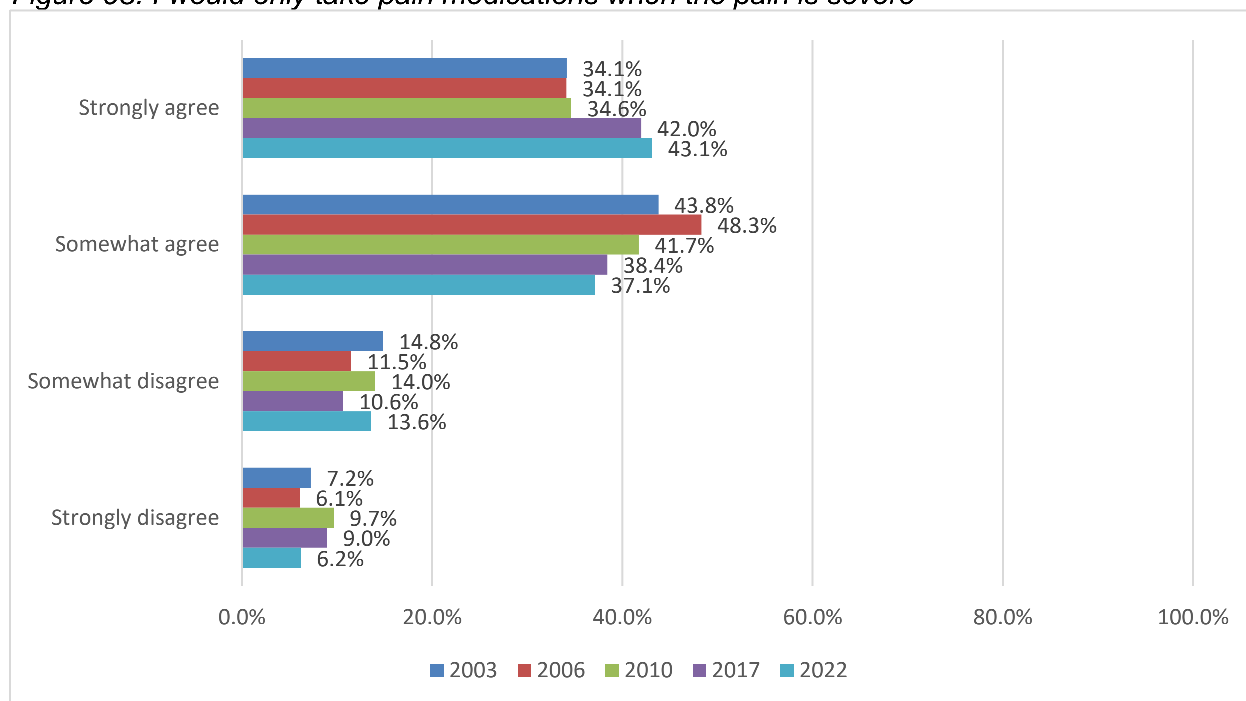
As shown in Figure 97, the percentage of participants who somewhat agree that they are afraid their doctor may not believe in or treat their pain made up the largest response category in 2003 (33.4%) and 2006 (33.9%). After dropping in 2010 (27.9%), strongly disagree became the largest response category (35.9% in 2010) and has remained the largest response category since (52.6% in 2017, 48.5% in 2022).

*Figure 97: I am afraid my doctor may not believe I am in pain or may not treat my pain****



The percentage of respondents who reported they strongly agree that they would only take pain medications when the pain is severe has significantly increased since past years (Figure 98). While around one-third of respondents consistently stated this in 2003 (34.1%), 2006 (34.1%), and 2010 (34.6%), this jumped to closer to two-fifths (42.0%) in 2017 and remained constant (43.1%) in 2022.

*Figure 98: I would only take pain medications when the pain is severe****



Similarly, respondents in 2017 and 2022 were more likely to strongly agree to being afraid of becoming addicted to pain medication than in previous years (34.1% in 2003, 43.1% in 2022) (Figure 99). And they were more likely to strongly agree that they would take the lowest amount of medicine possible than they had in years prior (30.9% in 2010, 43.7% in 2022) (Figure 100).

*Figure 99: I am afraid I will become addicted to pain medication****

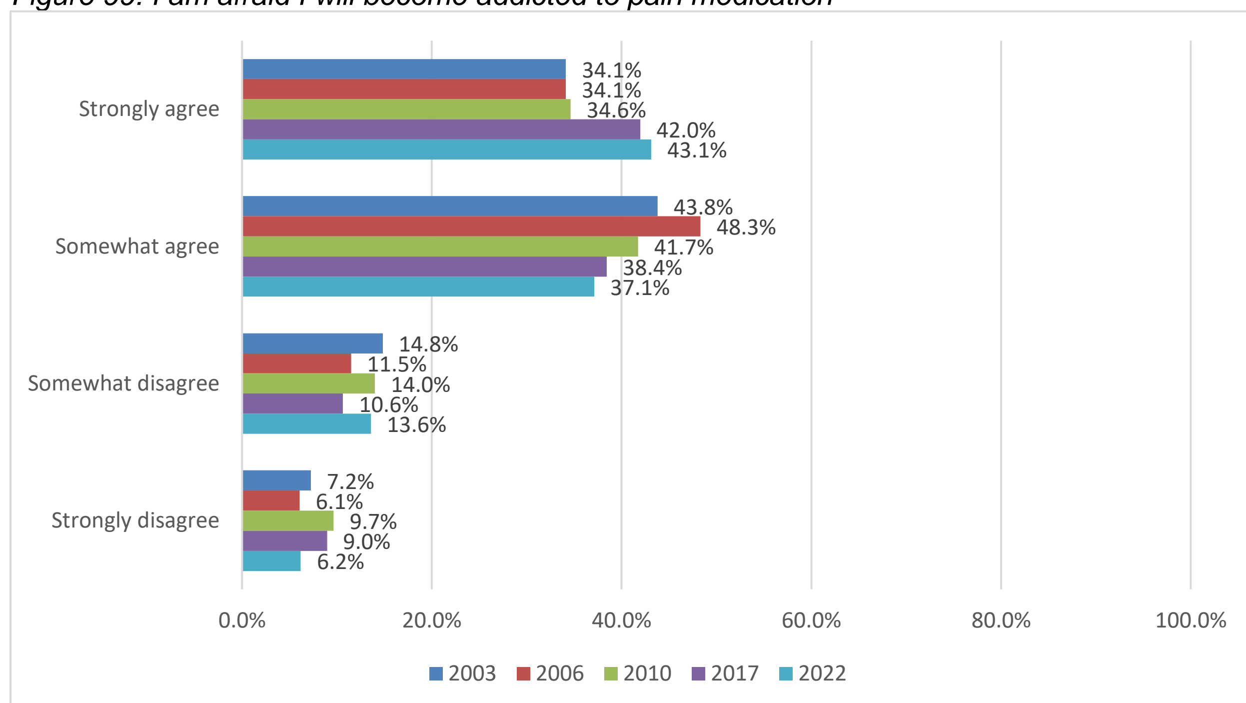
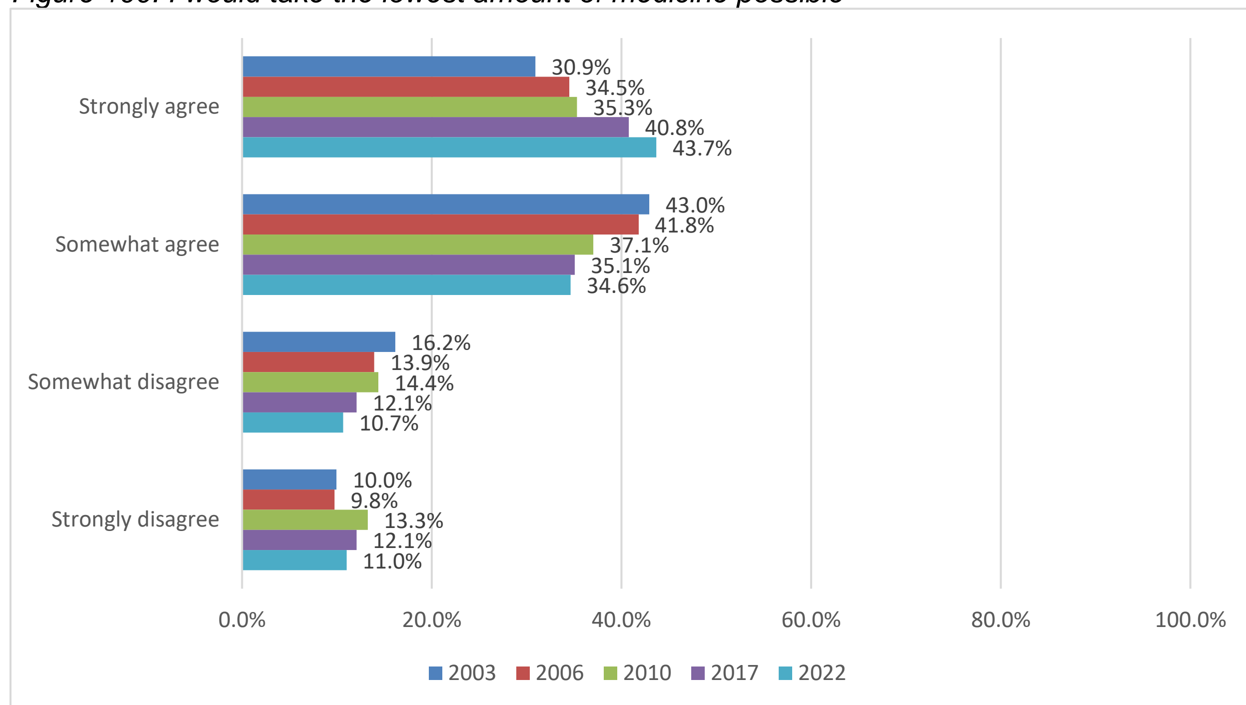
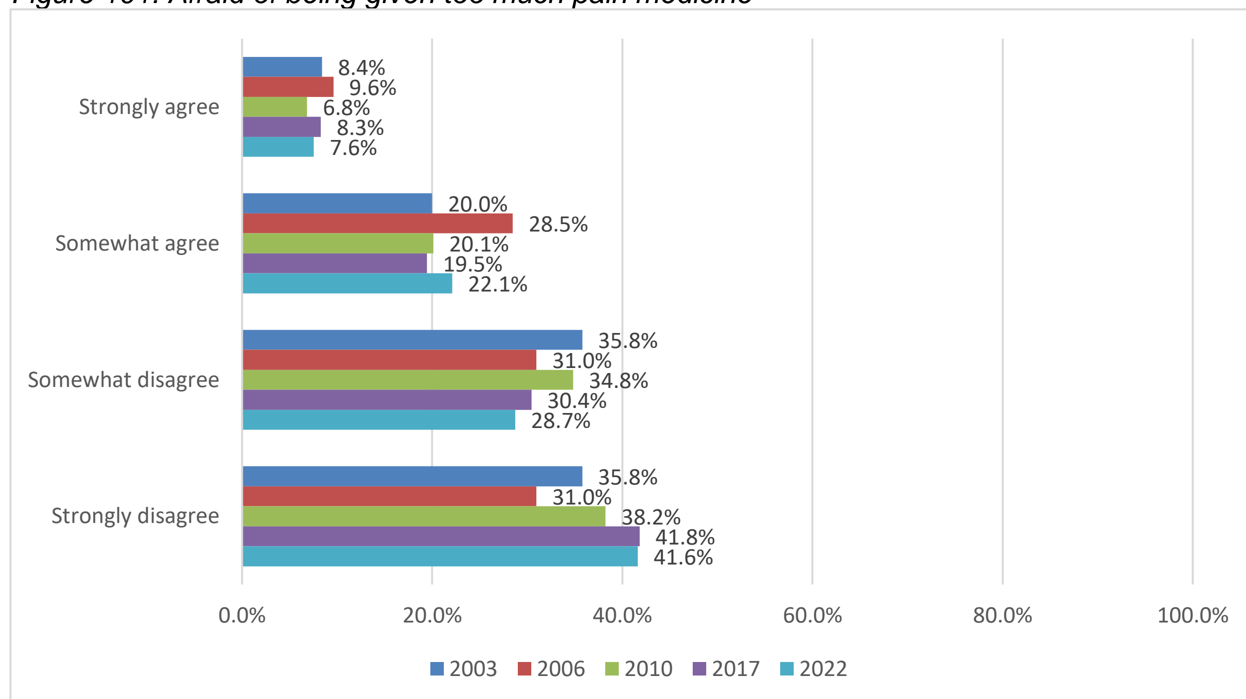


*Figure 100: I would take the lowest amount of medicine possible***



As shown in Figure 101, drastic shifts in respondents' reported level of agreement concerning how afraid they are about being given too much pain medicine occurred from 2003 (28.4% combined strongly and somewhat disagree) to 2006 (38.1% combined strongly and somewhat disagree).

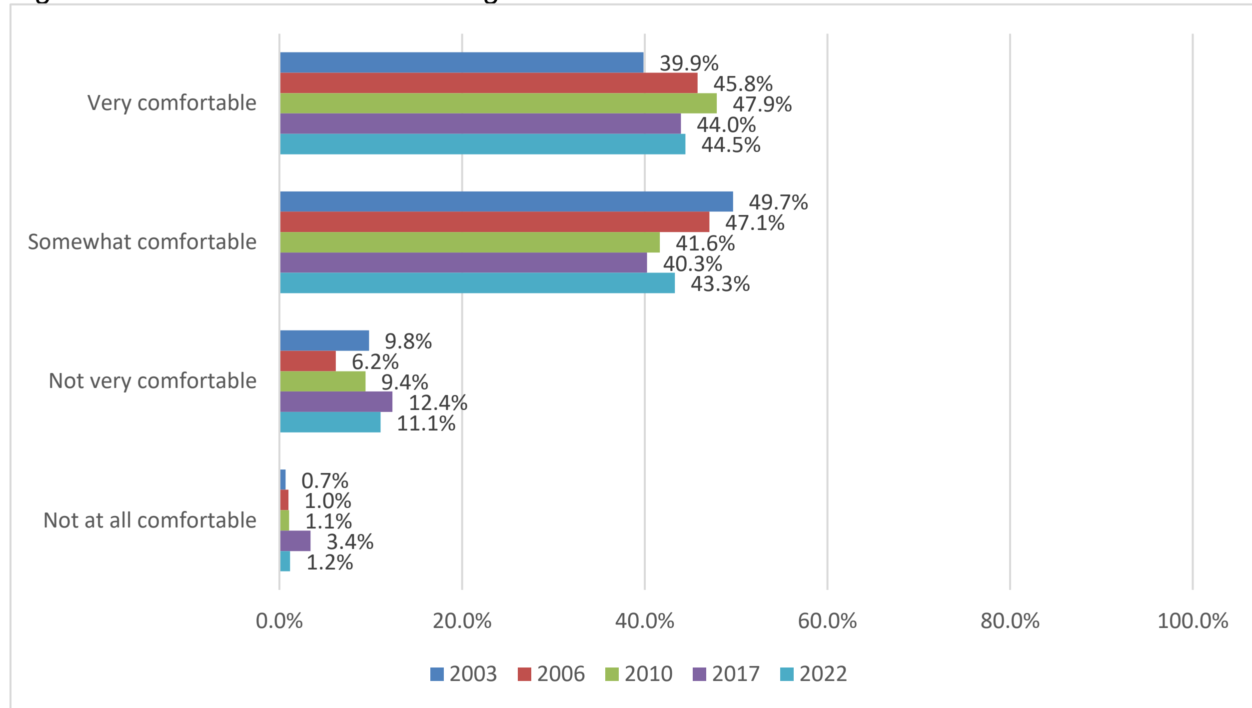
*Figure 101: Afraid of being given too much pain medicine***



Section 6: Thoughts on Death

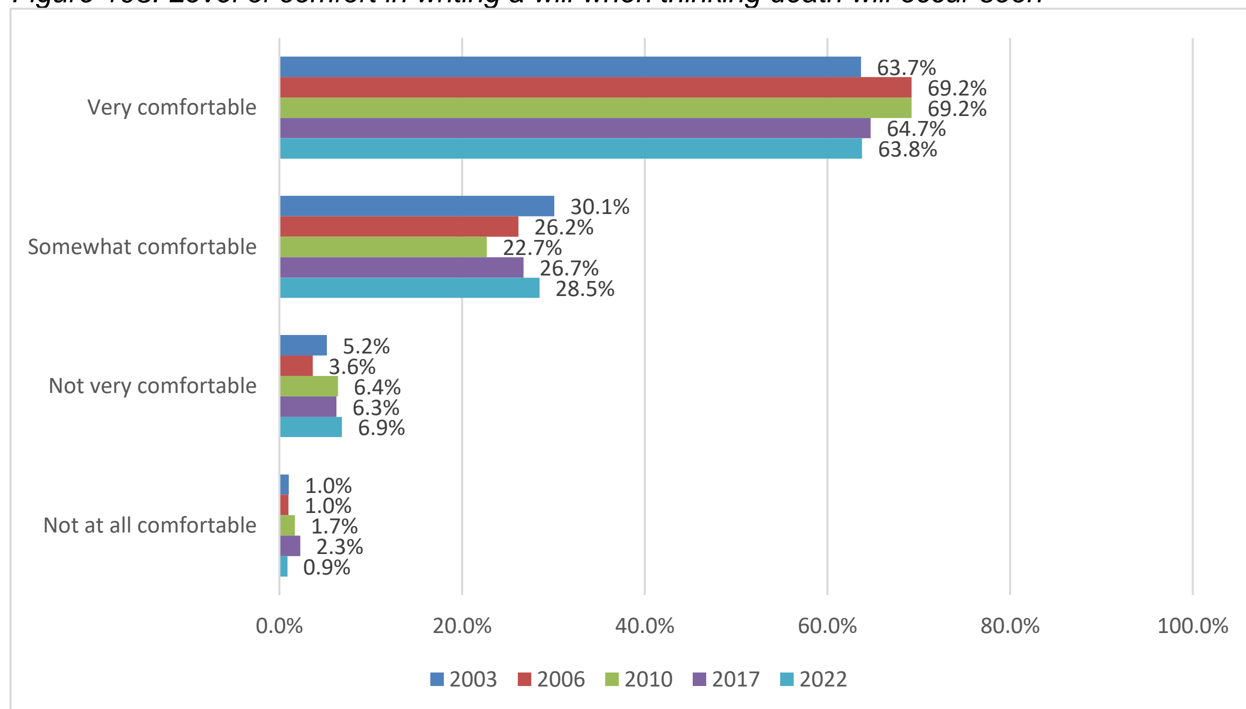
As seen in Figure 102, the percentage of respondents who reported feeling less comfortable in talking about death decreased from 2017 (15.8% combined) to 2022 (12.2% combined).

*Figure 102: Level of comfort in talking about death****



As seen in Figure 103, while the percentage of respondents who reported feeling very comfortable in writing their will if they thought death would occur soon decreased slightly from 2017 (64.7%) to 2022 (63.8%), so did the percentage of respondents who reported feeling not at all comfortable (2.3% in 2017, 0.9% in 2022).

Figure 103: Level of comfort in writing a will when thinking death will occur soon



As seen in Figure 104, as with years past, the majority (55.4%) of 2022 respondents feeling very comfortable in thinking about life after death. Similarly, the majority (64.5%) of 2022 respondents reported being very likely to attend funerals, visitations, or memorial services (Figure 105).

*Figure 104: Level of comfort in thinking about life after death**

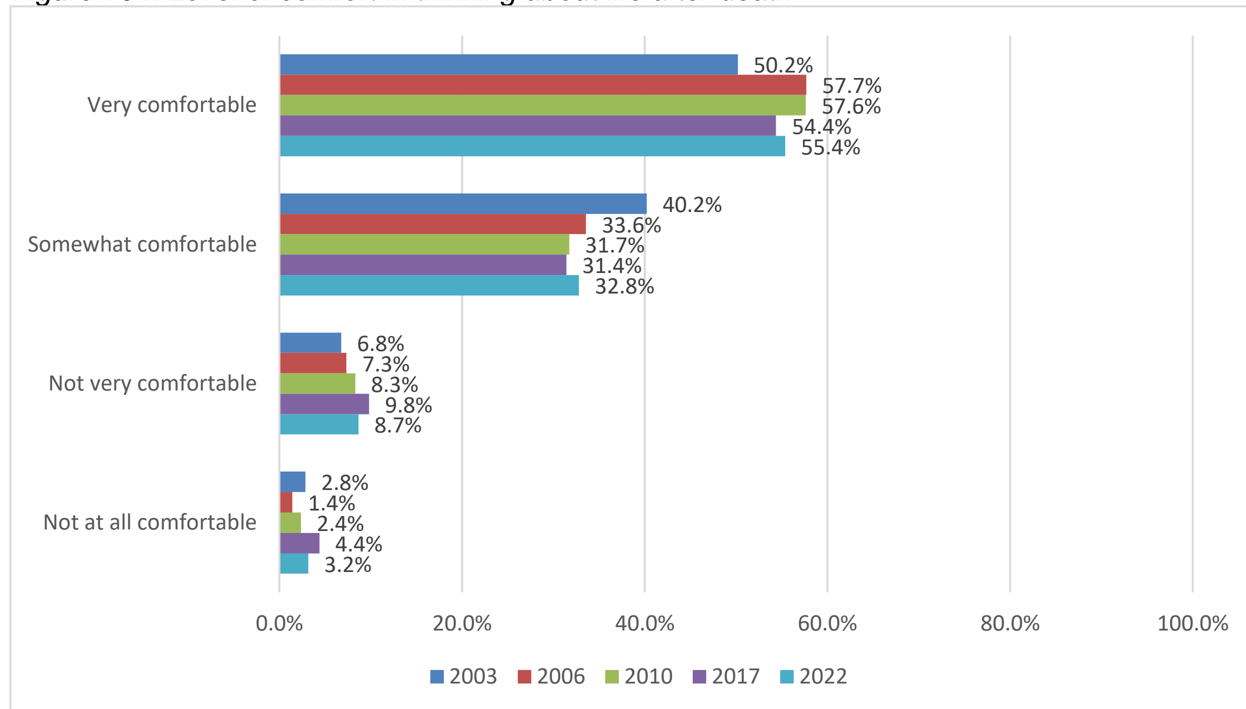
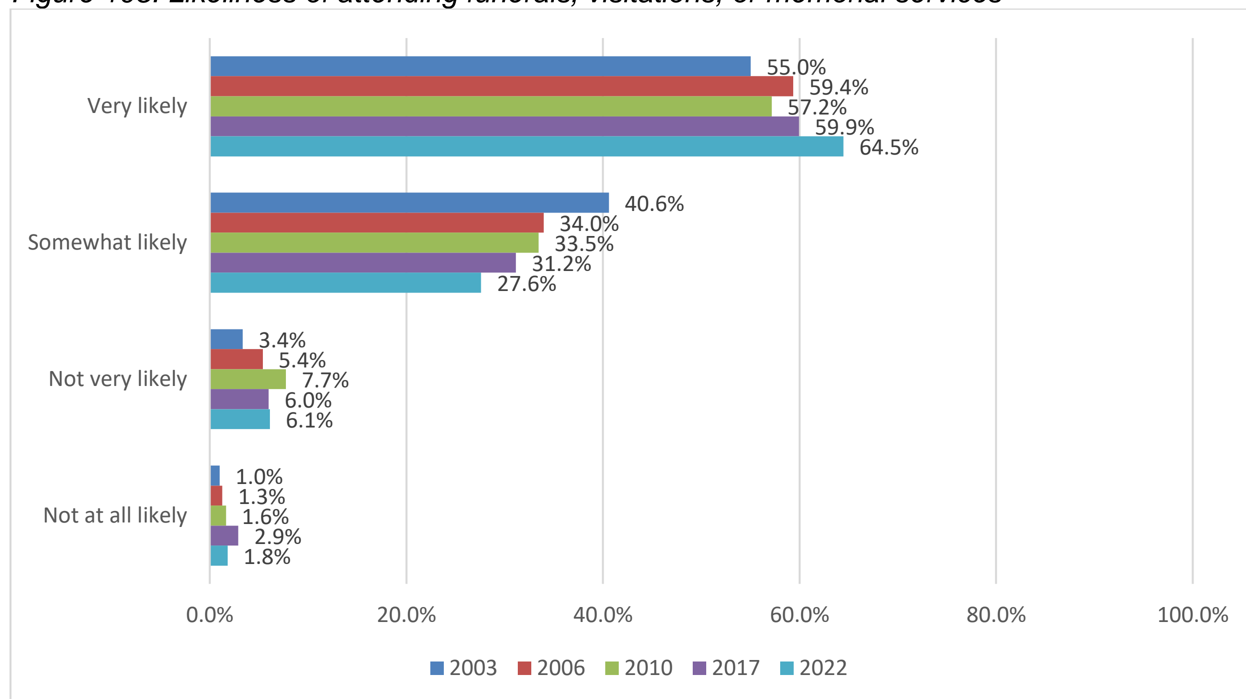


*Figure 105: Likeliness of attending funerals, visitations, or memorial services***



As with past years, more 2022 respondents reported being somewhat likely (37.6%) to read books, newspaper articles, and/or information that deals with the subject of death and dying than very likely (33.9), not very likely (23.1%) or not at all likely (5.4%) (Figure 106).

*Figure 106: Likeliness to read books, newspaper articles and/or other information that deal with the subject of death and dying**

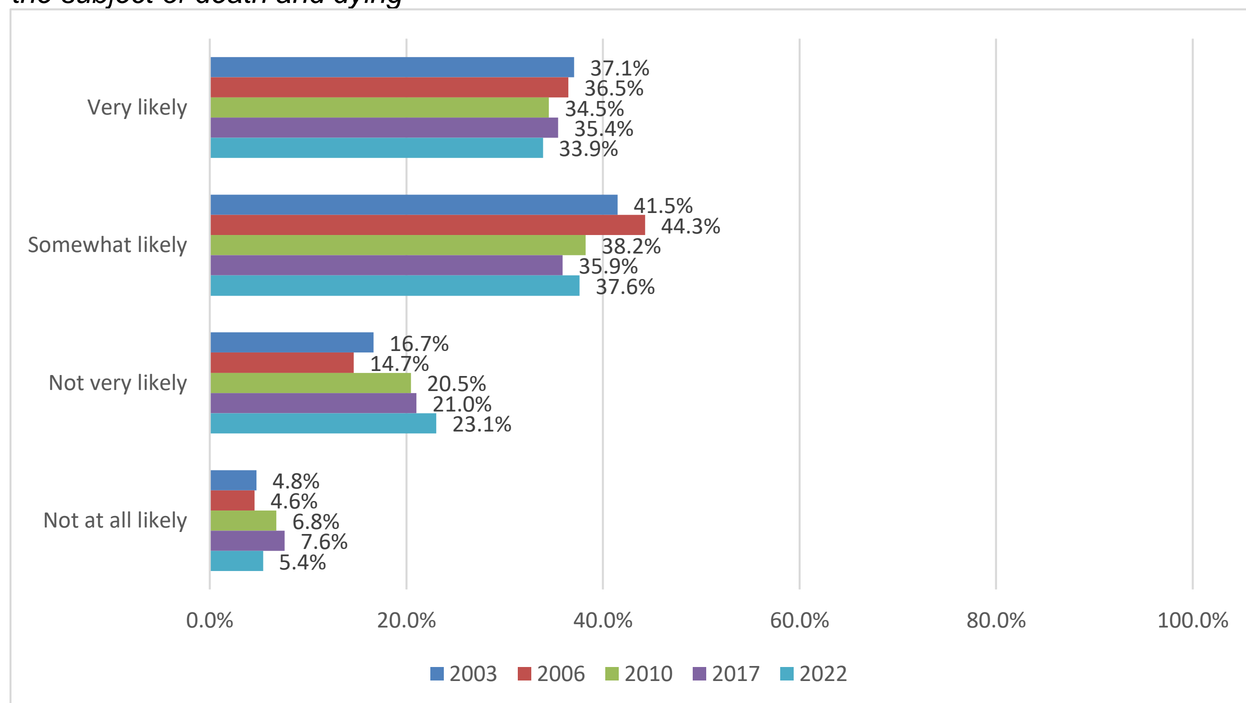
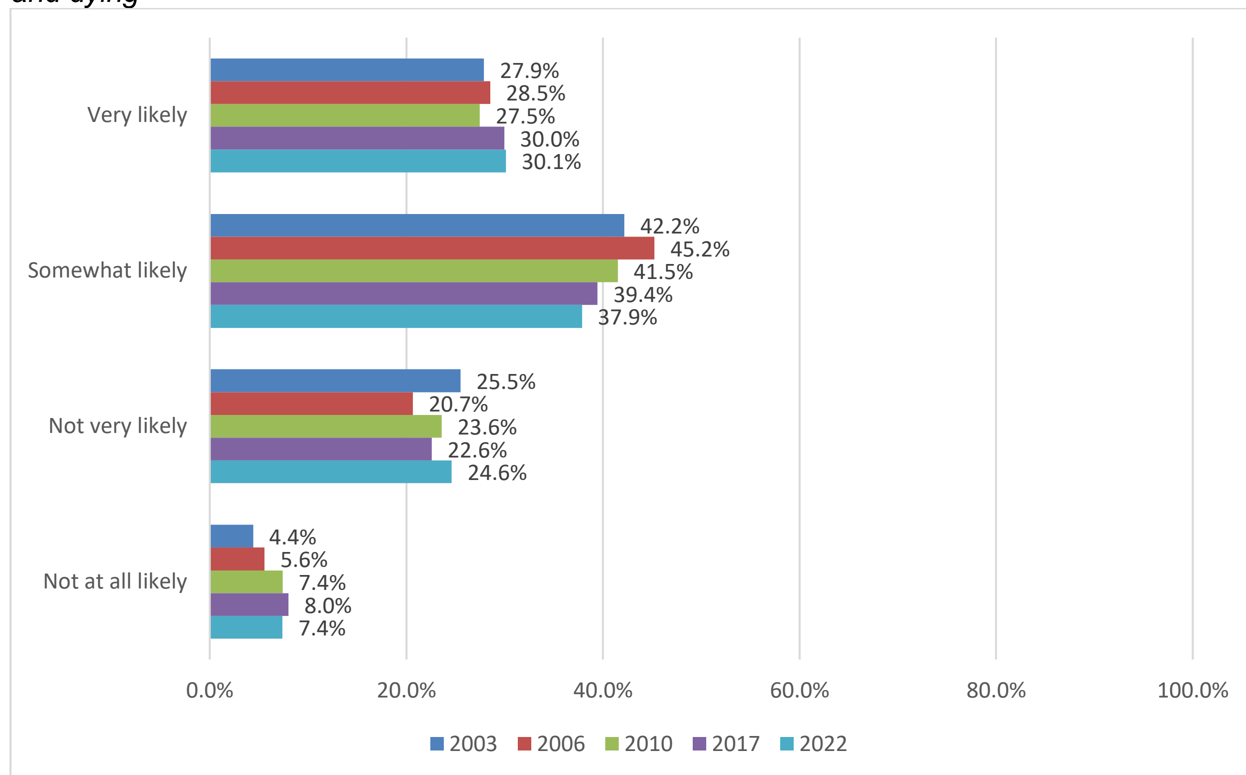


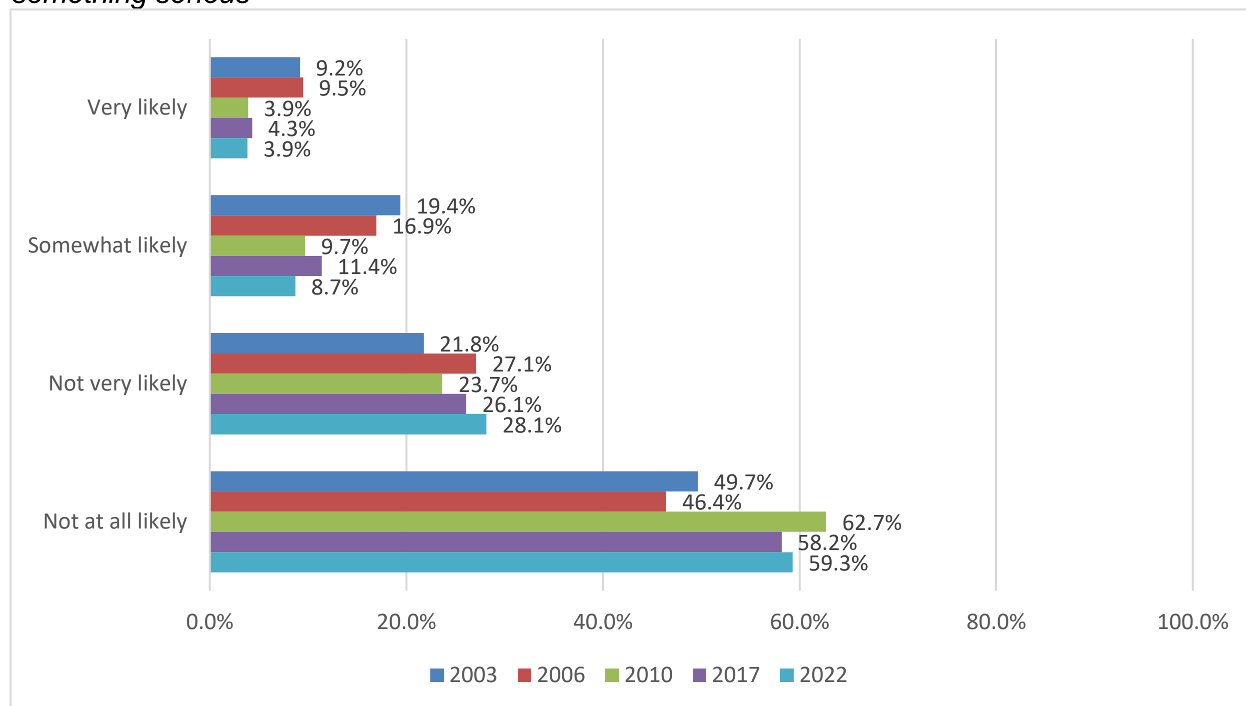
Figure 107 displays participants' reported level of likelihood that they will watch television programs or movies that deal with the subject of death and dying. As with previous years, more respondents reported somewhat likely (37.9%) in 2022 than very likely (30.1%), not very likely (24.6%), and not at all likely (7.4%). However, the percentage of those who reported somewhat likely in 2022 is smaller than in 2017 (39.4%).

Figure 107: Likeliness to watch television programs or movies that deal with the subject of death and dying



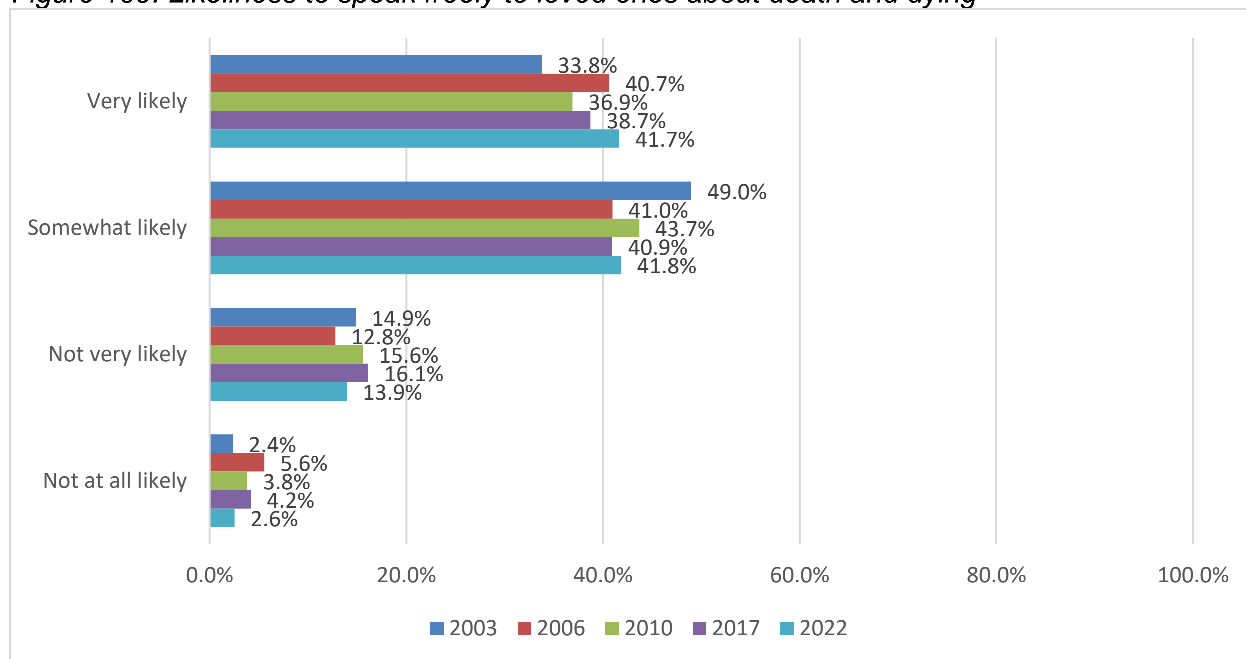
The percentage of respondents who reported being very likely and somewhat likely to avoid medical checkups in fear of their doctor finding something wrong was its lowest in 2022 (3.9% and 8.7% respectively) (Figure 108).

*Figure 108: Likeliness to avoid medical checkups because of fear that the doctor will find something serious****



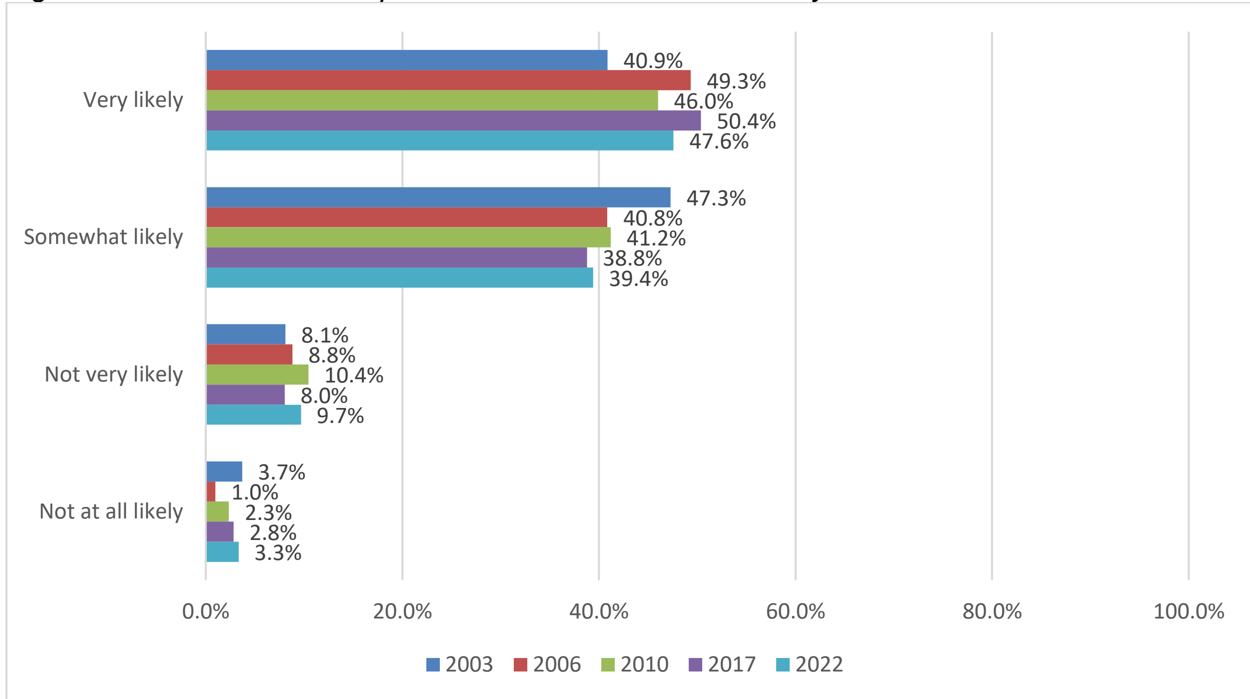
More participants reported being very likely to speak freely to loved ones about death and dying in 2022 (41.7%) than in previous years (Figure 109).

Figure 109: Likeliness to speak freely to loved ones about death and dying



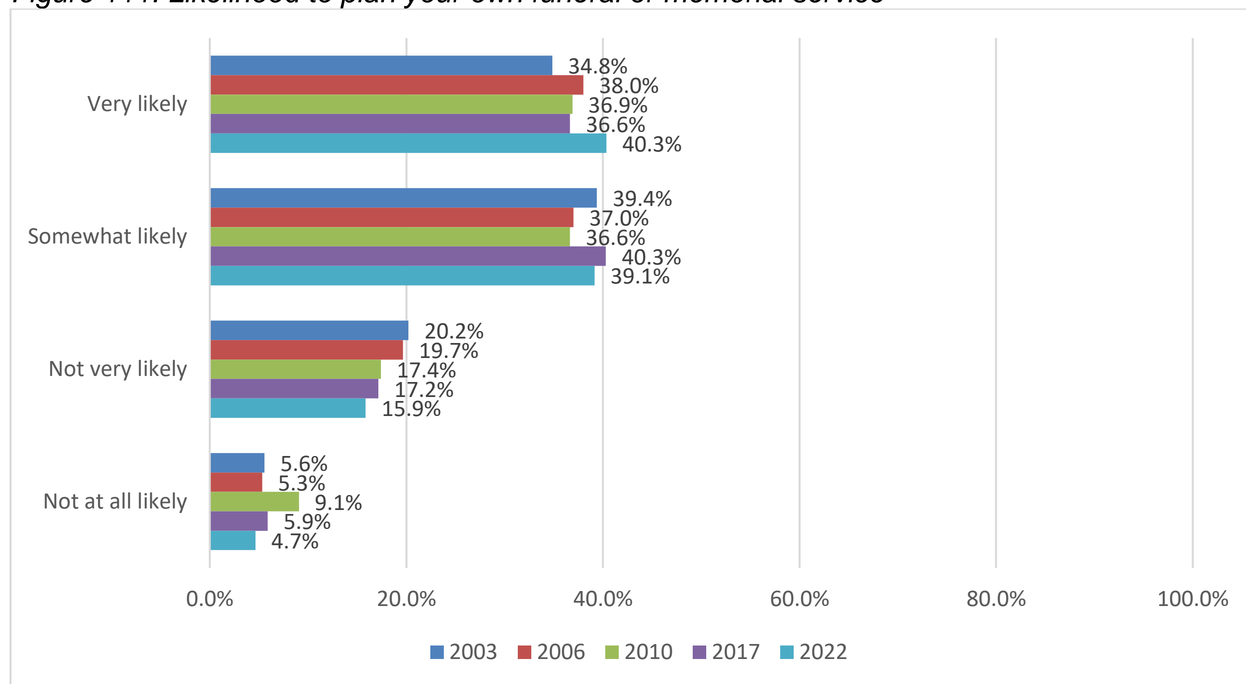
Following the trends from 2006 onwards, 2022 respondents were most likely (47.6%) to report being very likely to visit or telephone a friend or relative who has recently lost a loved one, followed by somewhat likely (39.4%), not very likely (9.7%) and not at all likely (3.3%) (Figure 110).

Figure 110: Likeliness to telephone or relative who has recently lost a loved one



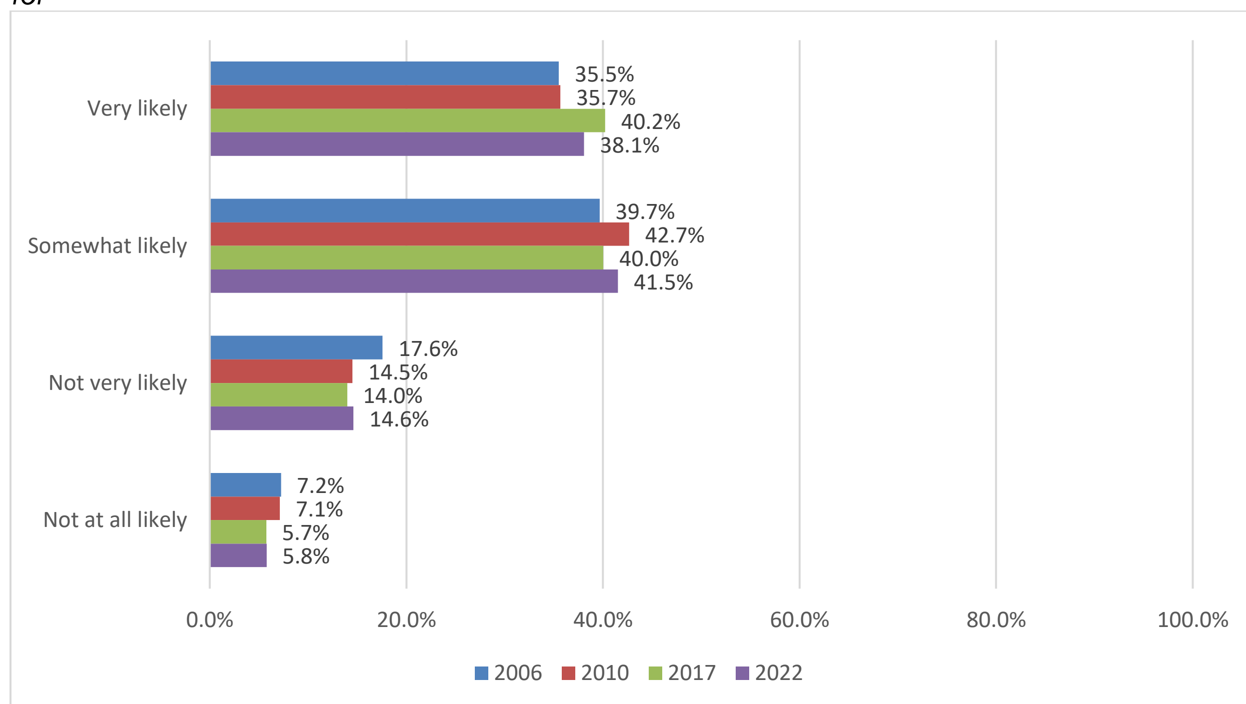
2022 respondents reported being very likely (40.3%) to preplan your own funeral or memorial services at a higher percent than previous years. Additionally, those who reported somewhat likely to the question in 2022 (39.1%) was lower than in 2017 (40.3%) (Figure 111).

Figure 111: Likelihood to plan your own funeral or memorial service



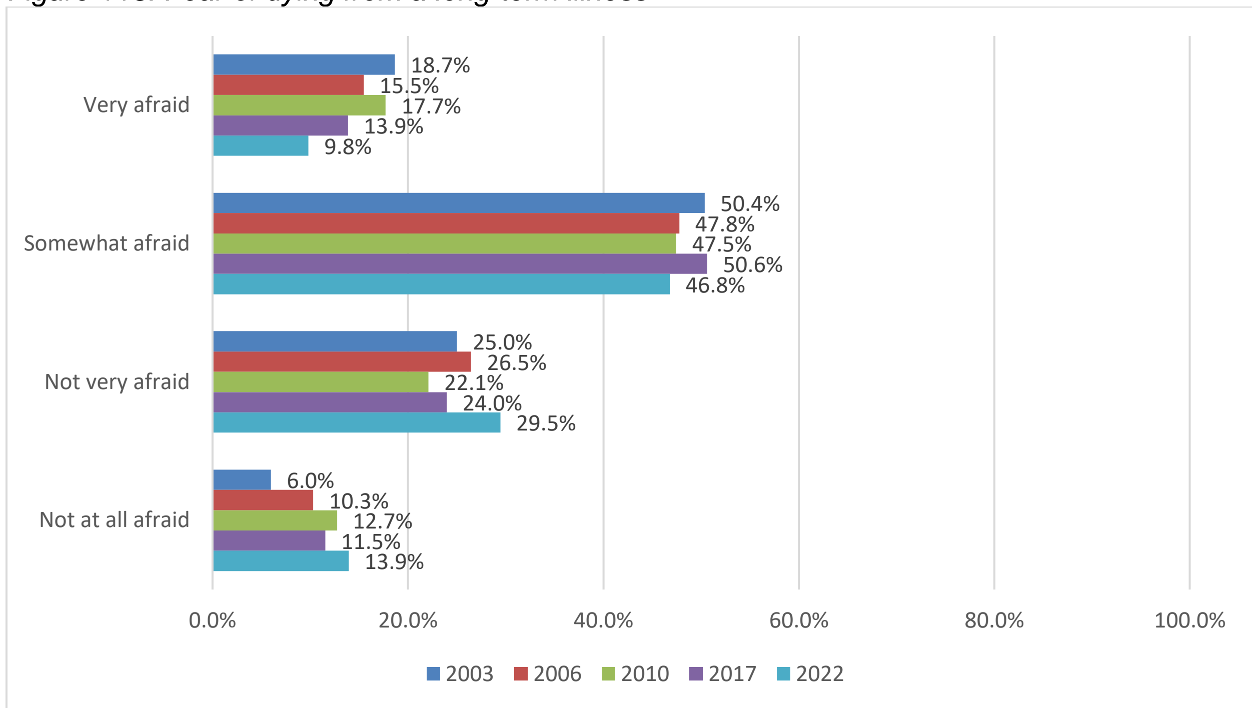
As shown in Figure 112, 2022 respondents were less likely to report being very likely or somewhat likely to preplan the funeral or memorial service of someone you're caring for at a (79.6% combined) than in 2017 (80.3%) combined.

Figure 112: Likelihood of preplanning the funeral or memorial service of someone you're caring for



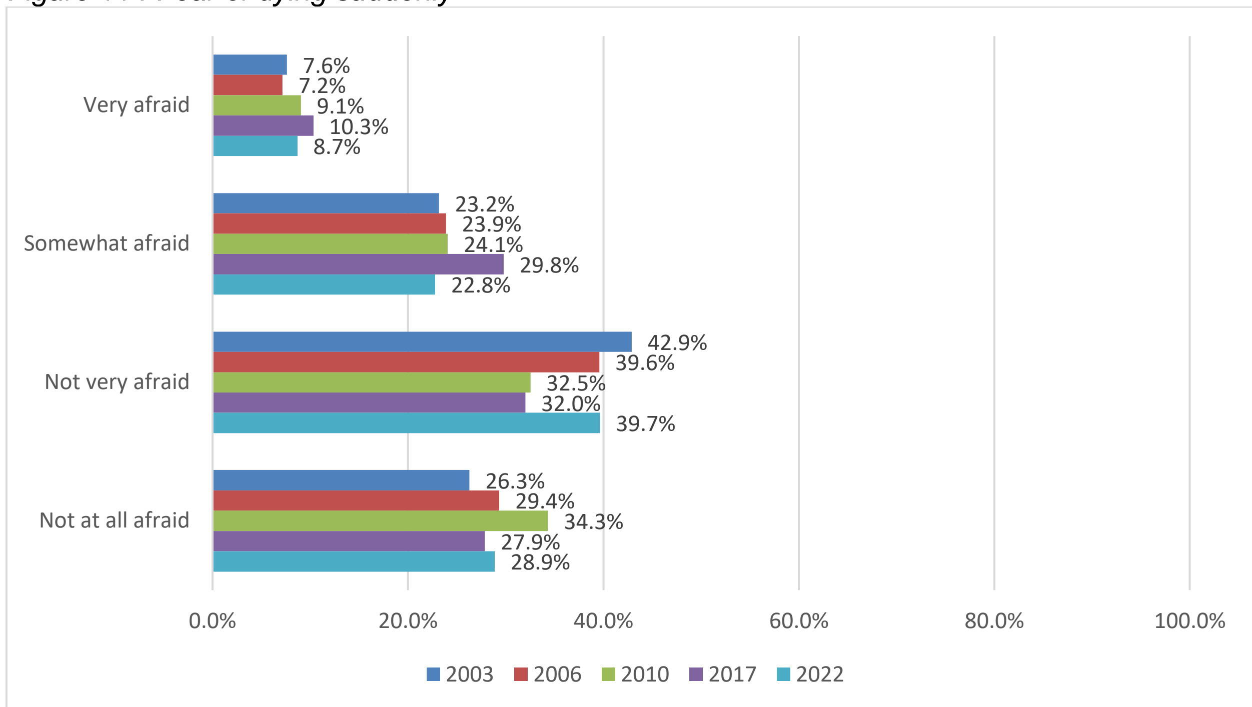
Participants were asked to rate their level of fear at the prospect of dying from a long-term illness. The majority of 2022 participants (56.6%) reported being very afraid or somewhat afraid, which is lower than in past years (Figure 113).

*Figure 113: Fear of dying from a long-term illness****



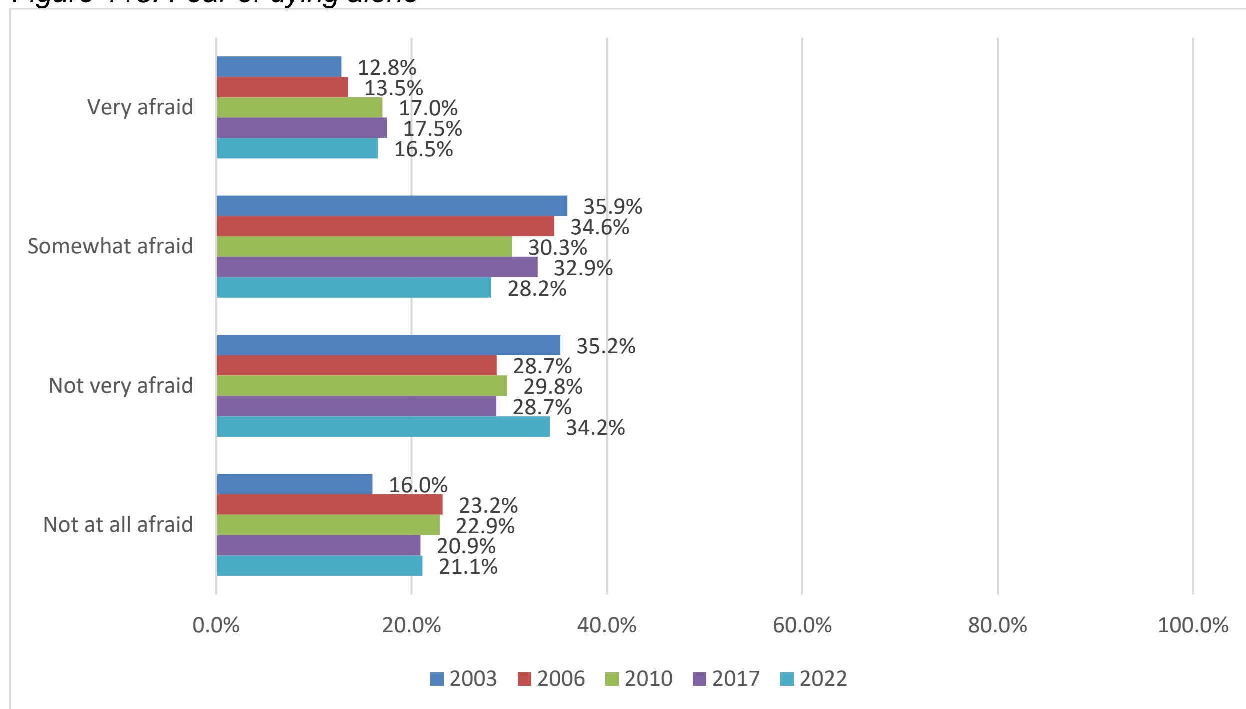
Participants remained fairly consistent in their reported level of fear about dying suddenly throughout the years. However, those reporting very afraid or somewhat afraid jumped from 2010 (33.1% combined) to 2017 (40.1%), then dropped again in 2022 (31.5%) (Figure 114).

*Figure 114 Fear of dying suddenly****



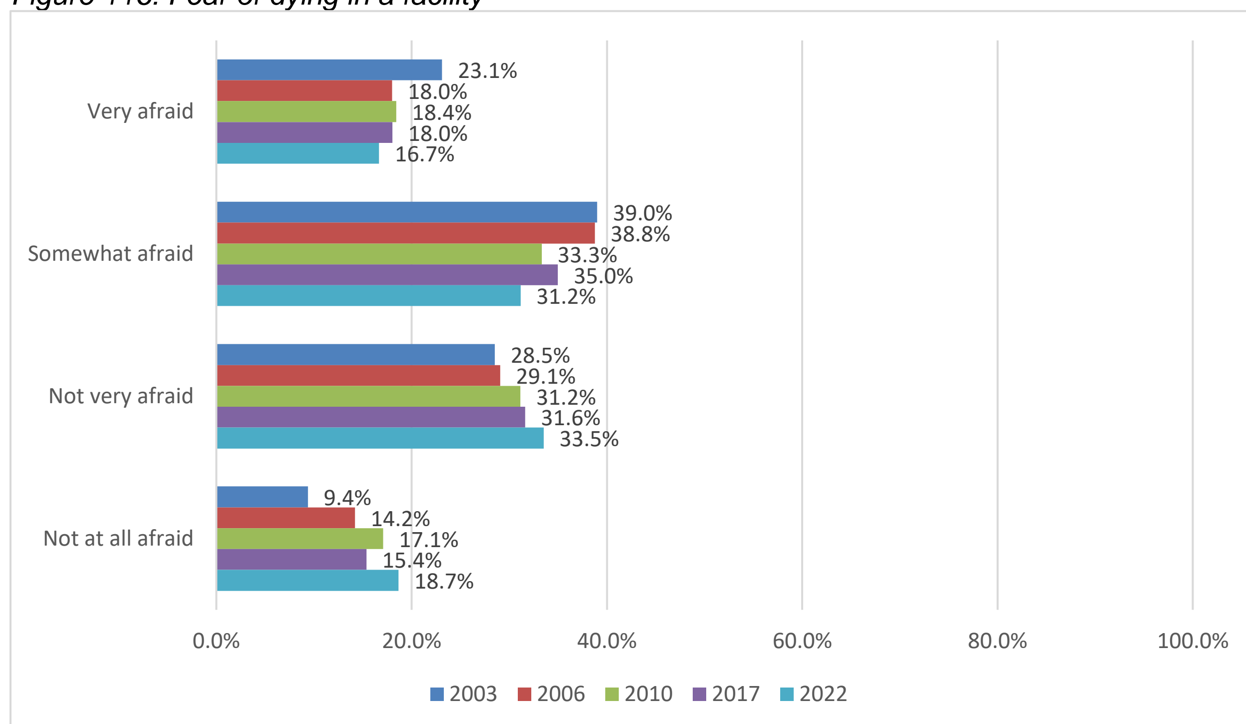
As shown in Figure 115, participants were less likely to report feeling very afraid of dying alone in 2022 (16.5%) than in 2017 (17.5%). Similarly, less respondents reported feeling somewhat afraid in 2022 (28.2%) than in 2017 (32.9%). Respondents who reported feeling not very afraid or not at all afraid was at its highest in 2022 (55.3% combined).

*Figure 115: Fear of dying alone**



When asked to report their level of fear concerning dying in a facility such as a nursing home or hospital, 2022 respondents reported feeling not at all afraid (18.7%) and not very afraid (33.5%) at higher rates than in prior years (Figure 116).

*Figure 116: Fear of dying in a facility**



As shown in Figure 117, 2022 participants reported feeling very afraid of dying painfully at a lower rate (29.5%) than in prior years. Additionally, 2022 respondents were more likely to report feeling not very afraid (20.3%) than in years prior.

Figure 117: Fear of dying painfully

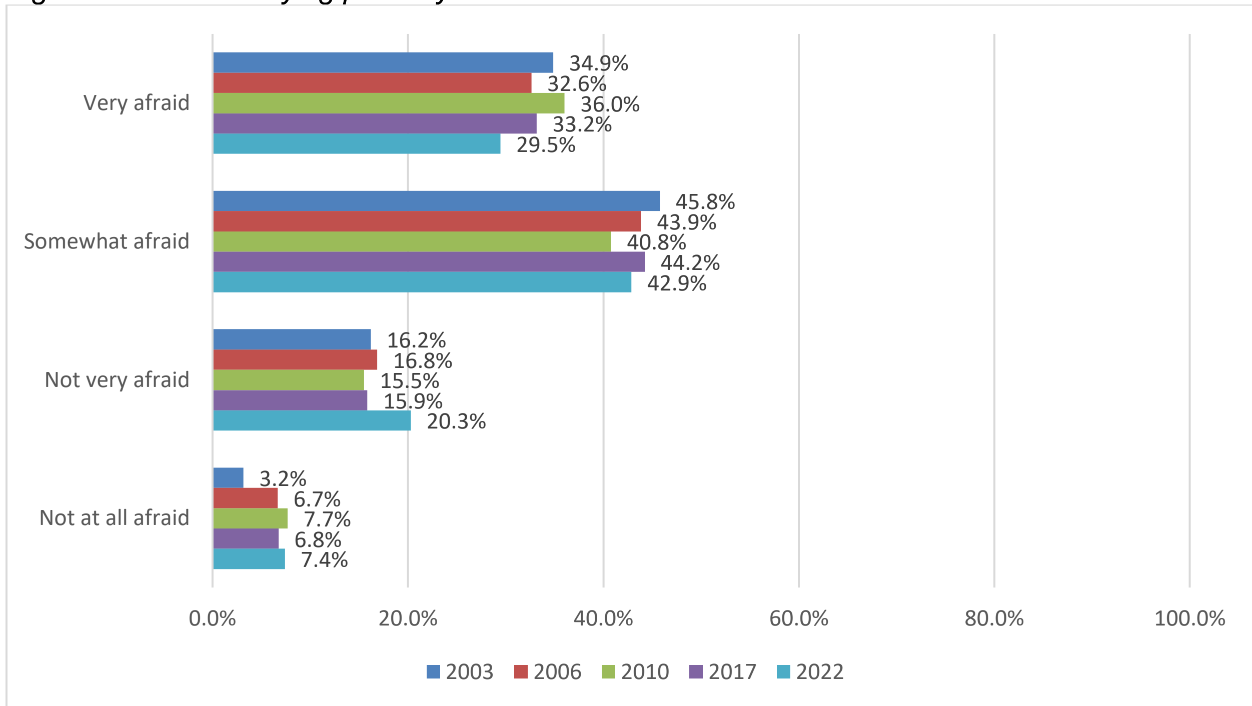


Figure 118 displays participants reported level of agreement with the statement "There is a special value in getting old." As with previous years, 2022 participants overwhelmingly strongly agree or somewhat agree with the statement (86.1% combined). Similarly, 91.4% combined of 2022 participants either strongly agree or somewhat agree that dying is an important part of life (Figure 119).

Figure 118: There is a special value in getting old

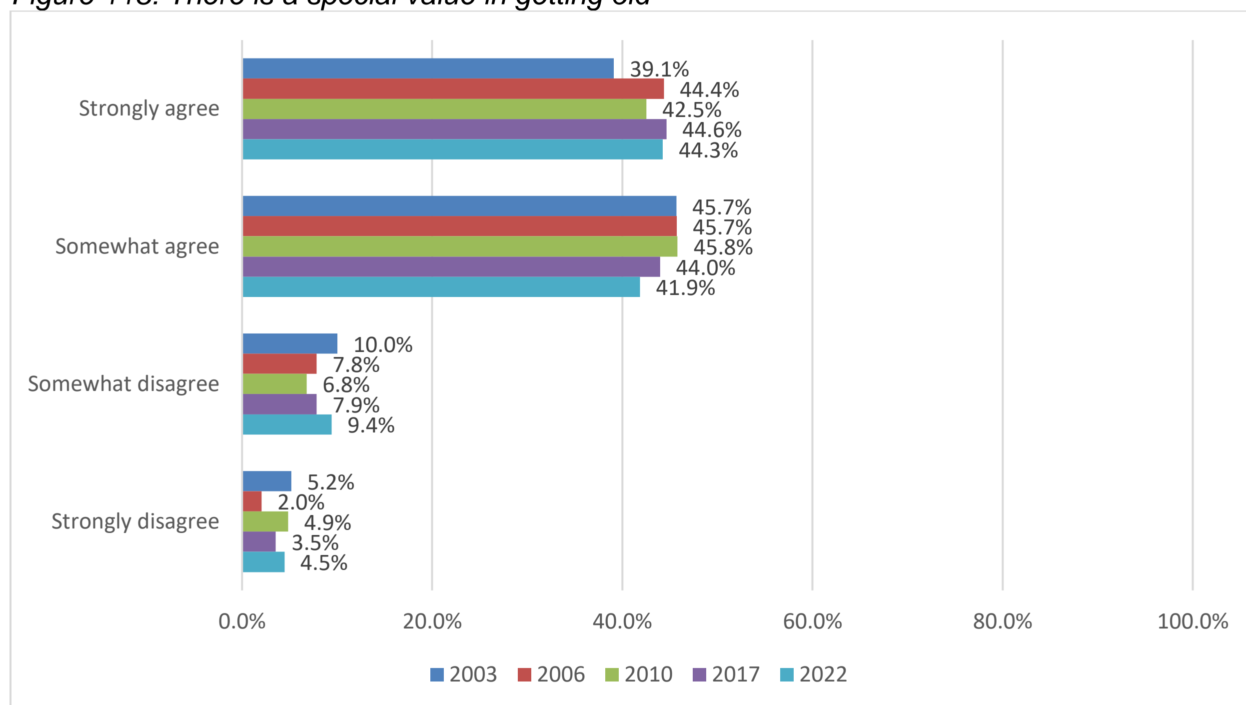
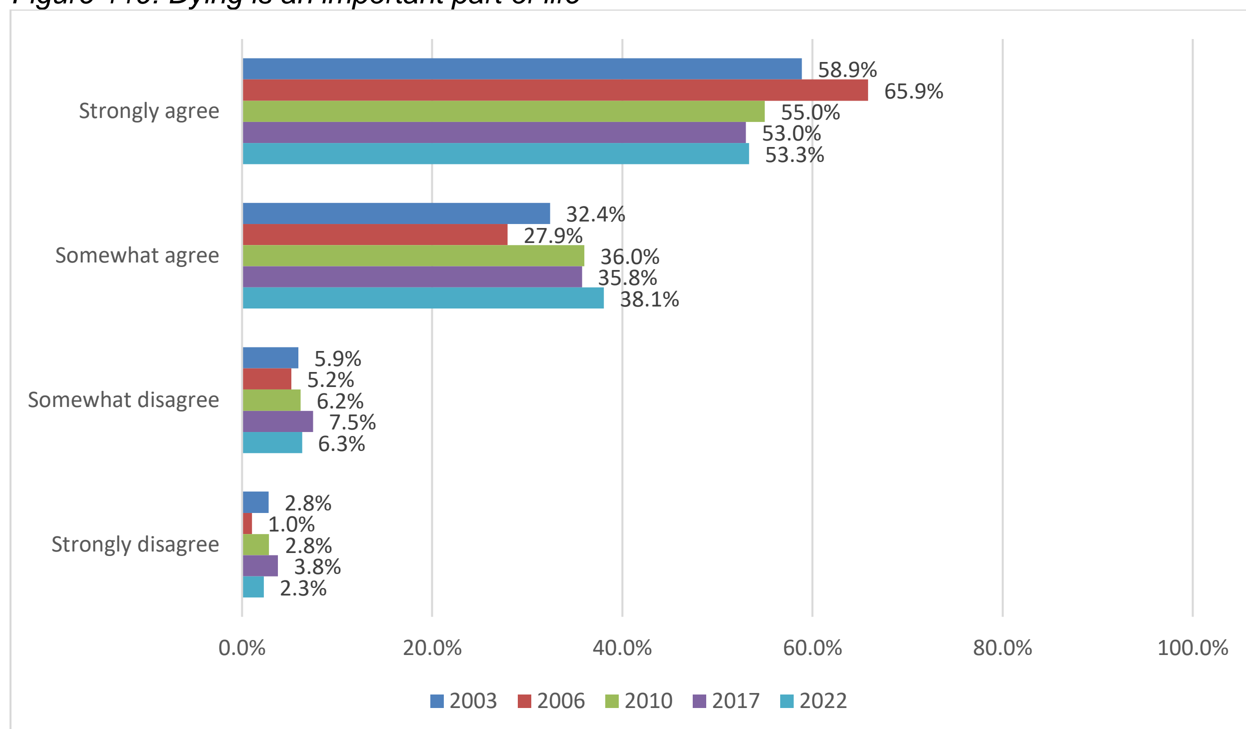


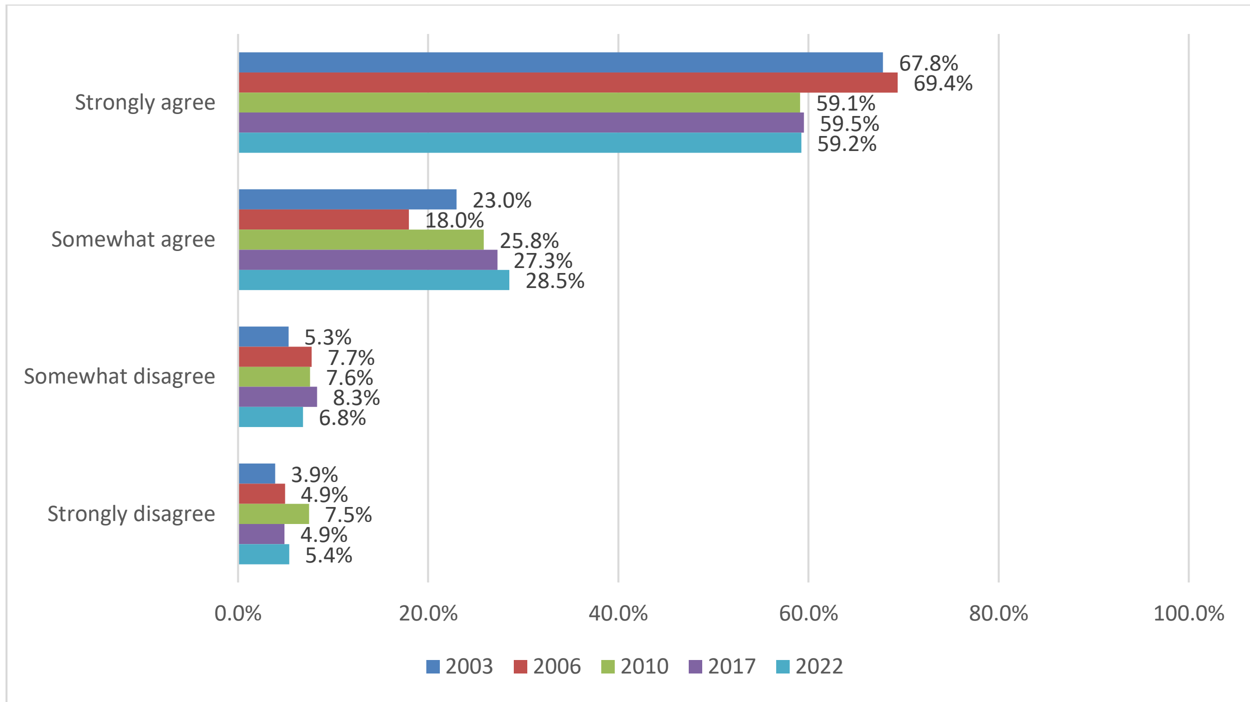
*Figure 119: Dying is an important part of life**



As shown in Figure 120, 2022 respondents were most likely to strongly agree (59.2%) with the statement, "If someone could tell me that I likely have six months or less to live, I would want to

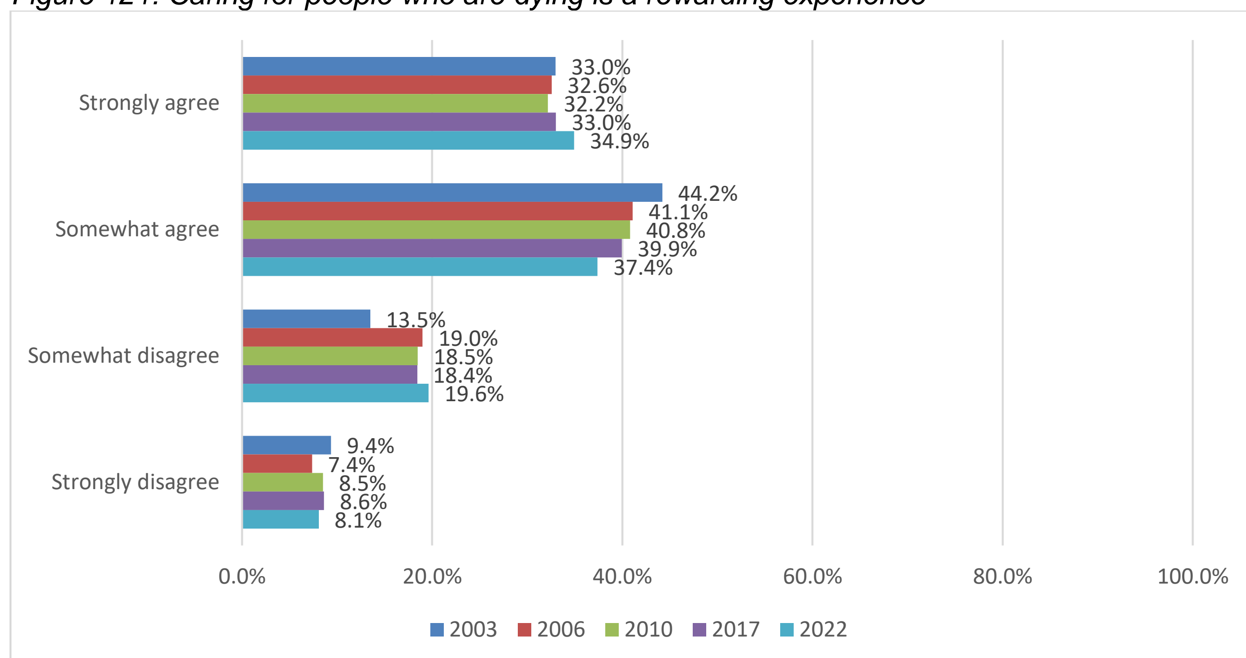
know.” Followed by somewhat agree, (28.5%), somewhat disagree (6.8%), and strongly disagree (5.4%).

*Figure 120. If someone could tell me that I likely have six months or less to live, I would want to know***



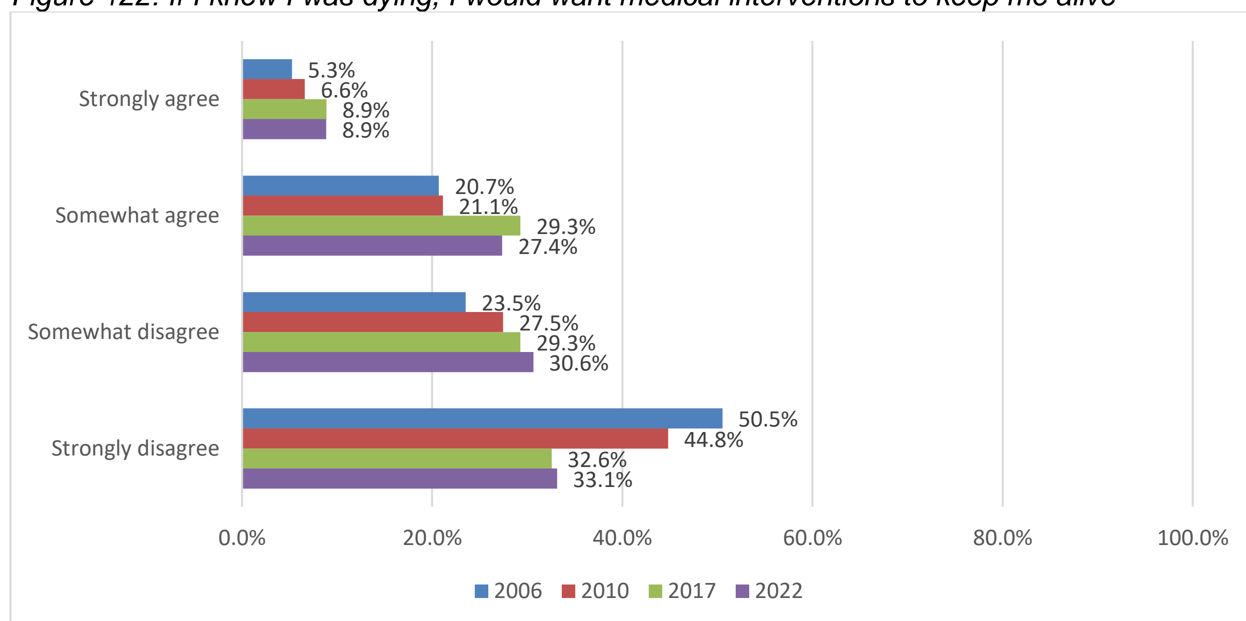
Little variation occurred throughout the years in how respondents rated the agreeableness to the statement, “Caring for people who are dying is a rewarding experience.” As with past years, more 2022 respondents reported somewhat agree (37.4%) than strongly agree (34.9%), somewhat disagree (19.6%), and strongly disagree (8.1%) (Figure 121).

Figure 121: Caring for people who are dying is a rewarding experience



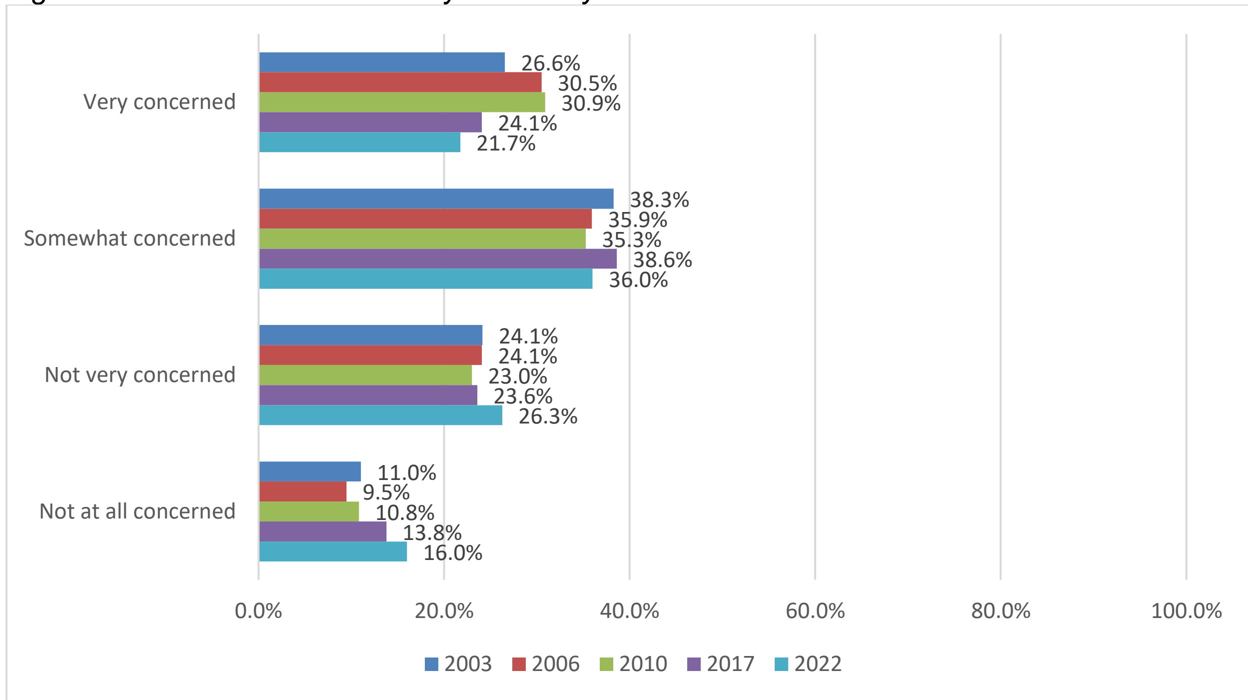
When asked to rate their agreeableness to the statement, "If I knew I was dying, I would want medical interventions to keep me alive as long as possible," 2022 respondents were more likely to report somewhat disagree or strongly disagree (63.8% combined) than to report strongly agree or somewhat agree (36.2% combined). Additionally, there is a large difference between those who reported strongly disagree in 2006 (50.5%) and 2022 (33.1%) (Figure 122).

*Figure 122: If I knew I was dying, I would want medical interventions to keep me alive****



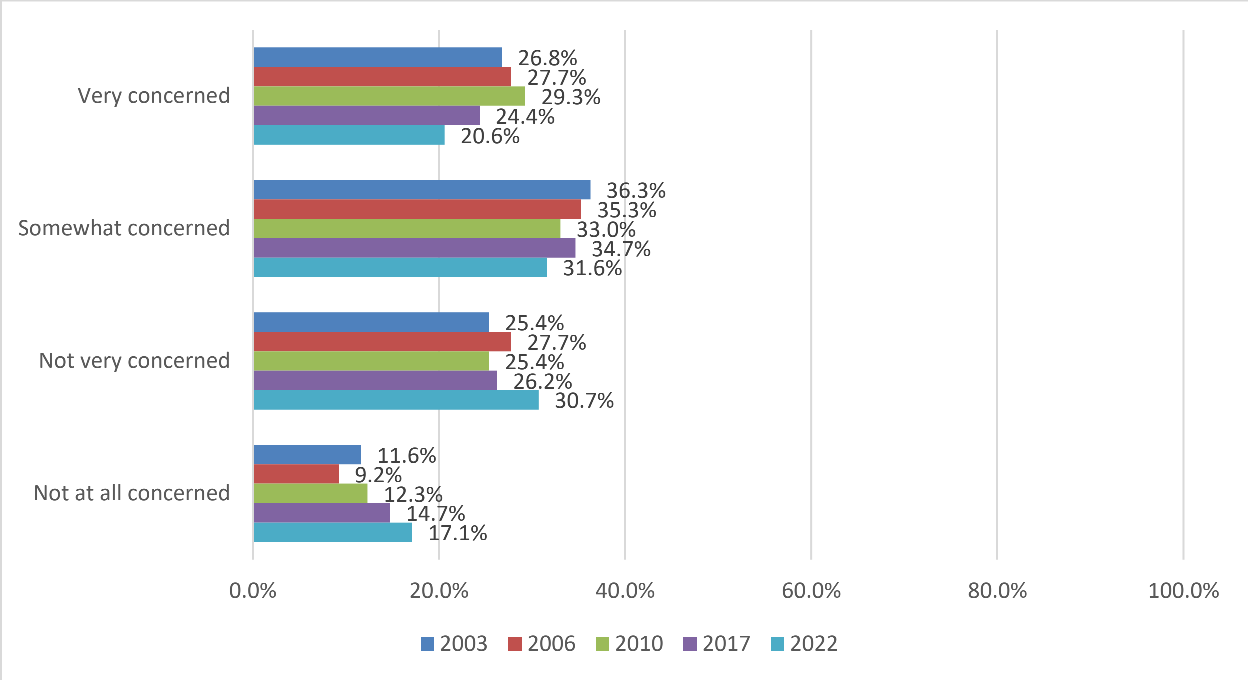
When thinking about death and dying, 2022 participants were more likely to report not at all concerned that your (or your spouse/partner's) money won't last (16.0%) and not very concerned (26.3%) than they had in prior years (Figure 123).

*Figure 123: Level of concern that your money won't last***



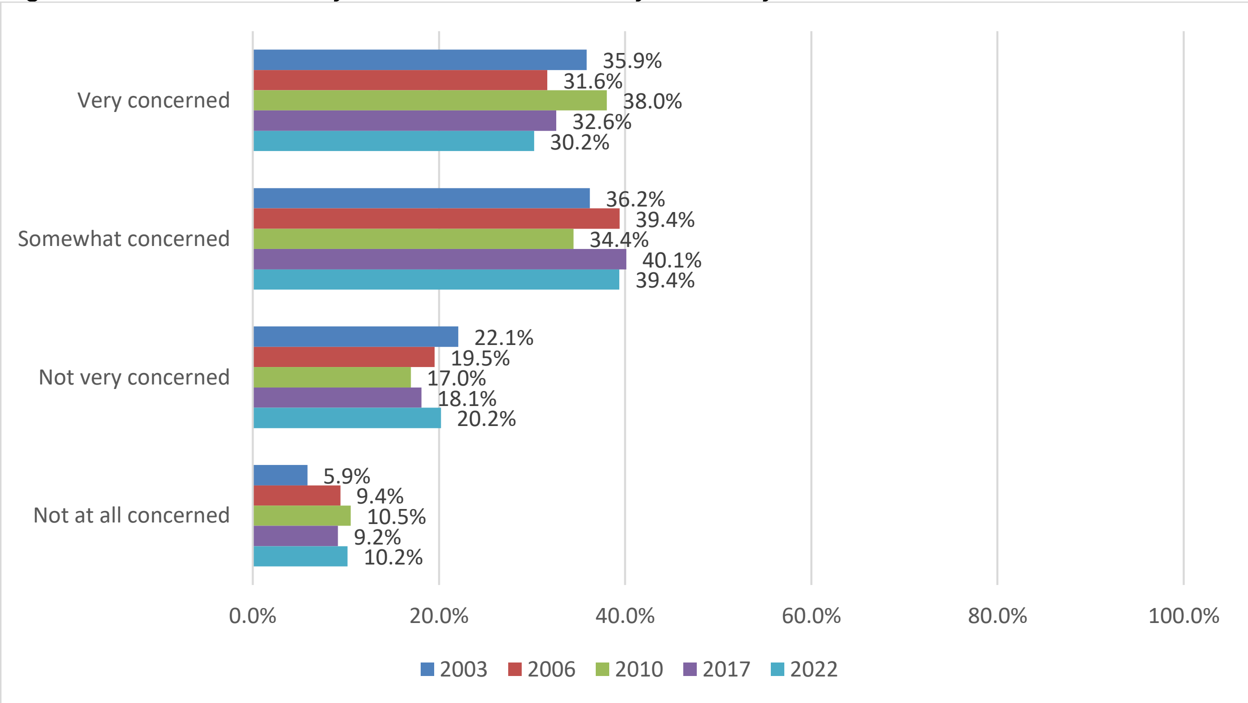
As shown in Figure 124, 2022 participants were more likely to report somewhat concerned (31.6%) when asked to report their level of concern that their family's money won't last. Somewhat concerned has consistently been the most reported level of concern regarding this issue.

*Figure 124: Concern that your family's money won't last***



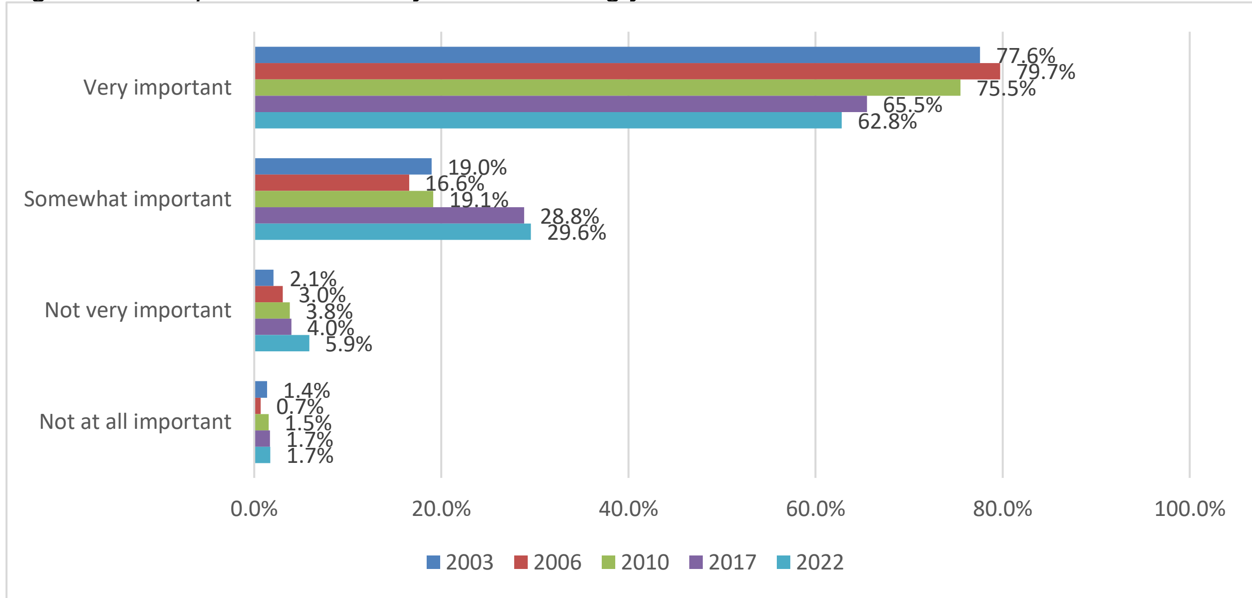
Similarly, as shown in Figure 125, 2022 participants were most likely (39.4%) to report being somewhat concerned that they will be a burden to their family and friends. Somewhat concerned has been the most reported level of concern regarding this issue in every year except 2010 (34.4%), when more respondents reported very concerned (38.0%).

*Figure 125: Concern that you will be a burden to your family and friends**



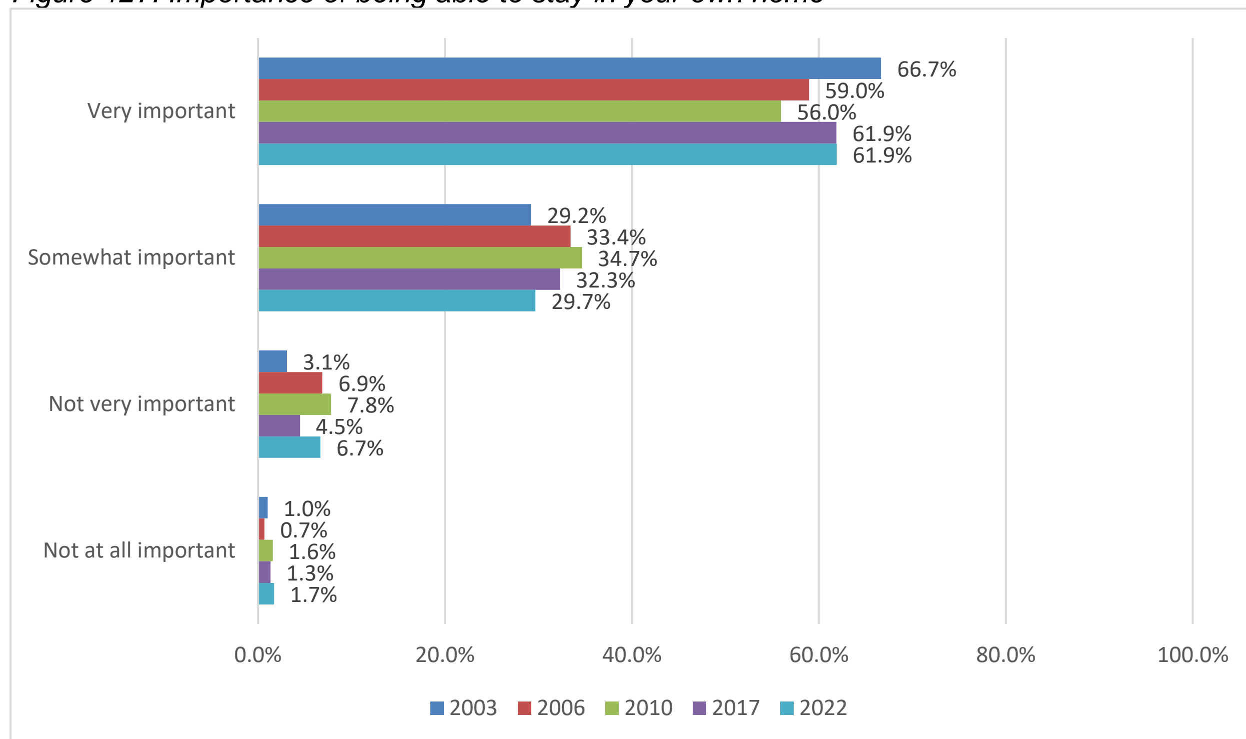
The percentage of those who reported that having friends/family visit them is somewhat important increased significantly from 2010 (19.1%) to 2017 (28.8%) and remained consistent in 2022 (29.6%) (Figure 126). During the same years, those who reported very important decreased from 2010 (75.5%) to 2017 (65.5%) and 2022 (62.8%).

*Figure 126: Importance of family/friends visiting you****



As with previous years, the majority of 2022 respondents reported being able to stay in your home as very important (61.9%). However, very important was at its highest in 2003 (66.7%) (Figure 127).

*Figure 127: Importance of being able to stay in your own home**



As shown in Figure 128, 2022 respondents were more likely to report comfort from religious/spiritual services as not very important (13.1%) or not at all important (9.3%) than previous years, which is significantly higher than in 2003 (10.6% combined).

*Figure 128: Importance of comfort from religious/spiritual services or persons****

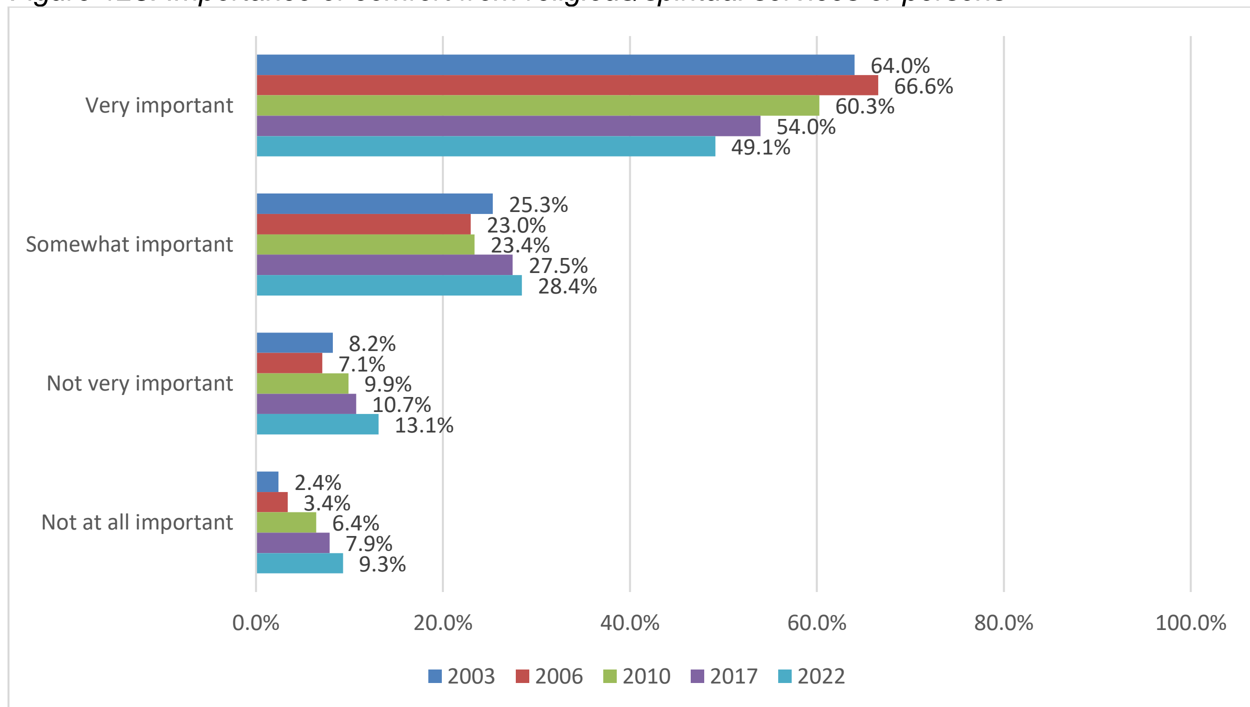
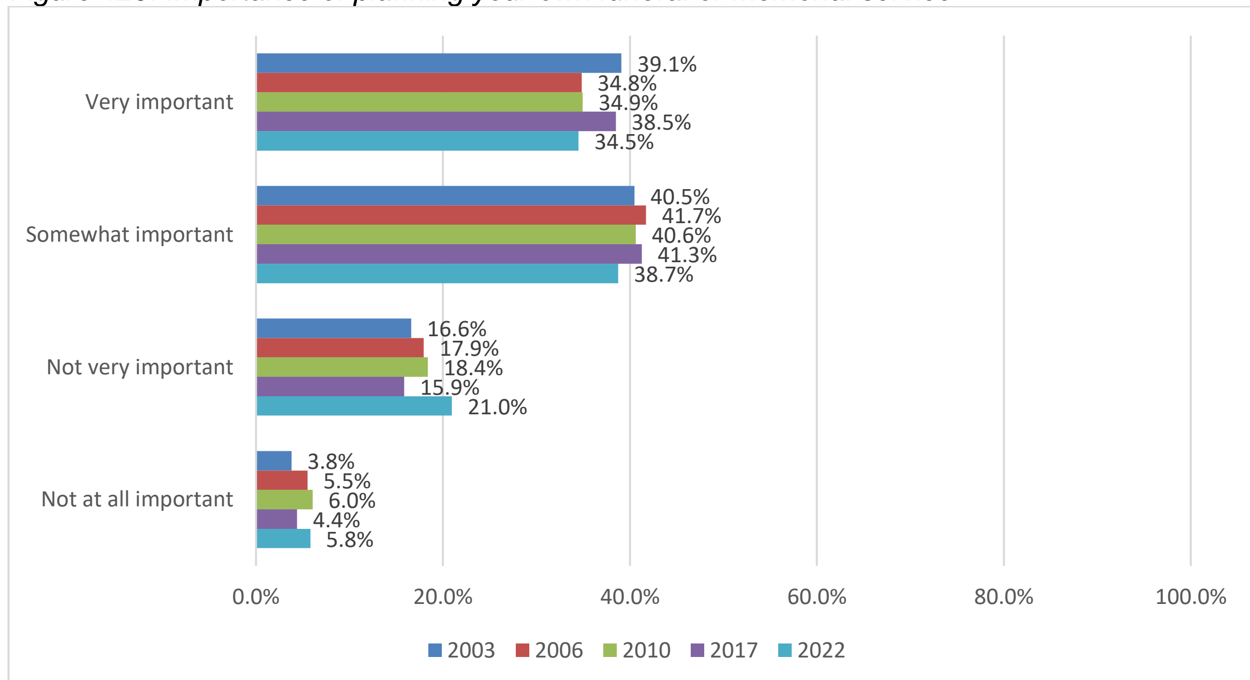


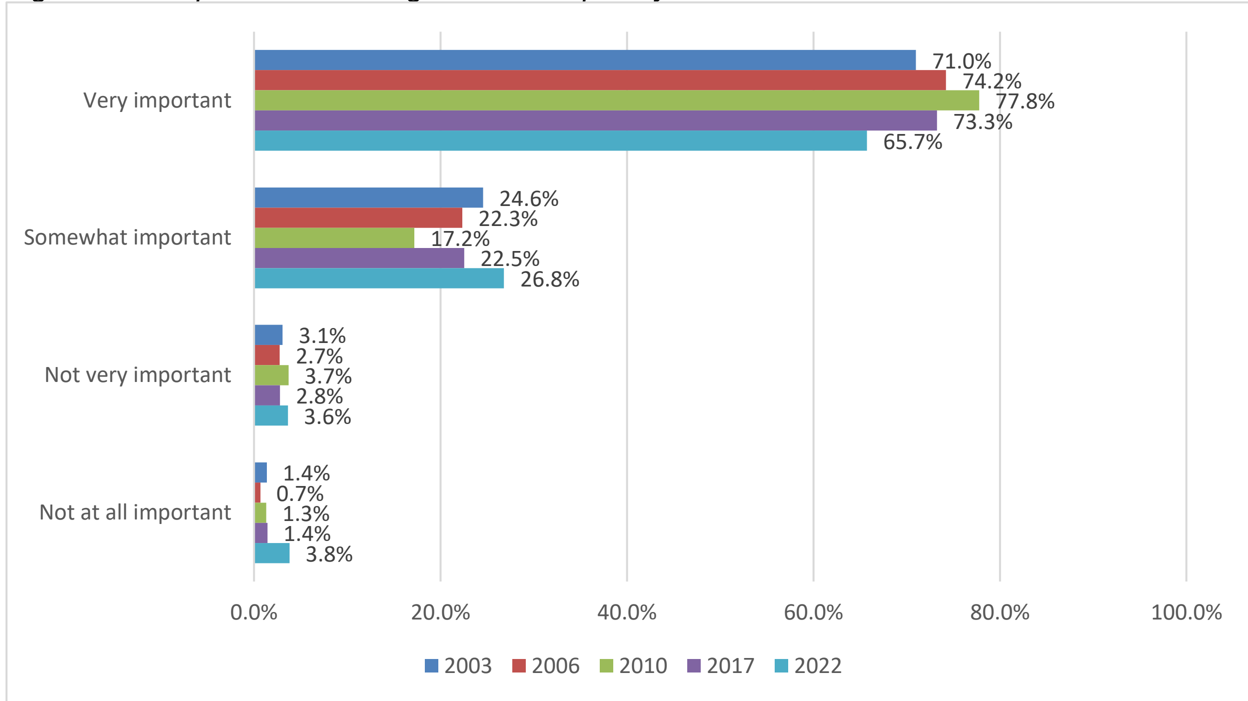
Figure 129 shows that, as with previous years, 2022 participants were most likely to report the level of importance in planning your own funeral or memorial service as somewhat important (38.7%), followed by very important (34.5%), not very important (21.0%), and not at all important (5.8%).

Figure 129: Importance of planning your own funeral or memorial service



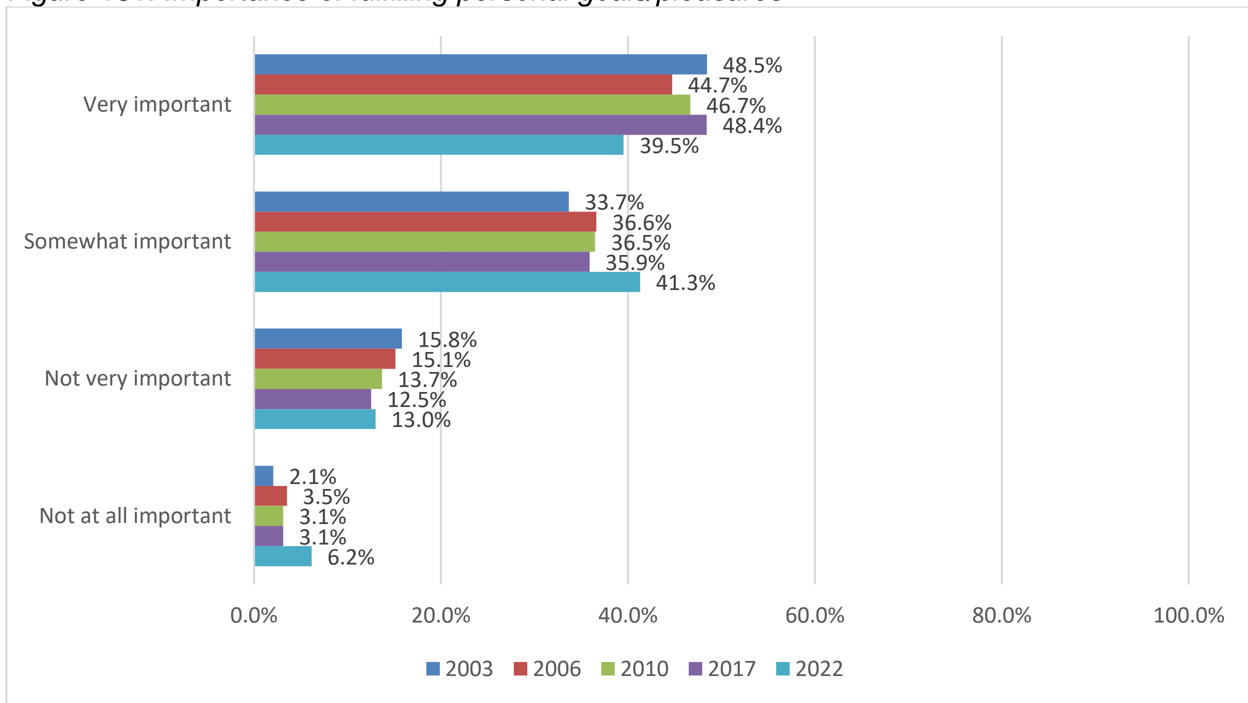
As with previous years, 2022 respondents were most likely to report the level of importance of being able to complete your will as very important (65.7%), followed by somewhat important (26.8%). However, not at all important (3.8%) outranked not very important (3.6%) for the first time in 2022 (Figure 130).

*Figure 130: Importance of being able to complete your will****



2022 respondents were most likely to report the importance of fulfilling personal goals/pleasures as somewhat important (41.3%), followed by very important (39.5%), not very important (13.0%), and not at all important (6.2%) (Figure 131). In previous years, very important was the most common response.

*Figure 131: Importance of fulfilling personal goals/pleasures***



As shown in Figure 132, 2022 participants were most likely to report the importance of reviewing your life history with your family as somewhat important (40.8%). Somewhat important has been the most reported level of importance since 2006.The highest in 2003 was very important (35.7%).

Figure 132: Importance of reviewing your life history with your family

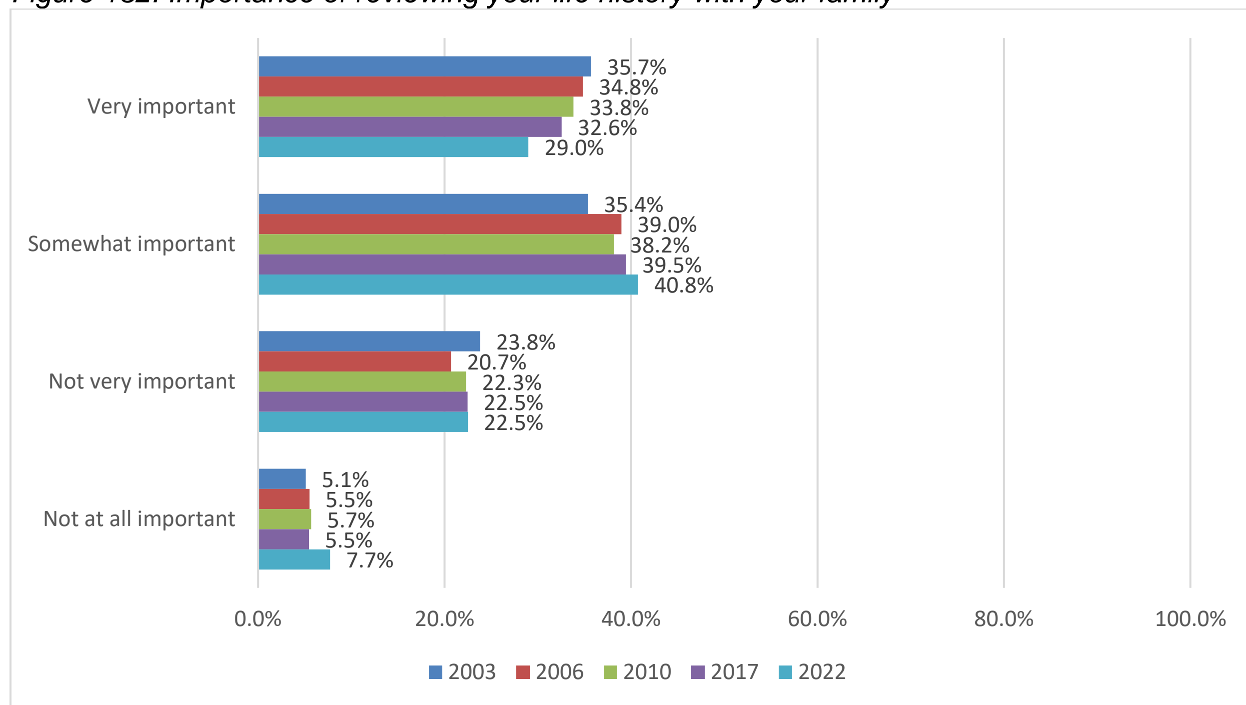
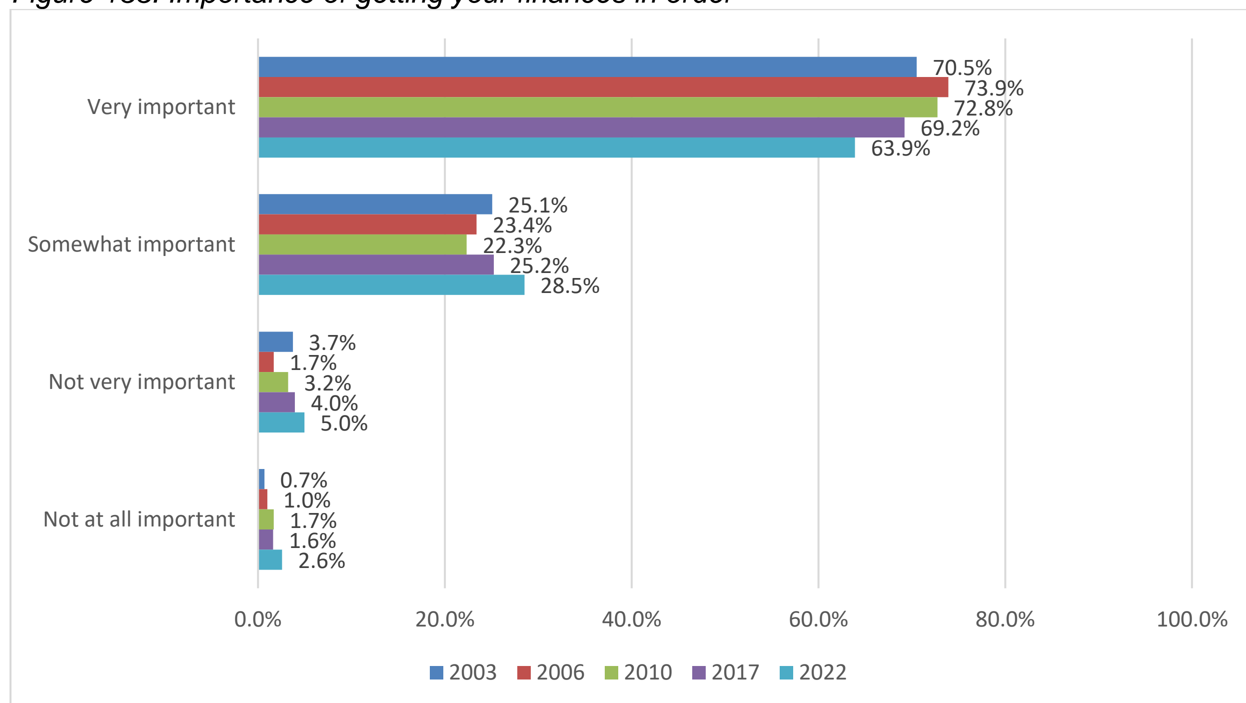


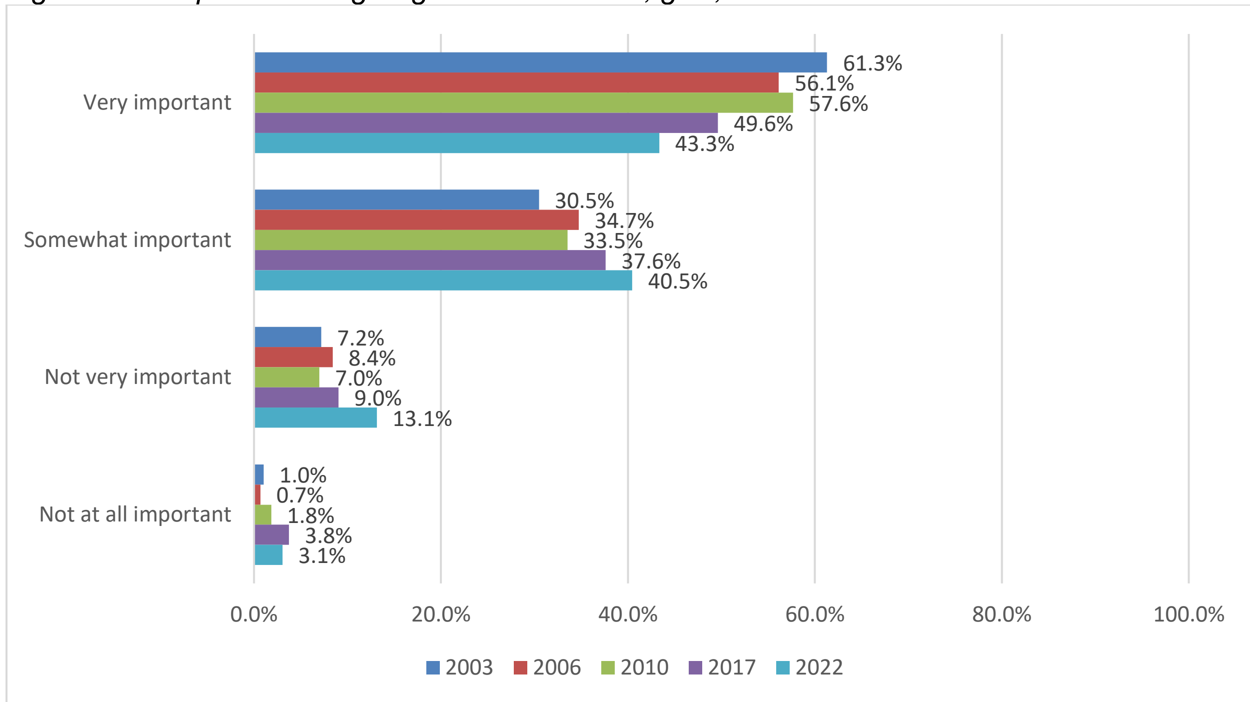
Figure 133 shows, as with past years, 2022 respondents were most likely to report getting your finances in order as very important (63.9%). However, this rate is much lower than it was at its highest in 2006 (73.9%).

*Figure 133: Importance of getting your finances in order**



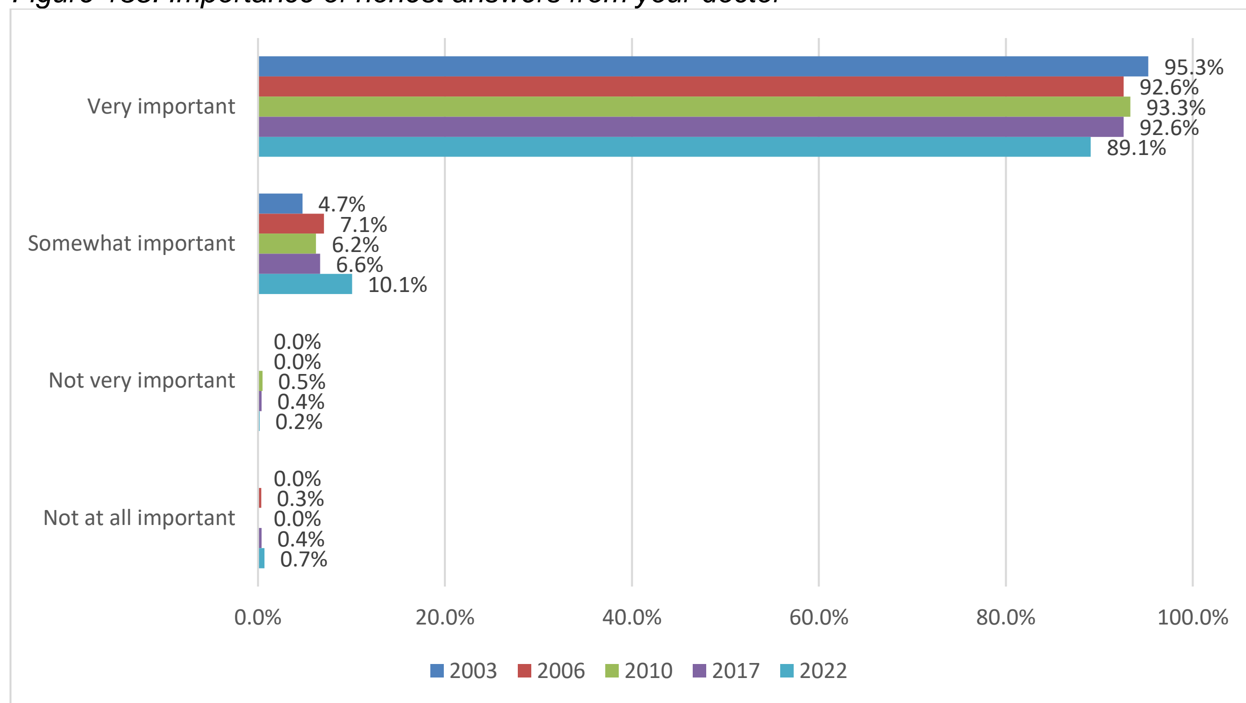
As with prior years, the overwhelming majority of 2022 participants report giving to others in time, gifts, or wisdom as very important or somewhat important (83.8% combined). However, this is much lower than it was in 2003 (91.8%) (Figure 134).

*Figure 134: Importance of giving to others in time, gifts, or wisdom****



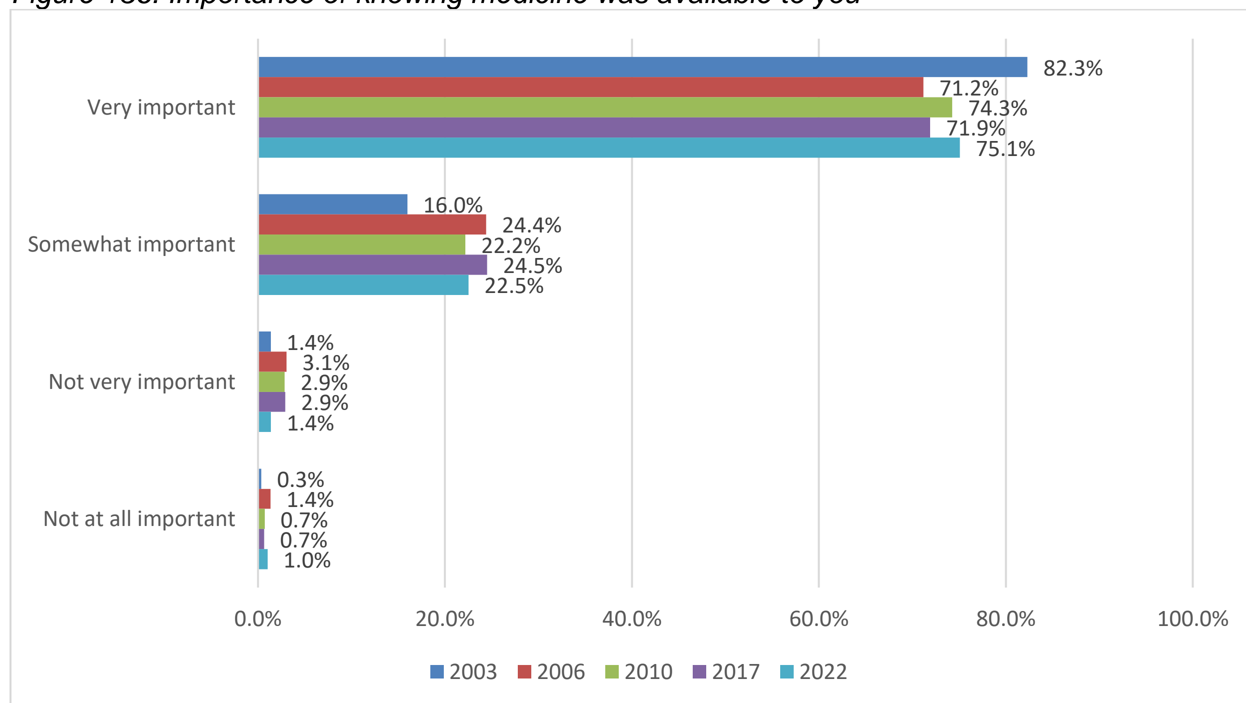
While the rate of participants who reported honest answers from your doctor as not very important or not at all important was at its highest in 2022 (0.9%), the overwhelming majority continue to report honest answers from your doctor as very important (89.1%) (Figure 135).

*Figure 135: Importance of honest answers from your doctor**



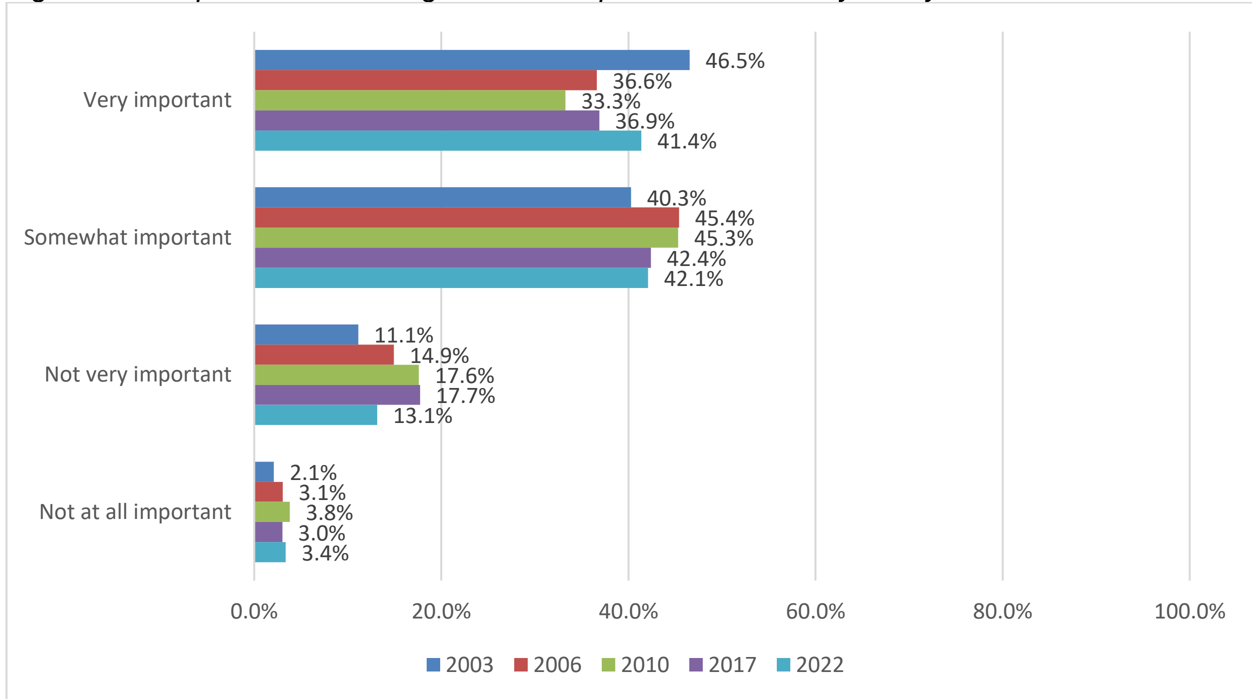
As shown in Figure 136, respondents have consistently reported the importance of knowing medicine was available to you as very important (75.1% in 2022).

Figure 136: Importance of knowing medicine was available to you



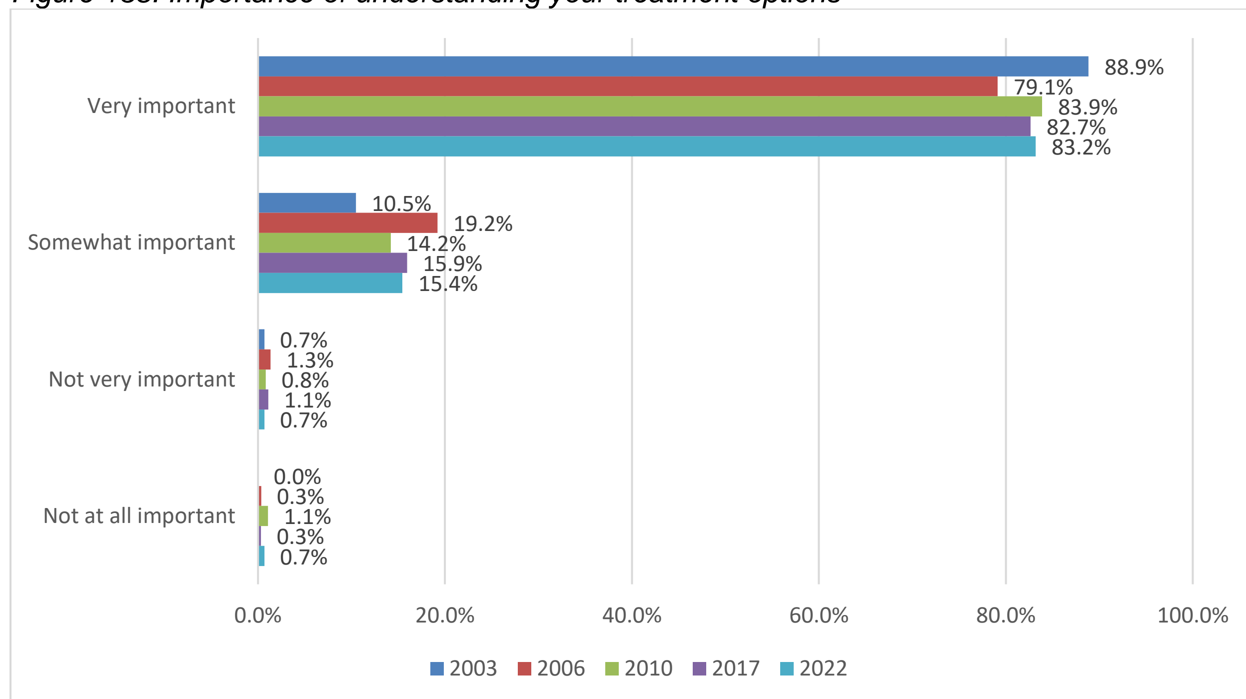
Since 2006, participants have reported having health care professionals visit you in your home as somewhat important more frequently than very important, not very important, or not at all important. In 2003, very important (46.5%) was reported at a higher rate than somewhat important (40.3%) (Figure 137).

*Figure 137: Importance of having health care professionals visit you in your home***



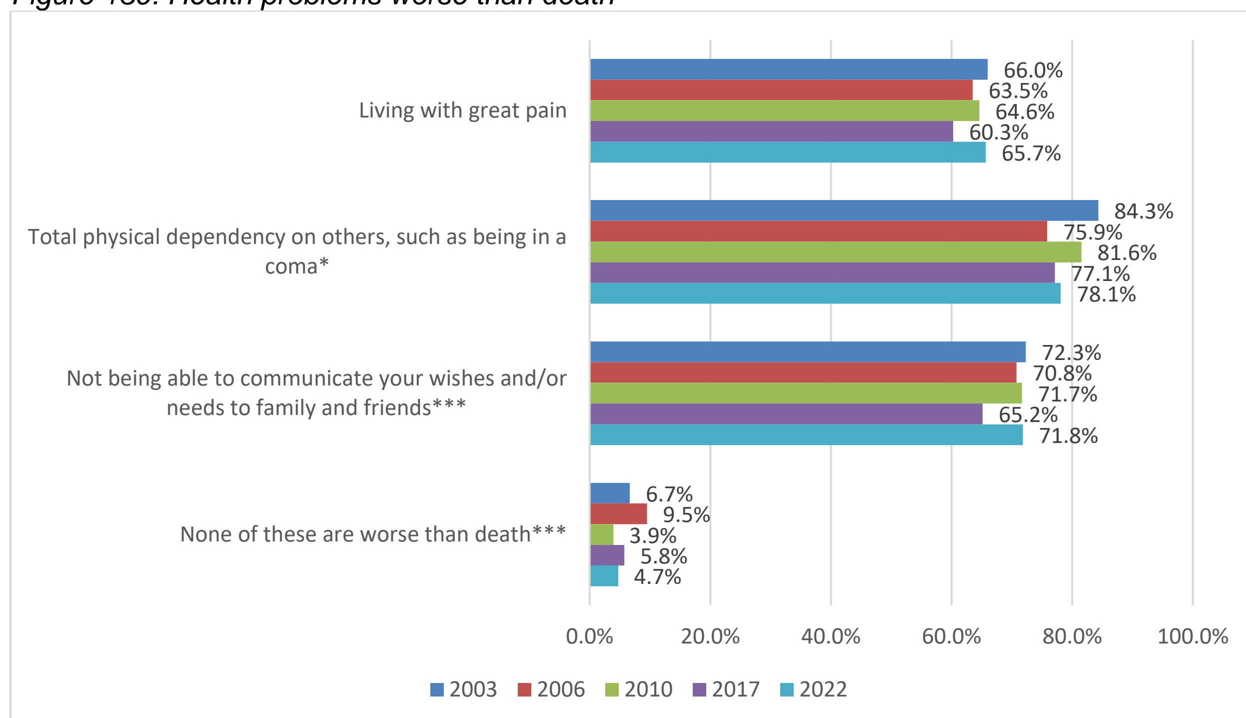
As shown in Figure 138, the overwhelming majority of participants have consistently reported understanding your treatment options as very important (83.2% in 2022). While the reported rate of very important dropped from 2003 (88.9%) to 2006 (79.1%), very important has maintained the majority.

Figure 138: Importance of understanding your treatment options



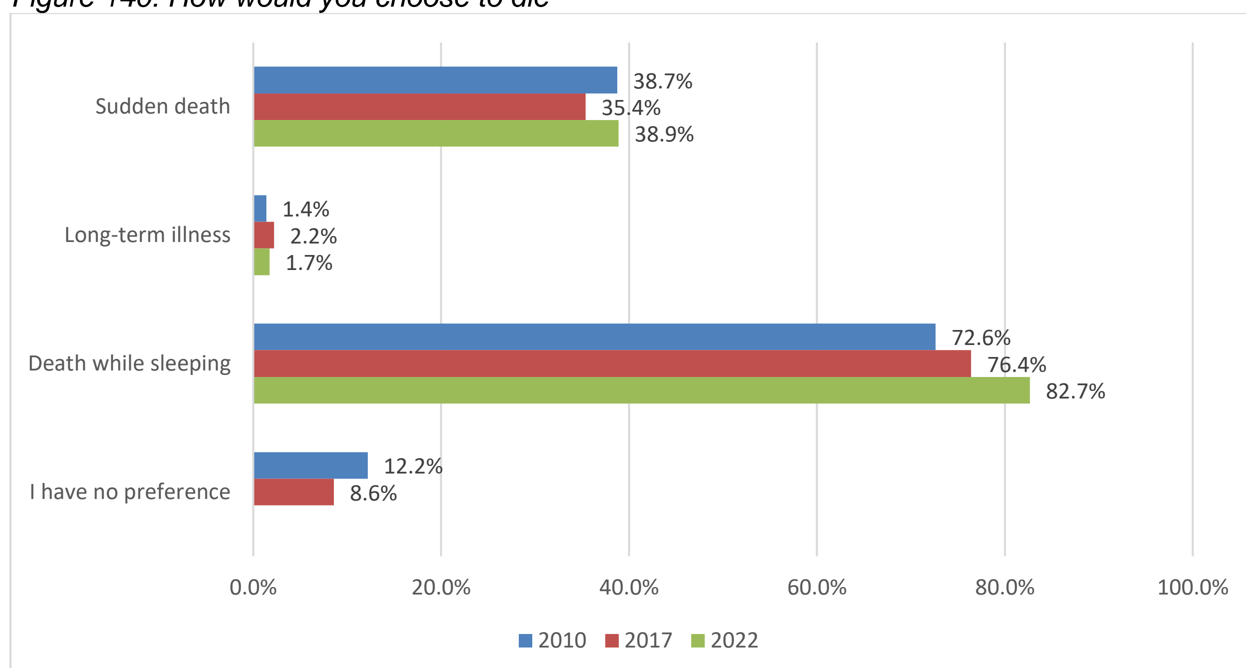
As shown in Figure 139, as with prior years, 2022 participants were more likely to report total physical dependency on others as worse than death (78.1%) than living with great pain (65.7%) or not being able to communicate your wishes and/or needs (71.8%). While not being able to communicate your wishes and/or needs has remained largely consistent, it dropped from 2010 (71.7%) to 2017 (65.2%) before rising again in 2022 (71.8%). Similarly, none of these are worth than death raised from 2003 (6.7%) to 2006 (9.5%), then came back down in 2010 (3.9%).

Figure 139: Health problems worse than death



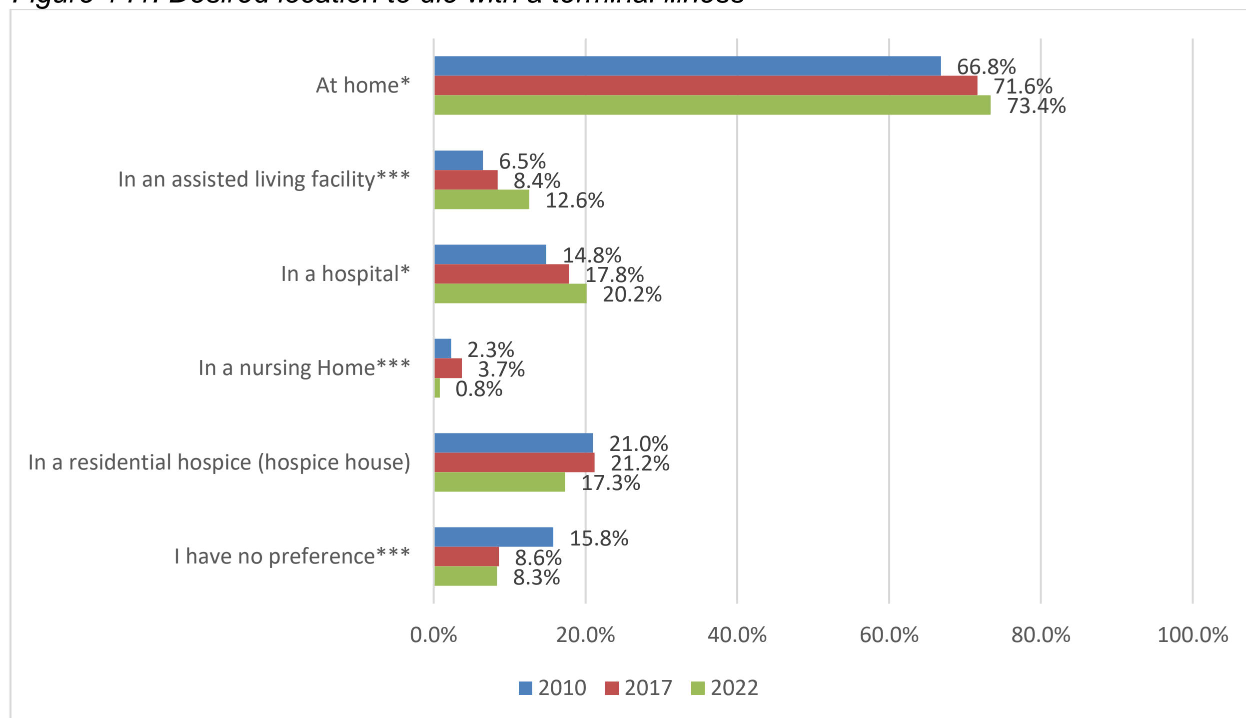
When asked how they would choose to die, 2022 respondents were most likely to report death while sleeping (82.7%). However, because the category options changed on later surveys, the data points obtained prior to the 2022 administration are no longer comparable (Figure 140).

Figure 140: How would you choose to die



When respondents were asked where they would most want to die if they were terminally ill and had the choice, at home, in an assisted living facility, and in a hospital, all rose in 2017 and 2022 (Figure 141). In a nursing home dropped from 2017 (3.7%) to 2022 (0.8%), as did in a residential hospice (21.2% in 2017, 17.3% in 2022). I have no preference dropped from 2010 (15.8%), 2017 (8.6%) and in 2022 (8.3%).

Figure 141: Desired location to die with a terminal illness



Section 7: Religion and Spirituality

As with previous years, 2022 participants were most likely to report being somewhat religious/spiritual (48.0%), followed by very religious/spiritual (32.7%), not very religious/spiritual (12.4%), and not at all religious/spiritual (6.9%). Additionally, the rate of participants who report not very religious/spiritual or not at all religious/spiritual rose significantly from 2003 (12.5%) to 2022 (19.3%) (Figure 142).

*Figure 142: Respondent level of religiosity/spirituality****

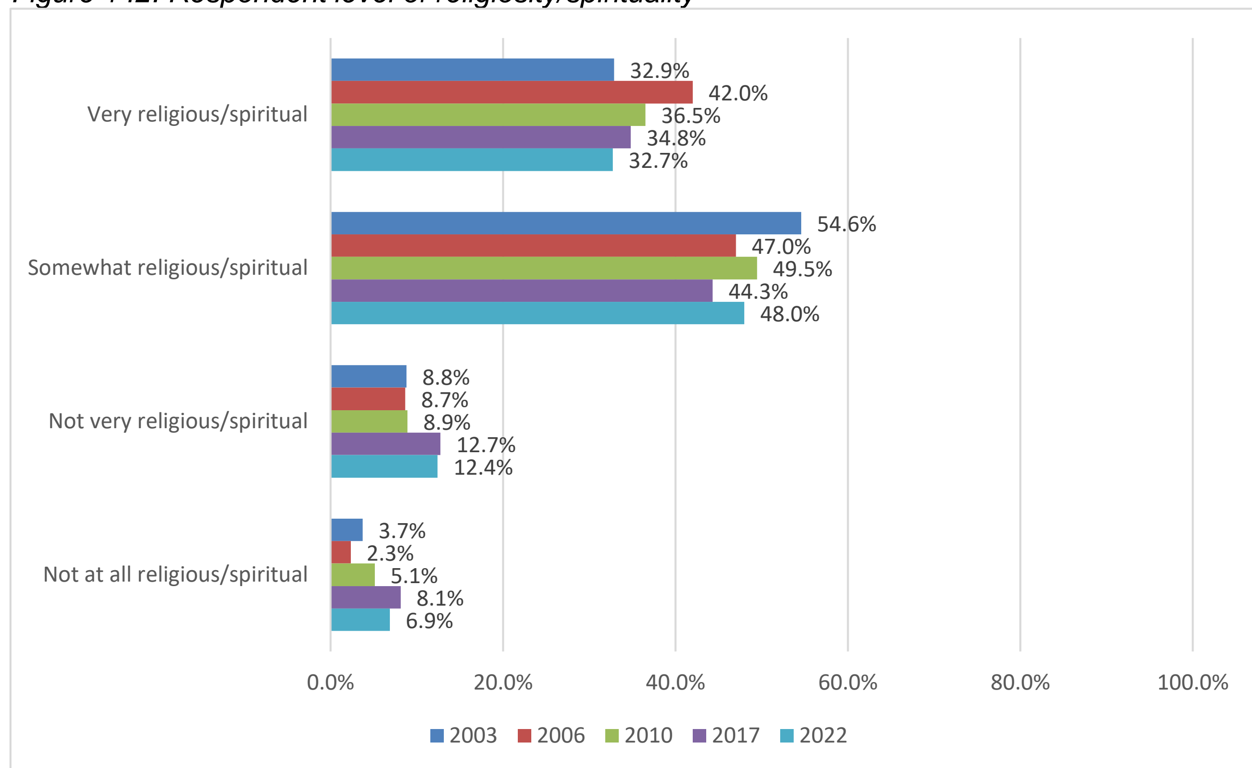
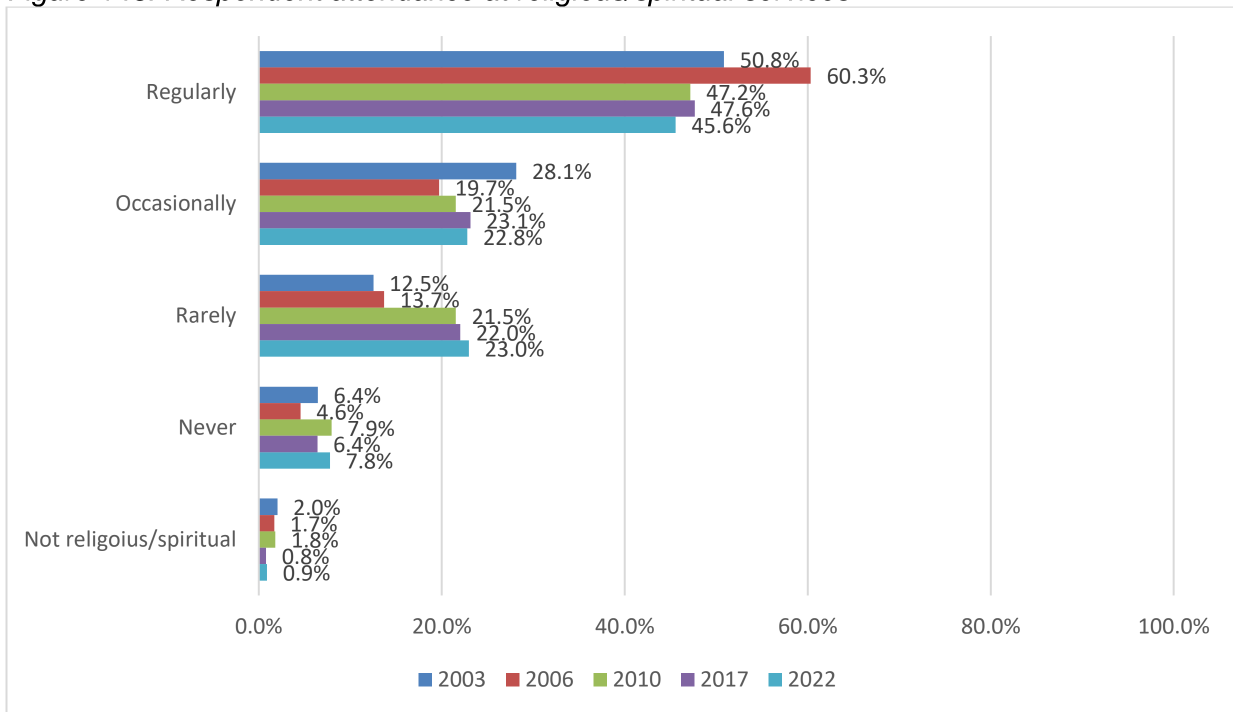


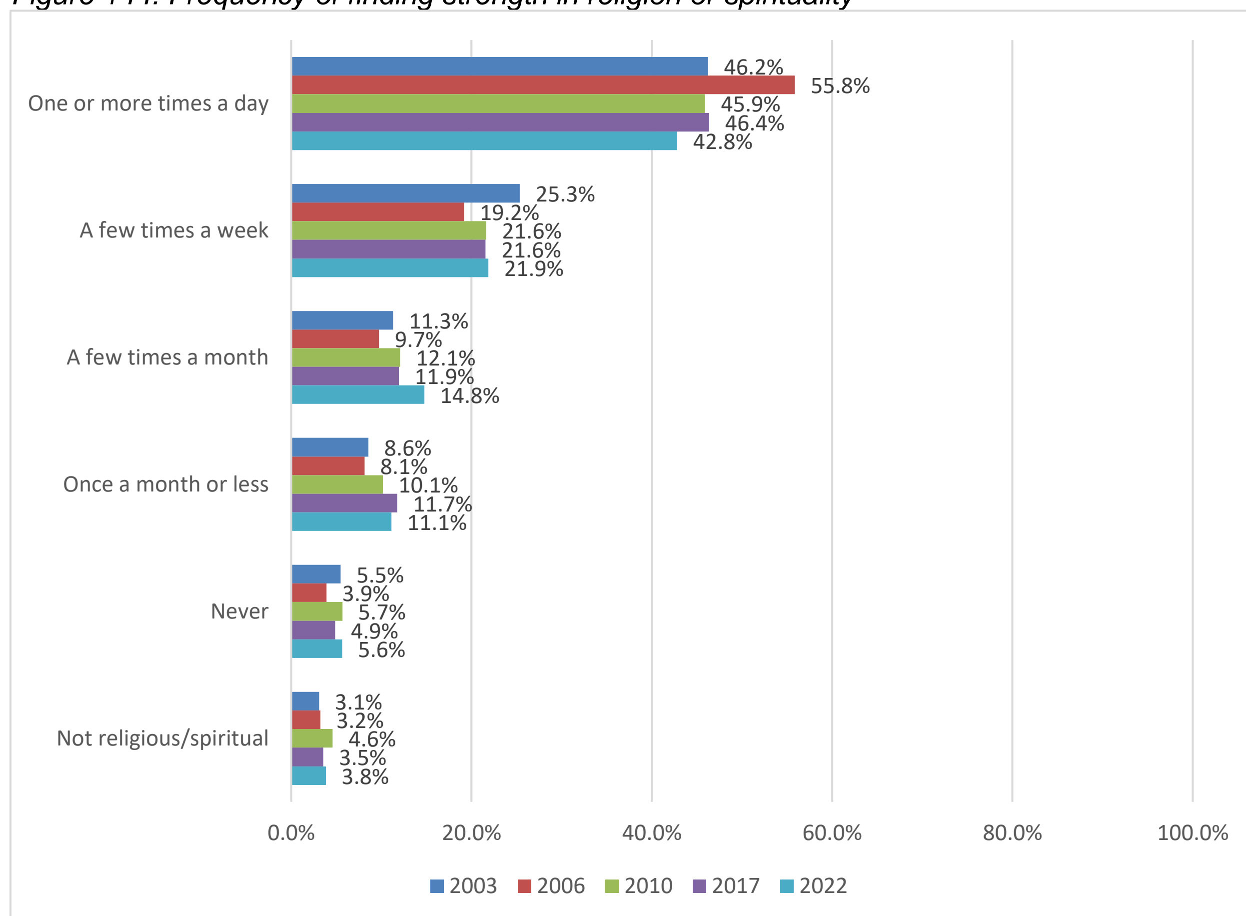
Figure 143 displays the frequency participants report attending religious or spiritual services. Regularly was at its highest in 2006 (60.3%) then dropped in 2010 (47.2%) and has remained consistent since. Occasionally was at its highest in 2003 (28.1%), and rarely has steadily increased since 2010 (21.5%).

*Figure 143: Respondent attendance at religious/spiritual services****



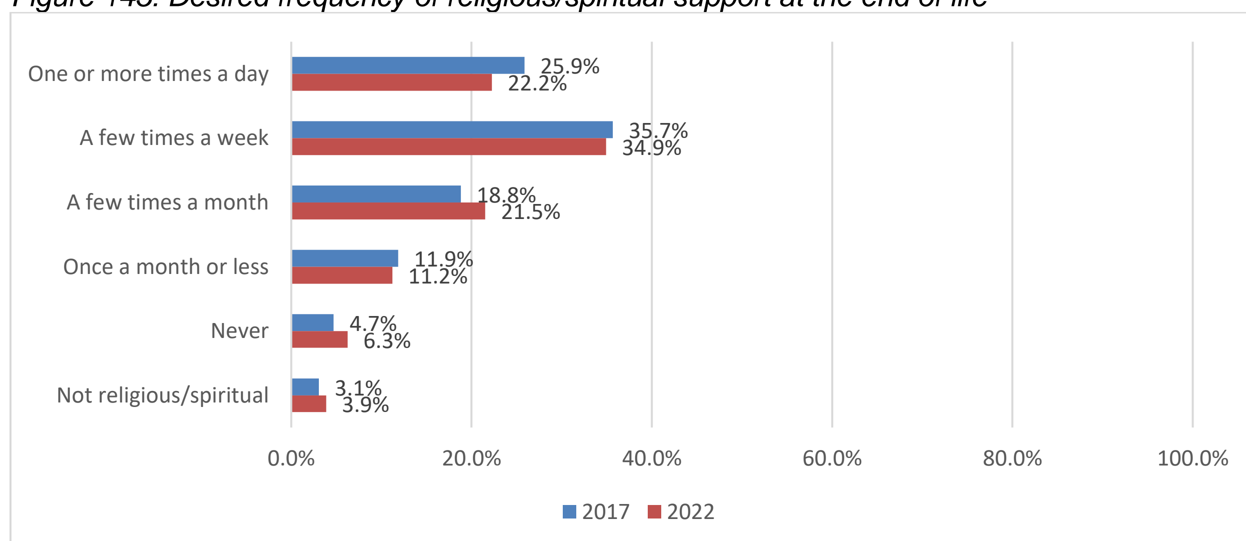
As shown in Figure 144, the frequency in which participants report finding strength in your religion or spirituality has remained consistent throughout the years.

Figure 144: Frequency of finding strength in religion or spirituality



In 2017, respondents were first asked to rate the desirability of receiving religious/spiritual support at the end of life (Figure 145). No significant changes occurred between 2017 and 2022.

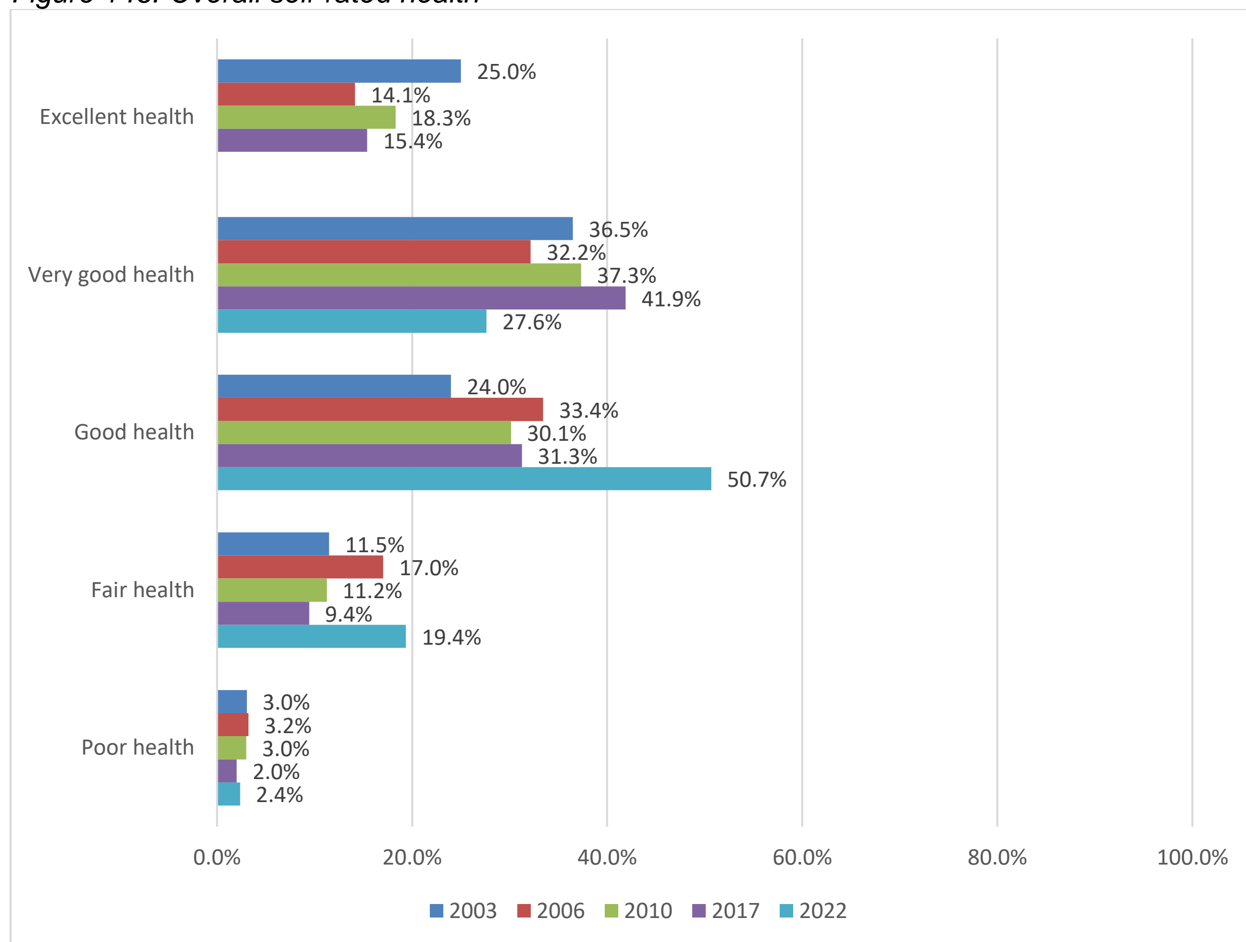
Figure 145: Desired frequency of religious/spiritual support at the end of life



Section 8: Demographic Information

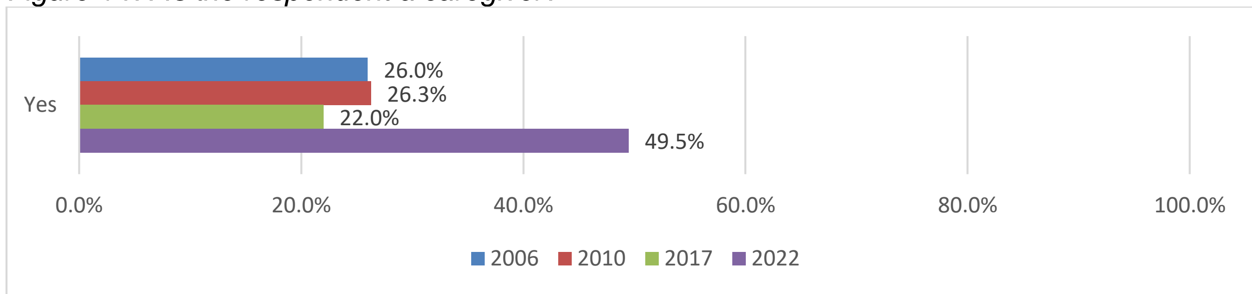
While there have been some significant changes in past years regarding respondents' self-rated level of health (Figure 146), due to category option changes on later surveys, the data points obtained prior to the 2022 administration are no longer comparable.

Figure 146: Overall self-rated health



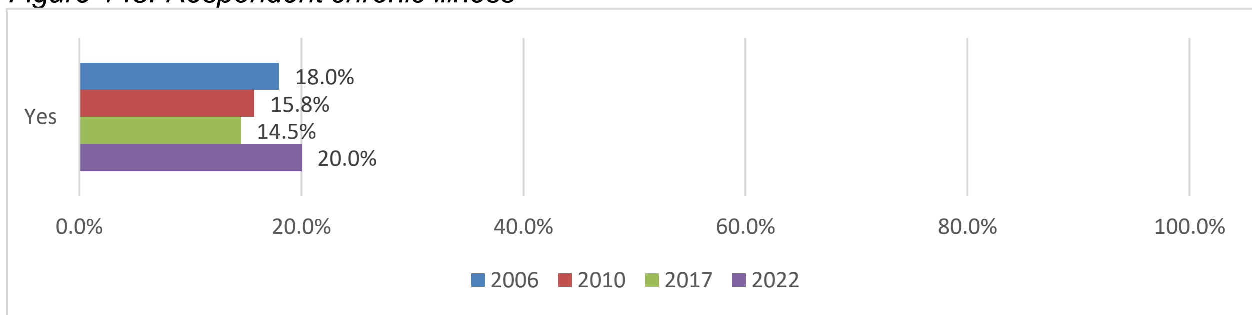
Respondents were asked if they are now or have ever been a caregiver. The rate of respondents reporting yes grew significantly from 2017 (22.0%) to 2022 (49.5%) (Figure 147). Similarly, those who responded yes to the question, "Do you have any serious chronic illnesses?" grew from 2017 (14.5%) to 2022 (20.0%) (Figure 148).

*Figure 147: Is the respondent a caregiver?****



Respondents were asked if they are now or have ever been a caregiver. The rate of respondents reporting yes grew significantly from 2017 (22.0%) to 2022 (49.5%) (Figure 142).

*Figure 148: Respondent chronic illness**



Since 2017, the NHPCA asked participants to describe their serious chronic illnesses (Figure 149). Due to the different question wording on the 2017 and 2022 administrations, the results cannot be compared to generate reliable statistics.

Figure 149: Respondent serious chronic illness

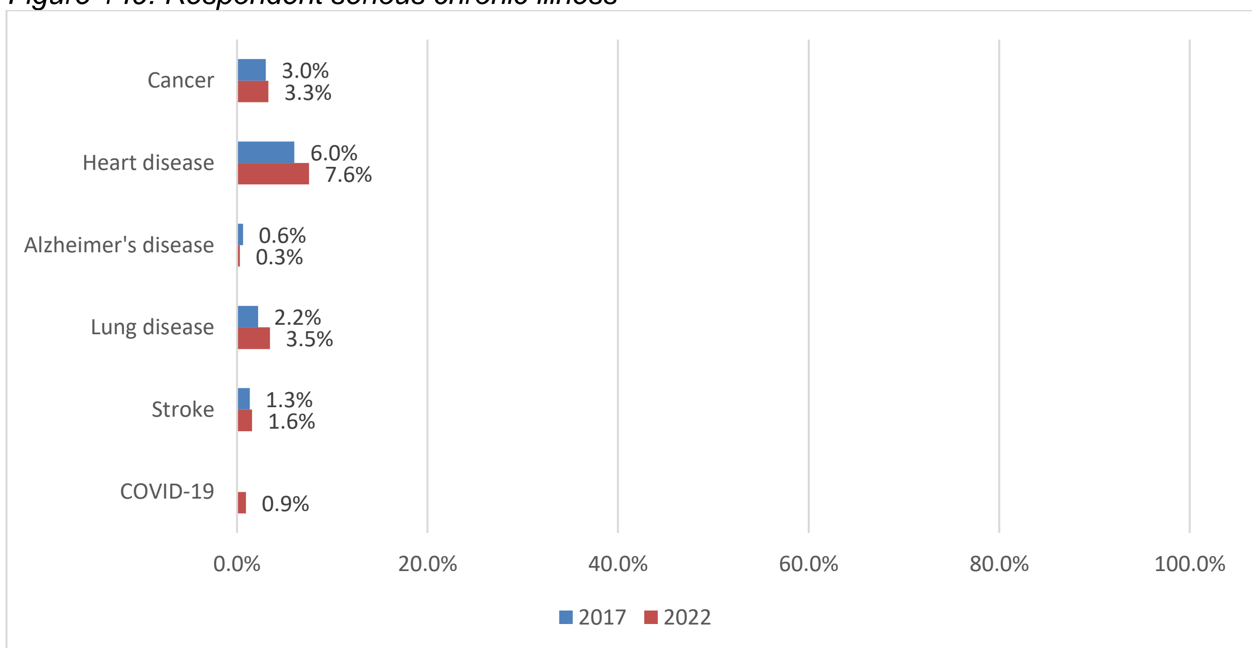
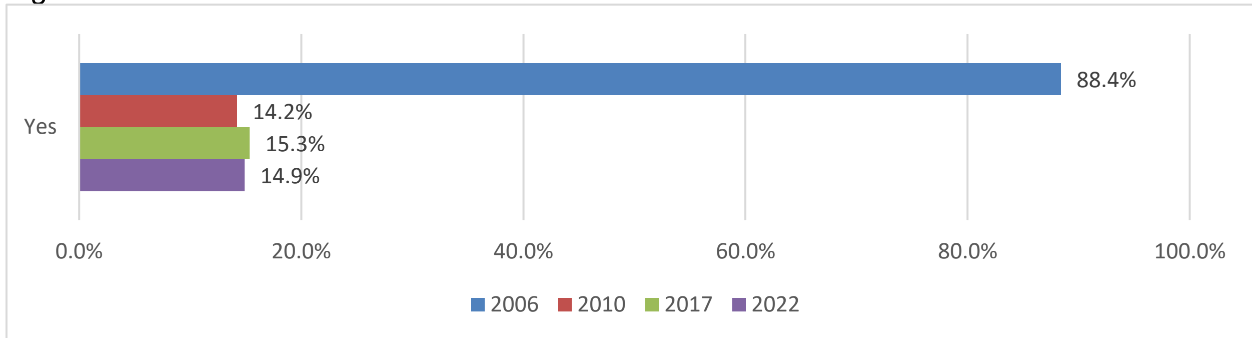


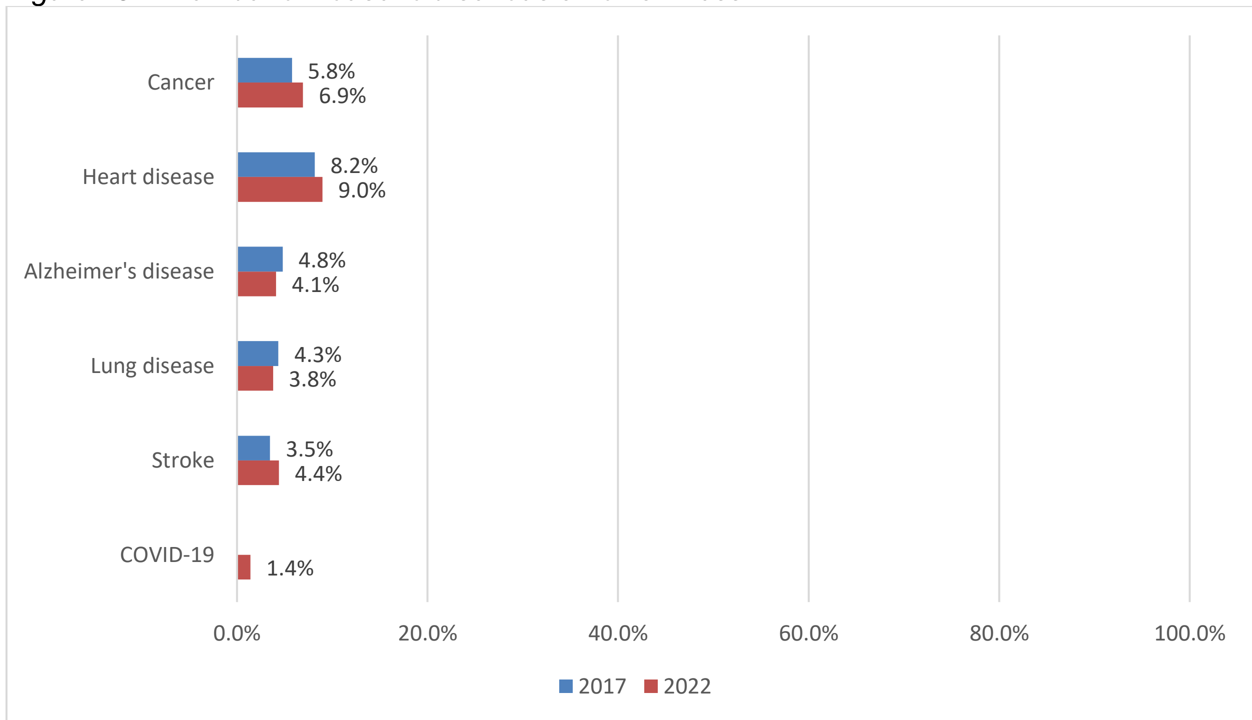
Figure 150 displays respondent reporting to the question, “Does a member of your household have any serious chronic illnesses?” The rate of respondents reporting yes dropped significantly from 2006 (88.4%) to 2010 (14.2%) and has remained steady since.

*Figure 150: Member of household chronic illness****



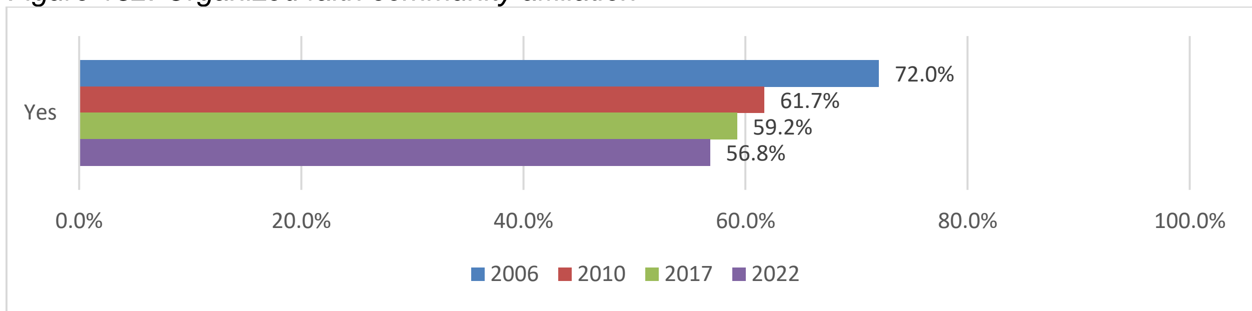
Since 2017, the NHPCA asked participants to describe the serious chronic illnesses of members in their household (Figure 151). Due to the different question wording on the 2017 and 2022 administrations, the results cannot be compared to generate reliable statistics.

Figure 151: Member of household serious chronic illness



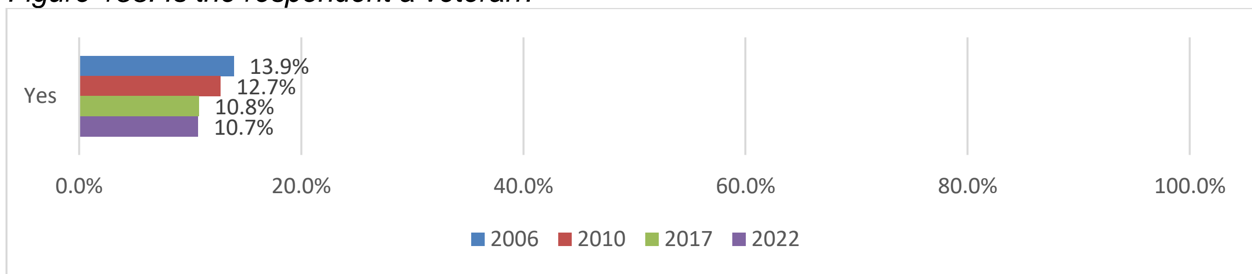
Participants were asked about their affiliation with an organized faith community (Figure 152). The highest rate of respondents who reported yes occurred in 2006 (72.0%) and has been declining since.

Figure 152: Organized faith community affiliation

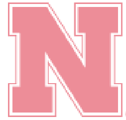


Since 2006, participants have been asked about their veteran status. While fewer 2022 respondents reported yes (10.7%) than in past years, the difference is not significant (Figure 153).

Figure 153: Is the respondent a veteran?



Appendix A: Cover Letters
First cover letter



Date

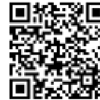
Dear [City] Resident,

We need your help with an important study. Your household has been chosen to participate in the fifth Nebraska End-of-Life Survey. The findings of this survey will help those working to improve end-of-life care and conditions across Nebraska. This study asks questions about end-of-life issues such as the kind of care you want, your wishes, and other choices you will make about the end of your life.

Your household was one of a small portion of US households randomly selected to complete this survey. To assure that we have heard from people of all types, please have the **adult age 19 or older in your household who will have the next birthday** complete and return the survey as soon as possible.

We have made the survey available online because it allows us to collect information quickly and be responsible with our research money. However, some people do not use the internet and it is important to hear from all participants, so we have also enclosed a paper copy and a postage-paid return envelope. To complete this survey online, please go to the survey link or QR code listed below and enter your unique identification number.

Survey Link: https://go.unl.edu/hospice2022
Unique Identification Number: [ID]



Some of the survey's questions may make you feel uncomfortable. End-of-life issues are not discussed often, but they are important. Participation in this study is optional, and you have the right to not answer any question you wish. You can help us by taking a few minutes to share your thoughts and/or experiences.

Enclosed you will find $1 as a small token of thanks. Once you have completed the survey, please use the postage-paid, addressed return envelope enclosed in the survey packet to return your survey to the Bureau of Sociological Research (BOSR). Your answers are completely private. Data will be given to the researchers only as summaries and no individual's answers will be identified.

Please contact us by telephone at 1-800-480-4549 or by e-mail at bosr@unl.edu with any questions you may have about this survey.

Thank you for participating in the Nebraska End-of-Life Survey.

Lindsey Witt-Swanson

Lindsey Witt-Swanson
Associate Director
Bureau of Sociological Research

Second mailing cover letter

Date

Dear [City] Resident,

A few weeks ago we sent a letter asking a member of your household to complete the Nebraska End-of-Life Survey. We are writing again because we have not yet received your household's response. We believe this survey will help those working to improve end-of-life care and conditions across Nebraska. This important study asks questions about end-of-life issues such as the kind of care you want, your wishes, and the choices you will make concerning the end of your life.

Your household's response is important to the quality of this research and will only take 15-20 minutes. To represent Nebraska, it is important to hear from everyone who receives a survey. Please have the **adult age 19 or older in your household who will have the next birthday** complete and return the survey as soon as possible.

We have made the survey available online because it allows us to collect information quickly and be responsible with our research money. However, some people do not use the internet and it is important to hear from all participants, so we have also enclosed a paper copy and a postage-paid return envelope. To complete this survey online, please go to the survey link or QR code listed below and enter your unique identification number.

Survey Link: https://go.unl.edu/hospice2022
Unique Identification Number: [ID]

Some of the survey's questions may make you feel uncomfortable. End-of-life issues are not discussed often, but they are important. Participation in this study is optional, and you have the right to not answer any question you wish. However, you can help us by taking a few minutes to share your opinions and/or experiences.

This survey is completely optional. All results will be reported so that no individual can be identified. Please contact the Bureau of Sociological Research by telephone at 1-800-480-4549 or by e-mail at bosr@unl.edu with any questions you may have about this survey.

Thank you for helping with this Nebraska End-of-Life Survey.

Lindsey Witt-Swanson

Lindsey Witt-Swanson
Associate Director
Bureau of Sociological Research

University of Nebraska Lincoln
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unl.edu

Appendix B: Survey Instrument
Paper (Printed in black & white only)

Nebraska End-of-Life Survey

This survey is about end-of-life issues such as the kind of care you want, your wishes, and the choices you'll make regarding end-of-life care. Some topics may be sensitive, but your participation in this study is appreciated. Your responses are critical in helping support Nebraskans dealing with these issues. The survey should take approximately 20 minutes to complete.

Hospice Services

Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible. The services are provided by a team of health care professionals who maximize comfort for a person who is terminally ill by reducing pain and addressing physical, psychological, social and spiritual needs. To help families, hospice care also provides counseling, respite care and practical support.

1. Prior to reading the definition for this survey, have you heard of hospice services?

- ○ Yes, I have heard a lot about hospice services
- ○ Yes, I have heard a little about hospice services
- ○ No, I have never heard of hospice services → **Go to #4**

2. How did you learn about hospice services? *(Mark all that apply)*

- ☐ I know someone who has used hospice
- ☐ I have used hospice services myself
- ☐ I am/was a hospice volunteer
- ☐ I heard from a health care provider/doctor
- ☐ I heard from others
- ☐ I read literature/newspaper/TV/radio/other media
- ☐ On a website or social media - please specify: ____
- ☐ Other - please specify: ____

3. Do you know the difference between hospice and palliative care?

- ○ Yes
- ○ No
- ○ Not sure

4. If you were dying, would you want hospice support?

- ○ Yes
- ○ No → **Go to #6**
- ○ Don't know/not sure → **Go to #6**

5. Where would you want to receive hospice support? *(Mark all that apply)*

- ☐ In a hospice residence
- ☐ In a hospital
- ☐ In a nursing home
- ☐ In my own home
- ☐ In a residential facility such as an assisted living facility
- ☐ Telehealth
- ☐ Other – please specify: ____

6. To the best of your knowledge, does Medicare or other insurance pay for hospice services?

- ○ Yes
- ○ No
- ○ Not sure

7. For which of the following chronic illnesses do you think hospice services would be helpful? *(Mark all that apply)*

- ☐ Cancer
- ☐ Heart disease
- ☐ Alzheimer's disease
- ☐ Lung disease
- ☐ Stroke
- ☐ Hypertension
- ☐ HIV/AIDS
- ☐ Organ failure or disease (kidney/liver)
- ☐ Old age
- ☐ Infirmity
- ☐ Frailty
- ☐ COVID-19

8. How interested would you be to hear more about hospice services?

- ○ Very interested
- ○ Somewhat interested
- ○ Not very interested
- ○ Not at all interested
- ○ Not sure

9. Have you had experience with hospice?
- ○ Yes
- ○ No → **Go to #14**
- ○ Not sure

10. When did you last have experience with hospice services?

[|] Month [|] Year

11. How was your experience with hospice?
- ○ Very positive
- ○ Somewhat positive
- ○ Somewhat negative
- ○ Very negative

12. Why did you find the experience positive or negative?

[ ]

13. How helpful did you find the services?
- ○ Very helpful
- ○ Somewhat helpful
- ○ Not very helpful
- ○ Not at all helpful

Palliative Care Services

Palliative care is specialized medical care for people living with serious illnesses. This type of care is focused on providing relief from symptoms and stress of the illness. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

14. Prior to reading the definition for this survey, have you heard of palliative care?
- ○ Yes, I have heard a lot about palliative care
- ○ Yes, I have heard a little about palliative care
- ○ No, I have never heard of palliative care → **Go to #16**

15. How did you learn about palliative care? *(Mark all that apply)*
- ☐ I know someone who has used palliative care
- ☐ I have used palliative care myself
- ☐ I heard from a health care provider/doctor
- ☐ I heard from others
- ☐ I read literature/newspaper/TV/radio/other media
- ☐ On a website or social media - please specify: [ ]
- ☐ Other - please specify: [ ]

16. If you were seriously ill, would you want palliative care?
- ○ Yes
- ○ No → **Go to #18**
- ○ Don't know/not sure → **Go to #18**

17. If you had a serious illness that has a high risk of death that negatively impacts you or your caregiver on a daily basis, where would you want to receive palliative care? *(Mark all that apply)*
- ☐ In a hospital
- ☐ In a nursing home
- ☐ In my own home
- ☐ In a residential facility such as an assisted living facility
- ☐ Telehealth
- ☐ Other – please specify: [ ]

18. To the best of your knowledge, does Medicare or other insurance pay for palliative care?
- ○ Yes
- ○ No
- ○ Not sure

19. In the course of a chronic illness, which of these reasons would you consider palliative care for? *(Mark all that apply)*
- ☐ Management of physical care
- ☐ Management of physical symptoms
- ☐ Management of psychological wellness
- ☐ Management of spiritual wellness

20. How interested would you be to hear more about palliative care?
- ○ Very interested
- ○ Somewhat interested
- ○ Not very interested
- ○ Not at all interested
- ○ Not sure

Support Near the End of Life

When people are near the end of life, they may need support from others. The following questions are about the types of support you expect to need when near the end of your life and who should provide it to you.

21. I expect to need someone to provide transportation.

- ○ Yes
- ○ No → **Go to #23**

22. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

23. I expect to need someone to help with chores.

- ○ Yes
- ○ No → **Go to #25**

24. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

25. I expect to need someone to do fun things with me.

- ○ Yes
- ○ No → **Go to #27**

26. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

27. I expect to need someone to know what I want when I die.

- ○ Yes
- ○ No → **Go to #29**

28. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

29. I expect to need someone to help care for other family members.

- ○ Yes
- ○ No → **Go to #31**

30. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

31. I expect to need someone to encourage me when I'm down.

- ○ Yes
- ○ No → **Go to #33**

32. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

33. I expect to need someone to understand what I'm going through.

- ○ Yes
- ○ No → **Go to #35**

34. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

35. I expect to need someone to know about my illness.

- ○ Yes
- ○ No → **Go to #37**

36. Who should provide this type of support? ***(Mark all that apply)***

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

Advance Directives

Advance directives allow people to make their health care choices in advance of an incapacitating illness or death.

37. Which of the following advance directives and other pre-plans have you heard about and completed?

	Have heard about *and* completed for the first time	Have heard about *but not* completed	Have not heard about
a. A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated	○	○	○
b. A living will in which you state the kind of health care you want or don't want under certain circumstances	○	○	○
c. A last will and testament that controls how your assets are to be distributed	○	○	○
d. Funeral, burial, or cremation pre-plans in which you plan or purchase in advance any goods or services for yourself	○	○	○
e. Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants	○	○	○
f. Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/Do Not Intubate (DNI)	○	○	○

38. Have you updated each of the following advance directives and other pre-plans?

	Yes	No
a. A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated	○	○
b. A living will in which you state the kind of health care you want or don't want under certain circumstances	○	○
c. A last will and testament that controls how your assets are to be distributed	○	○
d. Funeral, burial, or cremation pre-plans in which you plan or purchase in advance any goods or services for yourself	○	○
e. Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants	○	○
f. Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/Do Not Intubate (DNI)	○	○

39. Have you filed each of the following advance directives and other pre-plans with the appropriate entities?

	Yes	No
a. A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated	○	○
b. A living will in which you state the kind of health care you want or don't want under certain circumstances	○	○
c. A last will and testament that controls how your assets are to be distributed	○	○
d. Funeral, burial, or cremation pre-plans in which you plan or purchase in advance any goods or services for yourself	○	○
e. Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants	○	○
f. Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/Do Not Intubate (DNI)	○	○

40. Of the forms you have completed, do your intended people have access to the forms?

- ○ Yes, they know where they are and we have discussed them
- ○ Yes, they know where they are but we have not discussed them
- ○ Yes, we have discussed them but they do not know where they are
- ○ No, they do not know where they are and we have not discussed them
- ○ Not applicable

41. Have you completed an advance directive?

- ○ Yes
- ○ No → **Go to #43**

42. Where did you get the advance directive form? *(Mark all that apply)*

- ☐ DMV
- ☐ Physician's/health care provider's office
- ☐ Hospital
- ☐ Presentation about advance directives
- ☐ Website - please specify:
- ☐ Other - please specify:

43. With whom have you talked about your wishes for care at the end of your life? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends
- ☐ Lawyer
- ☐ Financial planner/insurance agent
- ☐ My primary physician
- ☐ Specialty physician, such as cancer doctor, heart doctor, etc.
- ☐ Clergy or other religious/spiritual leader (e.g., priest, minister, rabbi)
- ☐ Employer
- ☐ Other - please specify:
- ☐ No one

44. Who would you want to initiate a conversation with you regarding end-of-life issues? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends
- ☐ Lawyer
- ☐ Financial planner/insurance agent
- ☐ My primary physician
- ☐ Specialty physician, such as cancer doctor, heart doctor, etc.
- ☐ Clergy or other religious/spiritual leader (e.g., priest, minister, rabbi)
- ☐ Employer
- ☐ Other - please specify:
- ☐ No one

45. Who would you trust to provide information on end-of-life issues? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends
- ☐ Lawyer
- ☐ Financial planner/insurance agent
- ☐ My primary physician
- ☐ Specialty physician, such as cancer doctor, heart doctor, etc.
- ☐ Clergy or other religious/spiritual leader (e.g., priest, minister, rabbi)
- ☐ Employer
- ☐ Other - please specify:
- ☐ No one

Thinking about Pain

46. How strongly do you agree or disagree with each statement?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
a. I am afraid my doctor may not believe I am in pain or may not treat my pain.	○	○	○	○	○
b. I would only take pain medicines when the pain is severe.	○	○	○	○	○
c. I am afraid I will become addicted to the pain medicines over time.	○	○	○	○	○
d. I would take the lowest amount of medicine possible to save larger doses for later when pain is worse.	○	○	○	○	○
e. I am afraid I would be given too much pain medicine.	○	○	○	○	○

Thoughts on Death

47. How comfortable are you with…

	Very comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable	Not sure
a. Talking about death?	○	○	○	○	○
b. Writing your will if you thought my death would occur soon?	○	○	○	○	○
c. Thinking about the time after death?	○	○	○	○	○

48. How likely are you to…

	Very likely	Somewhat likely	Not very likely	Not at all likely	Not sure
a. Attend funerals, visitations, or memorial services in person?	○	○	○	○	○
b. Read books, newspapers articles and/or information that deal with the subject of death and dying?	○	○	○	○	○
c. Watch television programs or movies that deal with the subject of death and dying?	○	○	○	○	○
d. Avoid medical checkups because you are afraid the doctor will find "something serious"?	○	○	○	○	○
e. Speak freely to loved ones about death and dying?	○	○	○	○	○
f. Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing?	○	○	○	○	○
g. Preplan your own funeral or memorial service?	○	○	○	○	○
h. Preplan the funeral or memorial service of someone you're caring for?	○	○	○	○	○

49. How afraid, if at all, are you of...

	Very afraid	Somewhat afraid	Not very afraid	Not at all afraid	Not sure
a. Dying from a long-term illness?	○	○	○	○	○
b. Dying suddenly?	○	○	○	○	○
c. Dying alone?	○	○	○	○	○
d. Dying in a facility such as a nursing home or hospital?	○	○	○	○	○
e. Dying painfully?	○	○	○	○	○

50. How strongly do you agree or disagree with each statement?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
a. There is a special value in getting old.	○	○	○	○	○
b. Dying is an important part of life.	○	○	○	○	○
c. If someone could tell me that I likely have six months or less to live, I would want to know.	○	○	○	○	○
d. Caring for people who are dying is a rewarding experience.	○	○	○	○	○
e. If I knew I was dying, I would want medical interventions to keep me alive as long as possible.	○	○	○	○	○

51. When you think about death and dying, how concerned are you that...

	Very concerned	Somewhat concerned	Not very concerned	Not at all concerned	Not sure
a. Your (or your spouse/partner's) money won't last?	○	○	○	○	○
b. Your family's money won't last?	○	○	○	○	○
c. You will be a burden to your family and friends?	○	○	○	○	○
d. You will lose your independence?	○	○	○	○	○

52. How important would each of the following be to you when dealing with your own dying?

	Very important	Somewhat important	Not very important	Not at all important	Not sure
a. Family/friends visiting you	○	○	○	○	○
b. Being able to stay in your home	○	○	○	○	○
c. Comfort from religious/spiritual services	○	○	○	○	○
d. Planning your own funeral or memorial service	○	○	○	○	○
e. Being able to complete your will	○	○	○	○	○
f. Fulfilling personal goals/pleasures	○	○	○	○	○
g. Reviewing your life history with your family	○	○	○	○	○
h. Getting your finances in order	○	○	○	○	○
i. Giving to others in time, gifts, or wisdom	○	○	○	○	○
j. Honest answers from your doctor	○	○	○	○	○
k. Knowing medicine was available to you	○	○	○	○	○
l. Having health care professionals visit you are your home	○	○	○	○	○
m. Understanding your treatment options	○	○	○	○	○
n. Receiving comfort care	○	○	○	○	○

53. Which of the following health problems, if any, do you think are worse than death? *(Mark all that apply)*

- ☐ Living with great pain
- ☐ Total physical dependency on others, such as being in a coma
- ☐ Not being able to communicate your wishes and/or needs to family and friends
- ☐ Other - please specify:
- ☐ None of these are worse than death

54. If you could choose how to die, what would your choice be? *(Mark all that apply)*

- ☐ Sudden death
- ☐ Long-term illness
- ☐ Death while sleeping
- ☐ Other - please specify:

55. If you were terminally ill and could choose where to die, where would you want to die? *(Mark all that apply)*

- ☐ At home
- ☐ In an assisted living facility
- ☐ In a hospital
- ☐ In a residential hospice (hospice house)
- ☐ Other - please specify:
- ☐ I have no preference

Religion and Spirituality

56. Do you consider yourself…
- ○ Very religious/spiritual
- ○ Somewhat religious/spiritual
- ○ Not very religious/spiritual
- ○ Not at all religious/spiritual → **Go to #60**

57. How often do you attend religious or spiritual services?
- ○ Regularly
- ○ Occasionally
- ○ Rarely
- ○ Never
- ○ Not religious/spiritual

58. How often do you find strength in your religion or spirituality?
- ○ One or more times a day
- ○ A few times a week
- ○ A few times a month
- ○ Once a month or less
- ○ Never
- ○ Not religious/spiritual

59. How often would you want religious/spiritual support at the end of life?
- ○ One or more times a day
- ○ A few times a week
- ○ A few times a month
- ○ Once a month or less
- ○ Never
- ○ Not religious/spiritual

About You

The following questions are for classification purposes only and will kept entirely confidential.

60. In general, how would you rate your own health right now?
- ○ Very good health
- ○ Good health
- ○ Fair health
- ○ Poor health

61. Are you now or have you ever been a caregiver?
- ○ Yes
- ○ No → **Go to #63**

62. What is the age of the person whom you are or were caring for? ***(If multiple, please list the most recent person.)***

☐☐☐

63. Do you have any serious chronic illnesses?
- ○ Yes
- ○ No → **Go to #65**

64. Which of the following describes your serious chronic illness(es)? ***(Mark all that apply)***
- ☐ Cancer
- ☐ Heart disease
- ☐ Alzheimer's disease
- ☐ Lung disease
- ☐ Stroke
- ☐ COVID-19
- ☐ Other – please specify:

65. Does a member of your household have any serious chronic illnesses?
- ○ Yes
- ○ No → **Go to #67**

66. Which of the following describes the serious chronic illness(es)? ***(Mark all that apply)***
- ☐ Cancer
- ☐ Heart disease
- ☐ Alzheimer's disease
- ☐ Lung disease
- ☐ Stroke
- ☐ COVID-19
- ☐ Other – please specify:

67. Are you…
- ○ Male
- ○ Female
- ○

68. What was your age at your last birthday?

☐☐☐ Years old

69. What is your current marital status?

- ○ Single/never married
- ○ Married/domestic partnership
- ○ Widowed
- ○ Divorced
- ○ Separated

70. What is the highest level of education that you completed?

- ○ Less than high school
- ○ High school graduate or equivalent
- ○ Some college or technical training
- ○ College graduate (4 years)
- ○ Post-graduate or professional degree

71. Which of the following describes your current employment status? *(Mark all that apply)*

- ☐ Employed for wages (full time/part time)
- ☐ Self-employed
- ☐ Out of work/not looking
- ☐ Not employed outside the home
- ☐ Student
- ☐ Military
- ☐ Retired
- ☐ Unable to work

72. What is your ethnicity?

- ○ Hispanic or Latino
- ○ Not Hispanic or Latino

73. What is your race? *(Mark all that apply)*

- ☐ White
- ☐ Black or African American
- ☐ Asian
- ☐ American Indian or Alaska Native
- ☐ Native Hawaiian or Pacific Islander
- ☐ Some other race

74. How many people, including yourself, live in your household?

☐☐

75. What was your annual household income before taxes in 2021?

- ○ Less than $10,000
- ○ $10,000 to $19,999
- ○ $20,000 to $29,999
- ○ $30,000 to $39,999
- ○ $40,000 to $49,999
- ○ $50,000 to $59,999
- ○ $60,000 to $74,999
- ○ $75,000 to $99,999
- ○ $100,000 to $124,999
- ○ $125,000 to $149,999
- ○ $150,000 to $199,999
- ○ $200,000 or more

76. Are you affiliated with an organized faith community?

- ○ Yes - please specify: ____________
- ○ No

77. What services/information would be most useful to you?

- ☐ End-of-life support groups
- ☐ Advance directive forms/information
- ☐ Advance directive workshops
- ☐ Caregiving support groups

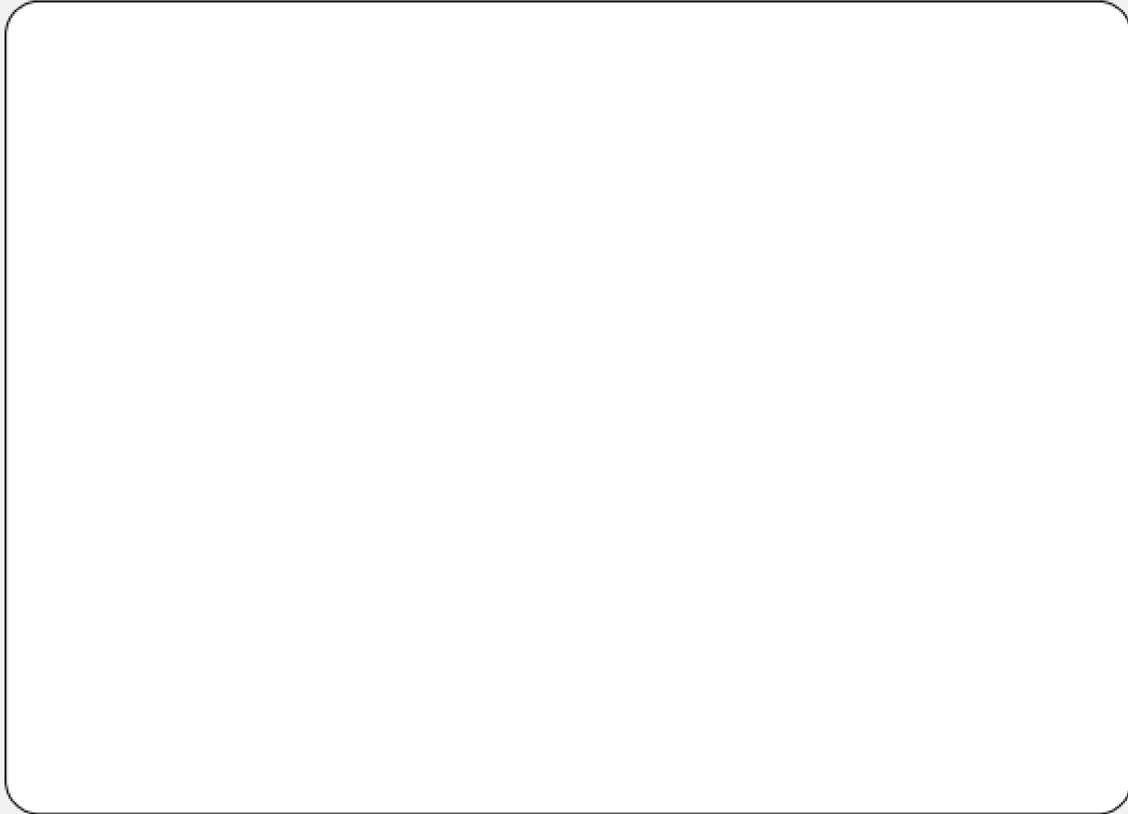
78. What is your 5 digit zip code?

☐☐☐☐☐

79. Are you a veteran?

- ○ Yes
- ○ No

80. Please use the space below to provide any comments or feedback.



Thank you!

We greatly appreciate the time you have taken to complete this survey. For your convenience, please use the postage-paid return envelope included in your survey packet to return your questionnaire.

Questions or requests from this survey can be directed to:
Bureau of Sociological Research
University of Nebraska-Lincoln
907 Oldfather Hall PO Box 880325
Lincoln, NE 68588-0325

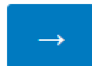
Phone: 1-800-480-4549 (toll free)
E-mail: bosr@unl.edu

Web

Thank you for completing this Nebraska End of Life Survey. This survey will help those working to improve end-of-life care and conditions across the state.

To begin the survey, please enter your unique ID number in the box below. Your ID number can be found in the survey invitation letter we mailed you.

Unique Identification Number



This survey is about end-of-life issues such as the kind of care you want, your wishes, and the choices you'll make regarding end-of-life care. Some topics may be sensitive, but your participation in this study is appreciated. Your responses are critical in helping support Nebraskans dealing with these issues. The survey should take approximately 20 minutes to complete.

Hospice Services

Hospice care is a special kind of care that focuses on the quality of life for people and their caregivers who are experiencing an advanced, life-limiting illness. Hospice care provides compassionate care for people in the last phases of incurable disease so that they may live as fully and comfortably as possible. The services are provided by a team of health care professionals who maximize comfort for a person who is terminally ill by reducing pain and addressing physical, psychological, social and spiritual needs. To help families, hospice care also provides counseling, respite care and practical support.

Prior to reading the definition for this survey, have you heard of hospice services?

- ◯ Yes, I have heard a lot about hospice services
- ◯ Yes, I have heard a little about hospice services
- ◯ No, I have never heard of hospice services

"If Yes, I have heard a lot about hospice services or Yes I have heard a little about hospice service is selected"

How did you learn about hospice services? *(Mark all that apply)*

- ☐ I know someone who has used hospice
- ☐ I have used hospice services myself
- ☐ I am/was a hospice volunteer
- ☐ I heard from a healthcare provider/doctor
- ☐ I heard from others
- ☐ I read literature/newspaper/TV/radio/other media
- ☐ On a website or social media - please specify: ________
- ☐ Other - please specify: ________

Do you know the difference between hospice and palliative care?

- ○ Yes
- ○ No
- ○ Not sure

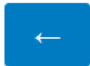
If you were dying, would you want hospice support?

- ○ Yes
- ○ No
- ○ Don't know/Not sure

"If No, I have never heard of hospice services is selected"

If you were dying, would you want hospice support?

- Yes
- No
- Don't know/Not sure



"If Yes is selected"

Where would you want to receive hospice support? *(Mark all that apply)*

- ☐ In a hospice residence
- ☐ In a hospital
- ☐ In a nursing home
- ☐ In my own home
- ☐ In a residential facility such as an assisted living facility
- ☐ Telehealth
- ☐ Other - please specify:

”If No or Don’t know/Not sure is selected”

To the best of your knowledge, does Medicare or other insurance pay for hospice services?

- ◯ Yes
- ◯ No
- ◯ Not sure

For which of the following chronic illnesses do you think hospice services would be helpful? *(Mark all that apply)*

- ☐ Cancer
- ☐ Heart disease
- ☐ Alzheimer's disease
- ☐ Lung disease
- ☐ Stroke
- ☐ Hypertension
- ☐ HIV/AIDS
- ☐ Organ failure or disease (kidney/liver)
- ☐ Old age
- ☐ Infirmity
- ☐ Frailty
- ☐ COVID-19

How interested would you be to hear more about hospice services?

- ◯ Very interested
- ◯ Somewhat interested
- ◯ Not very interested
- ◯ Not at all interested
- ◯ Not sure

Have you had experience with hospice?

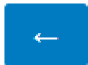
- ◯ Yes
- ◯ No
- ◯ Unsure

"If Yes or Unsure is selected"

When did you last have experience with hospice services?

☐ Month

☐ Month



How was your experience with hospice?

- ◯ Very positive
- ◯ Somewhat positive
- ◯ Somewhat negative
- ◯ Very negative

Why did you find the experience positive or negative?

How helpful did you find the services?

- ◯ Very helpful
- ◯ Somewhat helpful
- ◯ Not very helpful
- ◯ Not at all helpful

"If No is selected"

Palliative Care Services

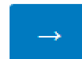
Palliative care is specialized medical care for people living with serious illnesses. This type of care of focused on providing relief from symptoms and stress of the illness. It is appropriate at any age and at any stage in a serious illness, and it can be provided along with curative treatment.

Prior to reading the definition for this survey, have you heard of palliative care?

◯ Yes, I have heard a lot about palliative care

◯ Yes, I have heard a little about palliative care

◯ No, I have never heard of palliative care



"If Yes, I have heard a lot about palliative care or Yes, I have heard a little about palliative care are selected"

How did you learn about palliative care? *(Mark all that apply)*

- ☐ I know someone who used palliative care
- ☐ I have used palliative care myself
- ☐ I heard from a health care provider/doctor
- ☐ I heard from others
- ☐ I read literature/newspaper/TV/radio/other media
- ☐ On a website or social media - please specify:
- ☐ Other - please specify:

If you were seriously ill, would you want palliative care?

- ◯ Yes
- ◯ No
- ◯ Don't know/Not sure

” If Yes is selected”

If you had a serious illness that has a high risk of death that negatively impacts you or your caregiver on a daily basis, where would you want to receive palliative care? *(Mark all that apply)*

- ☐ In a hospital
- ☐ In a nursing home
- ☐ In my own home
- ☐ In a residential facility such as an assisted living facility
- ☐ Telehealth
- ☐ Other - please specify:

“If No or Don’t know/not sure is selected”

To the best of your knowledge, does Medicare or other insurance pay for palliative care?

○ Yes

○ No

○ Not sure

In the course of a chronic illness, which of these reasons would you consider palliative care for? *(Mark all that apply)*

☐ Management of physical care

☐ Management of physical symptoms

☐ Management of psychological wellness

☐ Management of spiritual wellness

How interested would you be to hear more about palliative care?

- ◯ Very interested
- ◯ Somewhat interested
- ◯ Not very interested
- ◯ Not at all interested
- ◯ Not sure

Support Near the End-of-Life

When people are near the end of life, they may need support from others. The following questions are about the types of support you expect to need when near the end of your life and who should provide it to you.

I expect to need someone to provide transportation.

○ Yes

○ No

"If Yes is selected"

Who should provide this type of support? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

I expect to need someone to help with chores.

- ◯ Yes
- ◯ No

"If No is selected"

I expect to need someone to help with chores.

- Yes
- No

"If Yes is selected"

Who should provide this type of support? *(Mark all that apply)*

☐ Spouse/partner

☐ Children

☐ Other family

☐ Friends/neighbors

☐ Health care providers/doctor

☐ Work associates

☐ Community organizations

☐ Faith community

☐ Other - please specify:

I need someone to do fun things with me.

◯ Yes

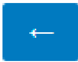
◯ No

"If No is selected"

I need someone to do fun things with me.

Yes

No



"If Yes is selected"

Who should provide this type of support? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care provider/doctor
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith Community
- ☐ Other - please specify:

I expect to need someone to know what I want when I die.

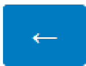
- ◯ Yes
- ◯ No

"If No is selected"

I expect to need someone to know what I want when I die.

◯ Yes

◯ No



“If Yes is selected”

Who should provide this type of support *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctors
- ☐ Work associates
- ☐ Community organizations
- ☐ Church/Place of worship
- ☐ Other - please specify:

I expect to need someone to help care for other family members.

- ◯ Yes
- ◯ No

"If No is selected"

I expect to need someone to help care for other family members.

- Yes
- No

"If Yes is selected"

Who should provide this type of support *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctors
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

I expect to need someone to encourage me when I'm down.

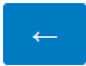
- ○ Yes
- ○ No

"If No is selected"

I expect to need someone to encourage me when I'm down.

Yes

No



"If Yes is selected"

Who should provide this type of support *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends/neighbors
- ☐ Health care providers/doctors
- ☐ Work associates
- ☐ Community organizations
- ☐ Faith community
- ☐ Other - please specify:

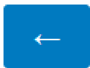
I expect to need someone to understand what I'm going through.

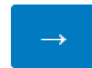
- ◯ Yes
- ◯ No

"If No is selected"

I expect to need someone to understand what I'm going through.

- Yes
- No





"If Yes is selected"

Who should provide this type of support *(Mark all that apply)*

◯ Spouse/partner

◯ Children

◯ Other family

◯ Friends/neighbors

◯ Health care providers/doctors

◯ Work associates

◯ Community organizations

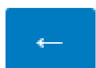
◯ Faith community

◯ Other - please specify:

I expect to need someone to know about my illness.

◯ Yes

◯ No

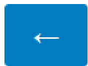


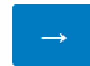
"If No is selected"

I expect to need someone to know about my illness.

Yes

No





"If Yes is selected"

Who should provide this type of support *(Mark all that apply)*

- [ ] Spouse/partner
- [ ] Children
- [ ] Other family
- [ ] Friends/neighbors
- [ ] Health care providers/doctors
- [ ] Work associates
- [ ] Community organizations
- [ ] Faith community
- [ ] Other - please specify:

"If No is selected"

Advance Directives

Advance directives allow people to make their health care choices in advance of an incapacitating illness or death.

Which of the following advance directives and other pre-plans have you heard about and completed?

	Have heard about and completed for the first time	Have heard about *but* not completed	Have not heard about
A Health Care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated	○	○	○
A living will in which you state the kind of health care you want or don't want under certain circumstances	○	○	○
A last will and testament that controls how your assets are to be distributed	○	○	○
Funeral, burial, or cremation pre-plans in which you plan or purchase in advance any goods or services for yourself	○	○	○
Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants	○	○	○
Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/Do Not Intubate (DNI)	○	○	○

Have you updated each of the following advance directives and other pre-plans?

	Yes	No
A Health care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated	○	○
A living will in which you state the kind of health care you want or don't want under certain circumstances	○	○
A last will and testament that controls how your assets are to be distributed	○	○
Funeral, burial, or cremation pre-plans in which you plan or purchase in advance any goods or services for yourself	○	○
Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants	○	○
Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/Do Not Intubate (DNI)	○	○

Have you filed each of the following advance directives and other pre-plans with the appropriate entities?

	Yes	No
A Health care Power of Attorney (HCPA) in which you name someone to make decisions about your health care in the event you become incapacitated	○	○
A living will in which you state the kind of health care you want or don't want under certain circumstances	○	○
A last will and testament that controls how your assets are to be distributed	○	○
Funeral, burial, or cremation pre-plans in which you plan or purchase in advance any goods or services for yourself	○	○
Signing up to have your organs and/or tissue donated after you die for use by others in need of transplants	○	○
Nebraska Emergency Treatment Orders (NETO), Physician Orders for Life-Sustaining Treatment (POLST), Do Not Resuscitate (DNR)/Do Not Intubate (DNI)	○	○

Of the forms you have completed, do your intended people have access to the forms?

◯ Yes, they know where they are and we have discussed them

◯ Yes, they know where they are but we have not discussed them

◯ Yes, we have discussed them but they do not know where they are

◯ No, they do not know where they are and we have not discussed them

◯ Not applicable

Have you completed an advance directive?

◯ Yes

◯ No

"If Yes is selected"

Where did you get the advance directive form? *(Mark all that apply)*

- ☐ DMV
- ☐ Physician's/health care provider's office
- ☐ Hospital
- ☐ Presentation about advance directives
- ☐ Website - please specify:
- ☐ Other - please specify:

"If No is selected"

With whom have you talked about your wishes for care at the end of your life? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends
- ☐ Lawyer
- ☐ Financial planner/insurance agent
- ☐ My primary physician
- ☐ Specialty physician, such as cancer doctor, heart doctor, etc.
- ☐ Clergy or other religious/spiritual leader (e.g., priest, minister, rabbi)
- ☐ Employer
- ☐ Other - please specify:
- ☐ No one

Who would you want to initiate a conversation with you regarding end-of-life issues? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends
- ☐ Lawyer
- ☐ Financial planner/insurance agent
- ☐ My primary physician
- ☐ Specialty physician, such as cancer doctor, heart doctor, etc.
- ☐ Clergy or other religious/spiritual leader (e.g., priest, minister, rabbi)
- ☐ Employer
- ☐ Other - please specify: ________
- ☐ No one

Who would you trust to provide information on end-of-life issues? *(Mark all that apply)*

- ☐ Spouse/partner
- ☐ Children
- ☐ Other family
- ☐ Friends
- ☐ Lawyer
- ☐ Financial planner/insurance agent
- ☐ My primary physician
- ☐ Specialty physician, such as cancer doctor, heart doctor, etc.
- ☐ Clergy or other religious/spiritual leader (e.g., priest, minister, rabbi)
- ☐ Employer
- ☐ Other - please specify:
- ☐ No one

Thinking about Pain

How strongly do you agree or disagree with each statement?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
I am afraid my doctor may not believe I am in pain or may not treat my pain.	○	○	○	○	○
I would only take pain medicines when the pain is severe.	○	○	○	○	○
I am afraid I will become addicted to the pain medicines over time.	○	○	○	○	○
I would take the lowest amount of medicine possible to save larger doses for later when pain is worse.	○	○	○	○	○
I am afraid I would be given too much pain medicine.	○	○	○	○	○

Thoughts on Death

How comfortable are you with...

	Very comfortable	Somewhat comfortable	Not very comfortable	Not at all comfortable	Not sure
Talking about death?	○	○	○	○	○
Writing your will if you thought your death would occur soon?	○	○	○	○	○
Thinking about the time after death?	○	○	○	○	○

How likely are you to...

	Very likely	Somewhat likely	Not very likely	Not at all likely	Not sure
Attend funerals, visitations, or memorial services in person?	◯	◯	◯	◯	◯
Read books, newspaper articles and/or other information that deal with the subject of death and dying.?	◯	◯	◯	◯	◯
Watch television programs or movies that deal with the subject of death and dying?	◯	◯	◯	◯	◯
Avoid medical checkups because I am afraid the doctor will find "something serious"?	◯	◯	◯	◯	◯
Speak freely to loved ones about death and dying?	◯	◯	◯	◯	◯
Visit or telephone a friend or relative who has recently lost a loved one in order to see how they are doing?	◯	◯	◯	◯	◯
Preplan your own funeral or memorial service?	◯	◯	◯	◯	◯
Preplan the funeral or memorial service of someone you're caring for?	◯	◯	◯	◯	◯

How afraid, if at all, are you of...

	Very afraid	Somewhat afraid	Not very afraid	Not at all afraid	Not sure
Dying from a long-term illness?	○	○	○	○	○
Dying suddenly?	○	○	○	○	○
Dying alone?	○	○	○	○	○
Dying in a facility such as a nursing home or hospital?	○	○	○	○	○
Dying painfully?	○	○	○	○	○

How strongly do you agree or disagree with each statement?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree	Not sure
There is a special value in getting old.	○	○	○	○	○
Dying is an important part of life.	○	○	○	○	○
If someone could tell me that I likely have six months or less to live, I would want to know.	○	○	○	○	○
Caring for people who are dying is a rewarding experience.	○	○	○	○	○
If I knew I was dying, I would want medical interventions to keep me alive as long as possible.	○	○	○	○	○

When you think about death and dying, how concerned are you that...

	Very concerned	Somewhat concerned	Not very concerned	Not at all concerned	Not sure
Your (or your spouse/partner's) money won't last?	◯	◯	◯	◯	◯
Your family's money won't last?	◯	◯	◯	◯	◯
You will be a burden to your family and friends?	◯	◯	◯	◯	◯
You will lose your independence?	◯	◯	◯	◯	◯

How important would each of the following be to you when dealing with your own dying?

	Very important	Somewhat important	Not very important	Not at all important	Not sure
Family/friends visiting you	○	○	○	○	○
Being able to stay in your home	○	○	○	○	○
Comfort from religious/spiritual services	○	○	○	○	○
Planning your own funeral or memorial service	○	○	○	○	○
Being able to complete your will	○	○	○	○	○
Fulfilling personal goals/pleasures	○	○	○	○	○
Reviewing your life history with your family	○	○	○	○	○
Getting your finances in order	○	○	○	○	○
Giving to others in time, gifts, or wisdom	○	○	○	○	○
Honest answers from your doctor	○	○	○	○	○
Knowing medicine was available to you	○	○	○	○	○
Having health care professionals visit you at your home	○	○	○	○	○
Understanding your treatment options	○	○	○	○	○
Receiving comfort care	○	○	○	○	○

Which of the following health problems, if any, do you think are worse than death? *(Mark all that apply)*

- ☐ Living with great pain
- ☐ Total physical dependency on others, such as being in a coma
- ☐ Not being able to communicate your wishes and/or needs to family and friends
- ☐ Other - please specify:
- ☐ None of these are worse than death

If you could choose how to die, what would your choice be? *(Mark all that apply)*

- ☐ Sudden death
- ☐ Long-term illness
- ☐ Death while sleeping
- ☐ Other - please specify:

If you were terminally ill and could choose where to die, where would you want to die? *(Mark all that apply)*

- ☐ At home
- ☐ In an assisted living facility
- ☐ In a hospital
- ☐ In a nursing home
- ☐ In a residential hospice (hospice house)
- ☐ Other - please specify:
- ☐ I have no preference

Religion and Spirituality

Do you consider yourself...

- ○ Very religious/spiritual
- ○ Somewhat religious/spiritual
- ○ Not very religious/spiritual
- ○ Not at all religious/spiritual

"If Very religious/spiritual, Somewhat religious/spiritual, or Not very religious/spiritual is selected"

How often do you attend religious or spiritual services?

- ◯ Regularly
- ◯ Occasionally
- ◯ Rarely
- ◯ Never
- ◯ Not religious/spiritual

How often do you find strength in your religion or spirituality?

- ◯ One or more times a day
- ◯ A few times a week
- ◯ A few times a month
- ◯ Once a month or less
- ◯ Never
- ◯ Not religious/spiritual

How often would you want religious/spiritual support at the end of life?

- ◯ One or more times a day
- ◯ A few times a week
- ◯ A few times a month
- ◯ Once a month or less
- ◯ Never
- ◯ Not religious/spiritual

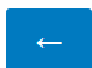
"If not at all religious/spiritual is selected"

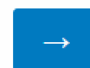
In general, how would you rate your own health right now?

- Very good health
- Good health
- Fair health
- Poor health

Are you now or have you ever been a caregiver?

- Yes
- No





“If Yes is selected”

What is the age of the person whom you are or were caring for?
(If multiple, please list the most recent person.)

☐

Do you have any serious chronic illnesses?

○ Yes

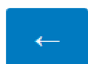
○ No

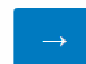
"If No is selected"

Do you have any serious chronic illnesses?

○ Yes

○ No





"If Yes is selected"

Which of the following describe your serious chronic illness(es)? *(Mark all that apply)*

- ☐ Cancer
- ☐ Heart disease
- ☐ Alzheimer's disease
- ☐ Lung disease
- ☐ Stroke
- ☐ COVID-19
- ☐ Other - please specify:

Does a member of your household have any serious chronic illnesses?

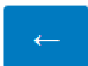
- ◯ Yes
- ◯ No

"If No is selected"

Does a member of your household have any serious chronic illnesses?

◯ Yes

◯ No



"If Yes is selected"

Which of the following describes the serious chronic illness(es)? *(Mark all that apply)*

- ☐ Cancer
- ☐ Heart disease
- ☐ Alzheimer's disease
- ☐ Lung disease
- ☐ Stroke
- ☐ COVID-19
- ☐ Other -please specify:

"If No is selected"

Are you...

- ◯ Male
- ◯ Female
- ◯ [ ]

What was your age at your last birthday?

[ ]

What is your current marital status?

- ◯ Single/never married
- ◯ Married/domestic partnership
- ◯ Widowed
- ◯ Divorced
- ◯ Separated

What is the highest level of education that you completed?

- ◯ Less than high school
- ◯ High school graduate or equivalent
- ◯ Some college or technical training
- ◯ College graduate (4 years)
- ◯ Post-graduate or professional degree

Which of the following describes your current employment status? *(Mark all that apply)*

- ☐ Employed for wages (full time/part time)
- ☐ Self-employed
- ☐ Out of work/not looking
- ☐ Not employed outside the home
- ☐ Student
- ☐ Military
- ☐ Retired
- ☐ Unable to work

What is your ethnicity?

- ◯ Hispanic or Latino
- ◯ Not Hispanic or Latino

What is your race? *(Mark all that apply)*

- ◯ White
- ◯ Black or African American
- ◯ Asian
- ◯ American Indian or Alaska Native
- ◯ Native Hawaiian or Pacific Islander
- ◯ Some other race

How many people, including yourself, live in your household?

☐

What was your annual household income before taxes in 2021?

- ◯ Less than $10,000
- ◯ $10,000 to $19,999
- ◯ $20,000 to $29,999
- ◯ $30,000 to $39,999
- ◯ $40,000 to $49,999
- ◯ $50,000 to $59,999
- ◯ $60,000 to $74,999
- ◯ $75,000 to $99,999
- ◯ $100,000 to $124,999
- ◯ $125,000 to $149,999
- ◯ $150,000 to $199,999
- ◯ $200,000 or more

Are you affiliated with an organized faith community?

- ◯ Yes - please specify: ____________
- ◯ No

What services/information would be most useful to you?

- ◯ End-of-life support groups
- ◯ Advance directive forms/information
- ◯ Advance directive workshops
- ◯ Caregiving support groups

What is your 5-digit zip code?

Are you a veteran?

- ◯ Yes
- ◯ No

Please use the space below to provide any comments or feedback.

Appendix C: Reminder Postcard

Back:

Last week we sent your household a survey asking for your help with the Nebraska End-of-Life Survey. Findings from this survey will help those working to improve end-of-life care and conditions across Nebraska. If someone at your address completed and returned the survey, please accept our thanks. If not, please have the **adult age 19 or older in your household who has the next birthday** complete the survey right away.

To access the survey online, please go to the survey link or QR code listed below and enter your unique identification number:

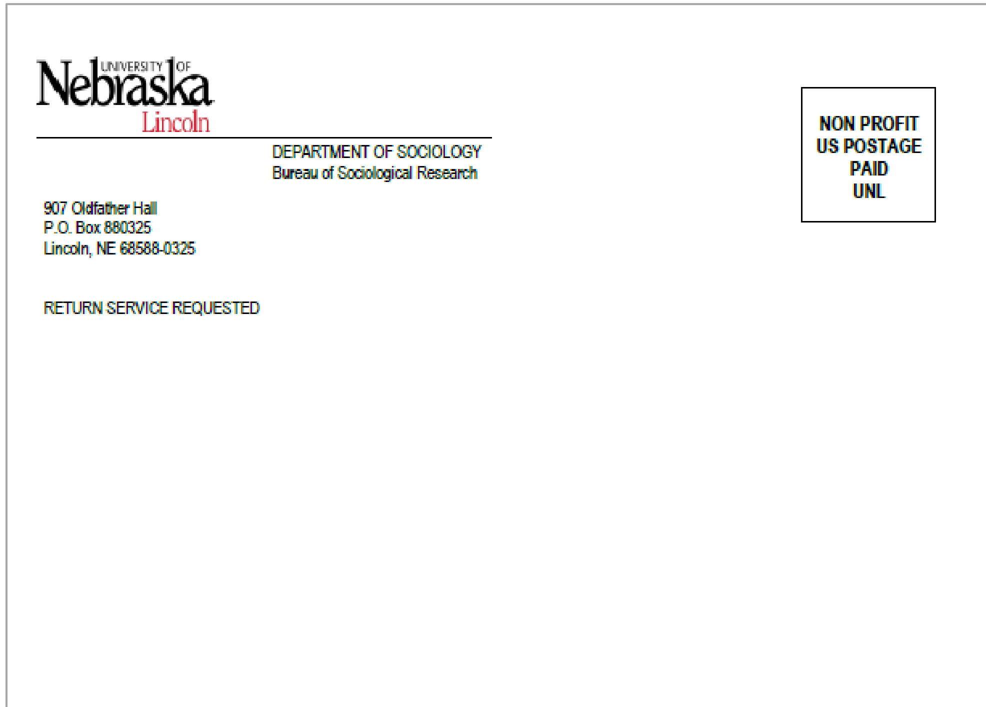
Survey Link: https://go.unl.edu/hospice2022
Unique Identification Number: [ID]

If you prefer to respond by mail, please complete and return the survey we sent to your household.

Participation in this study is optional and you may stop at any time. If you did not receive a paper survey or need another one sent to you, please call 1-800-480-4549 and we will send another one right away. Again, we thank you for your participation and look forward to receiving your survey.

Sincerely,
Lindsey Witt-Swanson, Associate Director
Bureau of Sociological Research
University of Nebraska-Lincoln

Front:



Appendix D: Estimate of Sampling Error

The 2022 End-of-Life Survey sample is a stratified random sample of households in the state. Because the data were weighted to account for within household selection and population characteristics, the estimates of the sampling error are not straightforward. Table 4 presents margins of sampling error for some of the most likely sample sizes *not* taking the design effect from sampling and weighting into account. Exact margins of error for alternative specifications of sample size and reported percentages can be easily computed by using the following formula for the 95% confidence level:

Margin of error = 1.96 * square root (p(1-p)/n)

p = the expected proportion selecting the answer

n = number of responses

Table 4. Approximate Margins of Error of Percentages by Selected Sample Size <u>NOT</u> Accounting for Design Effect (Expressed In Percentages)*

Reported Percentage	Full Sample* n=635	75% Sample n=476	50% Sample n=317	33.3% Sample n=211	25% Sample n=158	10% Sample n=63
50	3.89%	4.49%	5.50%	6.75%	7.80%	12.35%
40 or 60	3.81%	4.40%	5.39%	6.61%	7.64%	12.10%
30 or 70	3.56%	4.12%	5.04%	6.18%	7.15%	11.32%
20 or 80	3.11%	3.59%	4.40%	5.40%	6.24%	9.88%
10 or 90	2.33%	2.70%	3.30%	4.05%	4.68%	7.41%
5 or 95	1.70%	1.96%	2.40%	2.94%	3.40%	5.38%

* 95% confidence interval states that in 95 out of 100 samples drawn using the same sample size and design, the interval will contain the population value

When accounting a design effect, the adjusted sampling error will be increased as is shown when comparing Table 4 to Table 5 where the sampling design effect is incorporated:

Margin of error = square root (deff) * 1.96 * square root (p(1-p)/n)

deff = design effects

p = the expected proportion selecting the answer

n = number of responses

Table 5. Approximate Margins of Error of Percentages by Selected Sample Size Accounting for the Design Effect of Sampling

Reported Percentage	Full Sample* n=635	75% Sample n=476	50% Sample n=317	33.3% Sample n=211	25% Sample n=158	10% Sample n=63
50	3.51%	4.05%	4.97%	6.09%	7.03%	11.14%
40 or 60	3.44%	3.97%	4.86%	5.96%	6.89%	10.91%
30 or 70	3.22%	3.71%	4.55%	5.58%	6.45%	10.21%
20 or 80	2.81%	3.24%	3.97%	4.87%	5.63%	8.91%
10 or 90	2.10%	2.43%	2.98%	3.65%	4.22%	6.68%
5 or 95	1.53%	1.77%	2.16%	2.65%	3.07%	4.85%

* 95% confidence interval states that in 95 out of 100 samples drawn using the same sample size and design, the interval will contain the population value

The same is true when accounting for the design effect due to weighting, as is shown when comparing Table 4 to Table 6.

Table 6. Approximate Margins of Error of Percentages by Selected Sample Size Accounting for the Design Effect of Weighting

Reported Percentage	Full Sample* n=635	75% Sample n=476	50% Sample n=317	33.3% Sample n=211	25% Sample n=158	10% Sample n=63
50	7.09%	8.19%	10.03%	12.30%	14.21%	22.51%
40 or 60	6.95%	8.02%	9.83%	12.05%	13.93%	22.05%
30 or 70	6.50%	7.51%	9.20%	11.27%	13.03%	20.63%
20 or 80	5.67%	6.55%	8.03%	9.84%	11.37%	18.01%
10 or 90	4.25%	4.91%	6.02%	7.38%	8.53%	13.51%
5 or 95	3.09%	3.57%	4.37%	5.36%	6.20%	9.81%

* 95% confidence interval states that in 95 out of 100 samples drawn using the same sample size and design, the interval will contain the population value

Appendix E: AAPOR Transparency Initiative Immediate Disclosure Items

1. Describe the data collection strategies employed (e.g., surveys, focus groups, content analyses).

   Data Collection Process
2. Name the sponsor of the research and the party(ies) who conducted it. If the original source of funding is different than the sponsor, this source will also be disclosed.

   Introduction
3. The exact wording and presentation of any measurement tool from which results are reported as well as any preceding contextual information that might reasonably be expected to influence responses to the reported results and instructions to respondents or interviewers should be included.

   Appendix B
4. A definition of the population under study, including location, age, other social or demographic characteristics (e.g., persons who access the internet), time (e.g., immigrants entering the US between 2015 and 2019).

   Sampling Design
5. Dates of data collection.

   Data Collection Process
6. Explicitly state whether the sample comes from a frame selected using a probability-based methodology (meaning selecting potential participants with a known non-zero probability from a known frame) or if the sample was selected using non-probability methods (potential participants from opt-in, volunteer, or other sources).

   Sampling Design
7. Probability-based sample specification should include a description of the sampling frame(s), list(s), or method(s). If a frame, list, or panel is used, the description should include the name of the supplier of the sample or list and nature of the list (e.g., registered voters in the state of Texas in 2018, pre-recruited panel or pool). If a frame, list, or panel is used, the description should include the coverage of the population, including describing any segment of the target population that is not covered by the design.

   Sampling Design
8. Provide a clear indication of the method(s) by which participants were contacted, selected, recruited, intercepted, or otherwise contacted or encountered, along with any eligibility requirements and/or oversampling. Describe any use of quotas.

   Sampling Design and Data Collection Process
9. Provide details of any strategies used to help gain cooperation (e.g., advance contact, letters and scripts, compensation or incentives, refusal conversion contacts) whether for participation in a survey, group, panel, or for participation in a particular research project. Describe any compensation/incentives provided to research subjects and the method of delivery (debit card, gift card, cash).

   Data Collection Process
10. A description of all mode(s) used to contact participants or collect data or information (e.g., CATI, CAPI, ACASI, IVR, mail survey, web survey) and the language(s) offered or included.

Data Collection Process

11. Sample sizes (by sampling frame if more than one was used) and (if applicable) a discussion of the precision of the results. Provide sample sizes for each mode of data collection (for surveys include sample sizes for each frame, list, or panel used). For probability samples, report estimates of sampling error (often described as “the margin of error”) and discuss whether or not the reported sampling error or statistical analyses have been adjusted for the design effect due to weighting, clustering, or other factors. Reports of non-probability sample surveys will only provide measures of precision if they are defined and accompanied by a detailed description of how the underlying model was specified, its assumptions validated and the measure(s) calculated.

Sampling Design, Design Effects, and Appendix D

12. A description of how the weights were calculated, including the variables used and the sources of weighting parameters, if weighted estimates are reported.

Data Weights

13. Describe validity checks, where applicable, including but not limited to whether the researcher added attention checks, logic checks, or excluded respondents who straight-lined or completed the survey under a certain time constraint, any screening of content for evidence that it originated from bots or fabricated profiles, re-contacts to confirm that the interview occurred or to verify respondent’s identity or both, and measures to prevent respondents from completing the survey more than once. Any data imputation or other data exclusions or replacement will also be discussed.

Data Cleaning

14. Contact for obtaining more information about the study.

Questions

15. A general statement acknowledging the limitations of the design and data collection.

Limitations