

Summary of Results Advance Care Planning: Public Education Sessions

**Initiative #7 – Advance Directives on Care Choices
Ontario's Strategy for Alzheimer Disease and Related
Dementias**

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INTRODUCTION AND EVALUATION OVERVIEW

As part of Initiative 7 – Advance Directives on Care Choices, one of the initiatives within Ontario’s Strategy for Alzheimer Disease and Related Dementias, a number of individuals were trained in advance care planning (ACP) in order to serve as members of ACP Resource Teams. Once trained, these teams were responsible for providing education sessions in the area of ACP to two groups: (1) members of the general public and (2) service providers. The teams were asked to conduct at least one session with each group.

As with each of the initiatives within the Alzheimer Strategy, this initiative was evaluated. The evaluation was conducted through the use of pre and post session questionnaires (for the ACP Resource Teams and the individuals who attended the educational sessions for the public and service providers). For members of the public, the questionnaires focused on their understanding of ACP issues and what the participants may or may not have done in order to prepare for a time when they (or a loved one) may not be able to make decisions about their care. For the sessions with service providers, the evaluation questionnaires focused on their knowledge of ACP issues and the implementation of this knowledge within their agencies/long-term care homes. In addition to the pre and post session questionnaires, a follow-up questionnaire was sent to a subset of individuals who attended the educational sessions for members of the public. A similar questionnaire was originally planned for the service provider group as well, but because of logistical issues (i.e., the fact that individuals from more than one agency/home often attended a session and the lack of contact information provided) as well as the poor response rate obtained with the follow-up conducted with members of the public, the follow-up questionnaire for service providers was not administered.

This report provides a summary of the evaluation results for sessions conducted with members of the public. Those who attended the ACP public sessions were asked *not* to record their names on any of the questionnaires. This was done because of the personal nature of the questions being asked. By not having to record their names, it was felt that the participants would feel more comfortable answering the questions. The drawback with this approach was that statistical analyses comparing pre and post session responses could not be conducted.

RESPONSE RATE

The ACP Resource Teams conducted 88 sessions with members of the public. There were at least 1238 individuals who attended these sessions. (The exact number of attendees is not known because some of the information that the Resource Teams were asked to submit about the sessions was not complete or the information was not submitted.) However, with 1088 and 1014 individuals completing the pre-session and post-session evaluation forms, respectively, it appears that the response rate is relatively high, allowing one to have relative confidence in the results (see Table 1).

Table 1: Number of Individuals Completing the Pre and Post Questionnaires

Number of Individuals Completing Pre-Questionnaire	Number of Individuals Completing Post-Questionnaire
1088	1014

PRE-WORKSHOP QUESTIONNAIRE

The majority of the individuals who participated in the sessions were female (77%) and approximately 45% were between the ages of 65 and 84 (see Table 2).

Table 2: Characteristics of Pre-Questionnaire Respondents

Characteristic	Percentage (Number) of Respondents (N=1088)
Gender	
Male	22.3% (243)
Female	77.0% (838)
Age Group	
< 45 years of age	16.5% (180)
45 – 54 years of age	12.9% (140)
55 – 64 years of age	18.9% (206)
65 – 74 years of age	24.1% (262)
75 – 84 years of age	21.2% (231)
85 years of age or older	5.8% (63)

* Percentages may not sum to 100% because of missing values.

Participants were asked why they were interested in attending the session on ACP. Responses are summarized in Table 3. The most common response indicated that participants were attending the session for informational purposes and to provide support to their friends and family.

Table 3: Reason for Attending ACP Session

- Information (306)
- Family/friends/support (257)
- Work/course/volunteer (156)
- Self / own aging (144)
- Was invited / social gathering (38)
- Was coerced into attending (3)

Session participants were asked if they had ever talked with someone about what care that individual would like if, at some time in the future, they did not have the mental capacity to make decisions about their care. Those who responded “yes” were then asked to indicate whom they had spoken with. The majority (57%) of participants indicated that they had talked to someone about ACP; this person was most often a spouse or parent (see Table 4).

Table 4: Discussion of ACP about Others

Have you ever talked with someone about what care <i>they</i> would like <i>if</i> , at some time in the future, they did not have the mental capacity to make decisions about their care? *		If yes, percent (and number) of times each of the following individuals was indicated (N=622) **	
No	35.8% (389)	Your spouse	39.9 % (248)
Yes	57.2% (622)	Your parent(s)	39.7% (247)
		Your child or children	25.7% (160)
		Another relative	21.7% (135)
		Another individual	22.2% (138)

* Percentages may not sum to 100% because of missing values.

** Percentages may sum to greater than 100% because more than one response could be provided.

Participants were asked if they had ever talked to someone about **their own care** in case they were unable to make these kinds of decisions at some point in the future. For those responding “yes”, a series of supplemental questions was then asked regarding the nature of these discussions. Results to these questions are summarized in Table 5.

More than half (51%) of the participants indicated that they had had these kinds of discussions regarding their care. Of those who reported having such discussions, 72% indicated that they had appointed a Substitute Decision Maker and 67% indicated that they had completed a Power of Attorney for Personal Care. Approximately 45% of those who had discussed these issues with someone had written down their wishes for future care.

Table 5: Discussion of ACP about Self

Have you ever talked with someone about what care you would like <i>if</i> , at some time in the future, you did not have the mental capacity to make decisions about your care?		If yes ... (N=557)	
No	42.9% (467)	Have you appointed someone as a Substitute Decision Maker (SDM)?	
Yes	51.2% (557)	No	21.9% (122)
		Yes	72.4% (403)
		I do not know what a SDM is	3.4% (19)
		Have you completed a Power of Attorney for Personal Care?	
		No	29.6% (165)
		Yes	67.1% (374)
		I do not know what a POA for personal care is	1.6% (9)
		Have you written down any of your wishes for future care?	
		No	52.4% (292)
		Yes	45.4% (253)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate their knowledge regarding ACP on a five-point scale ranging (where 1=poor, 2=fair, 3=good, 4=very good and 5=excellent). Responses are summarized in Table 6. The majority of participants (57%) rated their knowledge of ACP as “fair” to “good”; 44 of the respondents said they did not know their level of knowledge of ACP.

Table 6: Knowledge of ACP Self-Assessment

How would you rate your knowledge of Advance Care Planning (i.e., planning for a time when a person may no longer have the mental capacity to make decisions about his or her care or treatment)?	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
	15.7% (171)	31.4% (341)	25.6% (278)	15.1% (164)	2.9% (32)	2.53 (1.1)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate how important they thought it was to plan for a time in the future when they may not be able to make decisions regarding their care. Ratings were recorded on a four-point scale ranging from “not at all important” (1) to “very important” (4). Responses are summarized in Table 7. The vast majority of respondents (86%) indicated that ACP was “quite” or “very” important.

Table 7: Perception of Importance of ACP

How important do you think it is to plan for a time in the future when you <i>may not</i> have the mental capacity to make decisions about your care?	Not that Important 1	Fairly Important 2	Quite Important 3	Very Important 4	Mean (SD)
	1.6% (17)	8.7% (95)	27.3% (297)	58.7% (639)	3.49 (.73)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate their understanding of the availability of resources to help with ACP on a five-point scale ranging from “poor” (1) to “excellent” (5). In general, the participants did not have a very good understanding of the resources available to assist with ACP; only 2% rated their understanding in this area as “excellent” (see Table 8).

Table 8: Understanding of Available ACP Resources

How would you rate your understanding of what resources are available to help you with Advance Care Planning?	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
	21.6% (235)	32.2% (350)	25.4% (276)	13.8% (150)	1.9% (21)	2.39 (1.1)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate their level of comfort with discussing ACP with their physician or other health care professional using a five-point scale ranging from “not comfortable” (1) to “very comfortable” (5). The participants indicated that they generally felt comfortable discussing ACP issues with their physician or other health care workers with the most common response being “very comfortable” (see Table 9).

Table 9: Level of Comfort in Discussing ACP with Physician or Health Care Worker

On a scale of 1 to 5, how comfortable are you in talking about Advance Care Planning issues with a physician or other health care professional?	Not Comfortable 1	2	3	4	Very Comfortable 5	Mean (SD)
	4.7% (51)	9.3% (101)	20.9% (227)	20.6% (224)	39.3% (427)	3.85 (1.2)

* Percentages may not sum to 100% because of missing values.

In a similar question, participants were asked to rate their level of comfort with discussing ACP with their family or friends. Again, participants generally felt comfortable discussing ACP issues with family and friends (see Table 10).

Table 10: Level of Comfort in Discussing ACP with Family Members or Friends

On a scale of 1 to 5, how comfortable are you in talking about Advance Care Planning issues with a family member or friend?	Not Comfortable 1	2	3	4	Very Comfortable 5	Mean (SD)
	2.9% (32)	6.4% (70)	17.8% (194)	23.5% (255)	44.5% (484)	4.05 (1.1)

* Percentages may not sum to 100% because of missing values.

POST-WORKSHOP QUESTIONNAIRE

A total of 1014 individuals completed the post session evaluation questionnaire.

On this questionnaire, participants were first asked to rate the education session on a five-point scale ranging from “poor” (1) to “excellent” (5). Responses are summarized in Table 11. The majority of participants (approximately 80%) rated the session as “very good” or “excellent”.

Table 11: Overall Session Rating

Overall, how would you rate today's session?	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
	0	2.0% (20)	17.7% (179)	47.7% (484)	32.2% (326)	4.11 (.75)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate their knowledge of ACP now that they had attended the session. Ratings were recorded on a five-point scale ranging from “poor” (1) to “excellent” (5). Responses are summarized in Table 12. Over half (51%) of the participants rated their knowledge as “very good”, whereas on the pre-test only 15% of participants provided this rating (see Table 6). This represents a dramatic increase in self-assessed knowledge surrounding ACP issues that may be attributable to participation in the ACP education sessions.

Table 12: Perception of Knowledge Rating

Now that you have attended this session, how would you rate your knowledge of Advance Care Planning (i.e., planning for a time when a person may no longer have the mental capacity to make decisions about his or her care or treatment)?	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
	0.4% (4)	5.2% (53)	30.5% (309)	51.1% (518)	11.9% (121)	3.69 (.76)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate the importance of planning for a time in the future when they may not have the mental capacity to make decisions about their care using a five-point scale ranging from “not that important” (1) to “very important” (5). Responses suggest that the vast majority of participants (72%) felt that planning for the future in relation to ACP was “very important” (see Table 13). This represents an increase over the perceived level of importance of ACP on pre-test (59%) (see Table 7).

Table 13: Importance of ACP Rating

How important do you think it is to plan for a time in the future when you <i>may not</i> have the mental capacity to make decisions about your care?	Not that Important 1	Fairly Important 2	Quite Important 3	Very Important 4	Mean (SD)
	0.3% (3)	2.9% (29)	24.5% (248)	71.7% (727)	3.69 (.54)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate their understanding of the resources available to help with ACP. Responses were recorded using a five-point scale ranging from “poor” (1) to “excellent” (5) and are summarized in Table 14. The average rating was 3.5 or between “good” and very good”; on the pretest, the average rating was 2.4 or between “fair” and “good” (see Table 8).

Table 14: Understanding of Resource Availability in Relation to ACP

How would you rate your understanding of what resources are available to help you with Advance Care Planning?	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
	0.7% (7)	10.7% (108)	35.5% (360)	39.9% (405)	9.8% (99)	3.49 (.85)

* Percentages may not sum to 100% because of missing values.

Participants were asked about their level of comfort in talking about ACP with their physician or other health care professional. Ratings were on a five-point scale ranging from “not comfortable” (1) to “very comfortable” (5) and responses are summarized in Table 15. Nearly half (47%) of participants felt “very comfortable” discussing ACP with physicians or health care professionals; this represents an increase from pre-test levels where 39% of participants reported this level of comfort (see Table 9).

Table 15: Comfort in Discussing ACP with Physicians or Health Care Professionals

On a scale of 1 to 5, how comfortable are you in talking about Advance Care Planning issues with a physician or other health care professional?	Not Comfortable 1	2	3	4	Very Comfortable 5	Mean (SD)
	1.8% (18)	4.7% (48)	17.0% (172)	26.8% (272)	47.0% (477)	4.16 (1.0)

* Percentages may not sum to 100% because of missing values.

A similar question asked participants to rate their level of comfort in discussing ACP with members of their family. Again, responses were recorded on a five-point scale ranging from “not comfortable” (1) to “very comfortable” (5). Over half (56%) of participants indicated that they felt “very comfortable” in discussing ACP with their family (see Table 16); this represents an increase from pre-test levels where 45% of participants indicated this level of comfort (see Table 10).

Table 16: Level of Comfort in Discussing ACP with Family Members or Friends

On a scale of 1 to 5, how comfortable are you in talking about Advance Care Planning issues with a family member or friend?	Not Comfortable 1	2	3	4	Very Comfortable 5	Mean (SD)
	1.0% (10)	2.2% (22)	12.1% (123)	25.8% (262)	56.0% (568)	4.38 (.86)

* Percentages may not sum to 100% because of missing values.

Participants were asked if they were going to talk to someone about the care they would like if, at some point in the future, they did not have the mental capacity to make decisions about their care. Those who responded “yes” were then asked to specify whom they planned to talk with. The majority (87%) of participants indicated that they were planning to discuss these issues with someone in the near future. The individuals most frequently identified as the potential audience for these discussions were their children (64%) and their spouse (49%) (see Table 17).

Table 17: Plan to Discuss ACP and Potential Audience

As a result of this session, do you plan to talk with someone about what care you would like if, at some time in the future, you do not have the mental capacity to make decisions about your care? (N=1014)		If yes, percent (and number) of times each of the following individuals was indicated (N=878) *	
No	3.2% (32)	Your spouse	49.3% (433)
Yes	86.6% (878)	Your parent(s)	13.3% (117)
		Your child or children	64.4% (565)
		Another relative	23.2% (204)
		Another individual	19.2% (169)

* Percentages may sum to greater than 100% because more than one response could be provided.

Participants who indicated that they were **not** planning to discuss their ACP issues were asked to specify why not. Their responses are summarized in Table 18. Of those participants who reported that they were not going to discuss these issues with someone, the main reason for not having these discussions was because they had already done so.

Table 18: Reasons for Not Discussing ACP Issues

- Already done (17)
- I am too young (8)
- I am not ready (4)
- I am unsure (3)

Participants were asked if, as a result of the session, they were planning to talk with someone else about what care **they** would like if they did not have the mental capacity to make such decisions about their care at some time in the future. Those who responded “yes” were then asked to indicate whom they planned to talk with. Again, the vast majority (79%) of respondents indicated that they planned to discuss ACP issues with someone else as a result of the session. Spouses were the most common potential targets for these discussions (see Table 19).

Table 19: Plan to Discuss ACP in Relation to Someone Else and the Potential Audience

As a result of this session, do you plan to talk with someone about what care they would like if they did not have the mental capacity to make decisions about their care at some time in the future? (N=1014)		If yes, percent (and number) of times each of the following individuals was indicated (N=801) *	
No	6.9% (70)	Your spouse	49.3% (395)
Yes	79.0% (801)	Your parent(s)	25.8% (207)
		Your child or children	38.8% (311)
		Another relative	23.3% (187)
		Another individual	21.8% (175)

Participants who indicated that they were **not** planning to speak with someone else about their wishes were asked to specify the reasons for this decision. Responses to this open-ended question are summarized in Table 20. Again, the most common reason for not discussing ACP issues was that participants had already done so.

Table 20: Reasons for Not Discussing ACP Issues in Relation to Others

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|---|
| <ul style="list-style-type: none">▪ Already done (20)▪ Too young /old (too early / late) (6)▪ Don't know who would be interested (5)▪ Not applicable (5)▪ Not appropriate (5)▪ I am uncomfortable (4)▪ With consent (2) |
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Participants were asked to indicate what other information about ACP would be helpful to them. A variety of responses were provided; these responses are summarized in Table 21.

Table 21: Additional Information Needs

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|---|
| <ul style="list-style-type: none">▪ Assistance / services available (16)▪ More information on POA & power over care (16)▪ The “booklet” mentioned at the session (16)▪ More information about LTC homes (15)▪ Forms to be filled out (10)▪ More information about medical and health decision making (10)▪ More information about financial issues (9)▪ More sessions (9)▪ Scenarios / situations (7)▪ More information about legal issues (7)▪ Check lists (7)▪ More written materials/resources (7)▪ Information about the difference between verbal and signed directives (6)▪ Internet information (5) |
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Participants were asked to provide their comments about the session or about ACP in general. The main themes are summarized in Table 22.

Table 22: General Comments about Session and ACP

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|---|
| <ul style="list-style-type: none">▪ Well done; positive comments regarding the session (253)▪ session “encouraged action” (10)▪ session “encouraged discussion” (7)▪ Informative (5)▪ Purpose of session not clear (4)▪ Too repetitive (4)▪ Too much info, too quickly (4)▪ Reinforced (information) (3)▪ Could be more specific (how to word POA, more details re: wills, funerals, samples of AC plans) (3)▪ Handouts needed (3)▪ Relieved fears (2)▪ Session too long for seniors (2) |
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FOLLOW-UP QUESTIONNAIRE

As described in the introduction of this report, in addition to the pre and post session questionnaires, a follow-up questionnaire was sent to a subset of individuals who attended the public education sessions. The purpose of this questionnaire was to assess the participants' understanding of ACP issues and to determine what the participants may or may not have done in order to prepare for a time when they (or a loved one) may not be able to make decisions about their care, a few months after having attended a session. As with the pre and post questionnaires, participants were asked **not** to put their name on the completed questionnaire. As a result, statistical analyses of the differences between results from the post session and follow-up questionnaires could not be conducted.

Almost 300 individuals were sent a follow-up survey. Only 37% of these individuals completed the questionnaire (see Table 23). Thus, one must be cautious in drawing conclusions from these results.

The results in the remainder of this report are based on the 109 responses received (unless otherwise specified).

Table 23: Follow-up Questionnaire Response Rate

Number of Individuals Surveyed	Percentage (Number) of Respondents
296	36.8% (109)

The first question on the follow-up questionnaire asked participants to rate their knowledge of ACP using the same scale as was used in the pre and post session questionnaires. The majority of participants (64%) felt their understanding of ACP was either "very good" or "excellent" (see Table 24). This rating was similar to that obtained from the post-session questionnaire where 63% of the respondents rated their knowledge of ACP as either "very good" or "excellent" (see Table 12).

Table 24: Perception of Knowledge Rating

How would you rate your knowledge of Advance Care Planning today (i.e., making choices now, while you are capable of deciding how you want to be cared for in the future if you become incapable of making decisions about your personal care or health treatment)?	Poor 1	Fair 2	Good 3	Very Good 4	Excellent 5	Mean (SD)
	2.8% (3)	6.4% (7)	25.7% (28)	46.8% (51)	17.4% (19)	3.70 (.93)

* Percentages may not sum to 100% because of missing values.

Participants were then asked if they had any questions about ACP that arose since they had completed the education session. Individuals who responded "yes", were asked to specify what questions they have had and whether these questions had been answered. Responses are summarized in Tables 24 and 25. Only 15 respondents reported having a question about ACP arise since the education session. Of these individuals, over half were able to find the answer to their question.

Table 24: Questions about ACP

Since the session, have you had any questions about ACP?	Percentage (Number) of Respondents (N=109)	
No	82.6% (90)	
Yes	13.8% (15)	
	If Yes, have you been able to find the answers to these questions? (N=15)	
	No	33.3% (5)
	Yes	53.3% (8)

* Percentages may not sum to 100% because of missing values.

Table 25: Questions that have arisen since the Education Sessions

<ul style="list-style-type: none"> ▪ Re: costs (1) ▪ Who is responsible for ACP? (1) ▪ How does ACP related to living will, POA, substitute decision maker etc? (1) ▪ What if you don't think the other person is capable of making decisions? (1) ▪ Still not sure what options are realistically available (1) ▪ Where are capacity assessments performed? (1) ▪ What kind of small details of my wishes should I be making clear? (1) ▪ Who has the final say, and what is needed to enforce this authority? (1) ▪ What will be still valid in 20 years? (Will what I want still be valid?) (1) ▪ What is a POA for personal care? (1) ▪ How do I convince my MD I want a DNR, think they can save everyone. (1) ▪ How to do proper wording on documents (1) ▪ How to deal with guilt of not being able to communicate with your CR? (can't make support groups because of work) (1)
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Participants were asked if they had used any of the ACP resources they had learned about during the education sessions and, if they had used them, to specify which ones they had used. Responses to these questions are summarized in Table 26. Almost 40% reported using at least one of the ACP resources they learned about from the session. The majority of these individuals (86%) reported using the *Guide to Advance Care Planning*; almost 17% used the wallet cards. In addition, over 80% of those who reported using a resource indicated that the resource was helpful to them.

Table 26: Use of ACP Resources

Have you used any of the ACP resources you learned about during the session?	Percentage (Number) of Respondents	
No	49.5% (54)	
Yes	38.5% (42)	
	If Yes, what resources have you used? (N=42) **	
	Guide to Advance Care Planning	85.7% (36)
	Wallet card	16.7% (7)
	Have these resources been helpful to you?	
	No	0
	Somewhat	9.5% (4)
	Yes	83.3% (35)

* Percentages may not sum to 100% because of missing values.

** Percentages may total greater than 100% because more than one response could be provided.

Participants were asked to rate how important it was to plan for a time when they may be incapable of making decisions about their personal care at some time in the future. Responses were recorded using a four-point scale ranging from “not that important” (1) to “very important” (4) and are summarized in Table 27. The majority of participants (68%) felt that ACP issues were “very important” and none of the respondents indicated that it was not that important. This represents a slight drop in importance when compared with post-session ratings where 72% of participants indicated that these issues were “very important” to them (see Table 13).

Table 27: Importance of ACP Issues

How important do you think it is to plan for a time when you may become incapable of making decisions about your personal care or health treatment at some time in the future?	Not that Important 1	Fairly Important 2	Quite Important 3	Very Important 4	Mean (SD)
	0	5.5% (6)	25.7% (28)	67.9% (74)	3.63 (.59)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate how comfortable they were in talking about ACP with a family member or a friend. Responses were recorded using a five-point scale ranging from “not comfortable” (1) to “very comfortable” (5) and are summarized in Table 28. Over half (55%) of participants felt “very comfortable” discussing ACP issues with family or friends. This is similar to the rating found on the post-session follow-up questionnaire. On that questionnaire, 56% of respondents reported that they were “very comfortable” having such discussions (see Table 16).

Table 28: Comfort Talking about ACP with Family or Friends

On a scale of 1 to 5, how comfortable are you in talking about Advance Care Planning issues with a family member or friend?	Not Comfortable 1	2	3	4	Very Comfortable 5	Mean (SD)
	0	5.5% (6)	6.4% (7)	32.1% (35)	55.0% (60)	4.38 (.84)

* Percentages may not sum to 100% because of missing values.

Participants were asked to rate how comfortable they felt discussing ACP issues with their physician or other health care professionals. Responses were recorded using a five-point scale ranging from “not comfortable” (1) to “very comfortable” (5) and are summarized in Table 29. The majority of participants (49%) indicated that they felt “very comfortable” talking to their physician or other health care professional about ACP issues. This, again, represents a similar finding to that on the post-session questionnaire (see Table 15).

Table 29: Comfort Talking about ACP with Physician or Other Health Care Professional

On a scale of 1 to 5, how comfortable are you in talking about Advance Care Planning issues with a physician or health care professional?	Not Comfortable 1	2	3	4	Very Comfortable 5	Mean (SD)
	3.7% (4)	0.9% (1)	12.8% (14)	31.2% (34)	48.6% (53)	4.24 (.98)

* Percentages may not sum to 100% because of missing values.

Participants were asked if they have had discussions, since the session, about the care **they** would like to receive if they were to become incapable of making decisions about their care in the future. This yes/no question was followed up with questions that asked for details about these discussions. Specifically, participants were asked if they had appointed a substitute decision maker, if they had written any of their wishes down, and if the information presented in the education sessions was of any help in dealing with these issues (see Table 30).

The majority of participants (62%) indicated that they have had discussions about ACP issues; of these individuals, most had appointed a SDM and had written their instructions down. As well, the majority of respondents indicated that the information presented in the education sessions was helpful for these discussions.

Table 30: Discussions about ACP since Education Session

Since the session, have you talked with anyone about what care you would like if you become incapable of making decisions about your personal care or health treatment at some time in the future?		If yes ... (N=67)	
No	32.1% (35)	Have you appointed anyone as a Substitute Decision Maker (SDM)?	
Yes	61.5% (67)		
		No	32.8% (22)
		Yes	64.2% (43)
		Have you written down any of your wishes for future care?	
		No	43.3% (29)
		Yes	55.2% (37)
		Did the information presented in the education session help you with talking about these issues?	
		No	7.5% (5)
		Yes	89.6% (60)

* Percentages may not sum to 100% because of missing values.

Participants were asked if they had talked with anyone about what care **those individuals** would like if they were not capable of making decisions about their care at some time in the future. A follow-up question asked those who responded “yes” to identify who this individual was that they were having discussions with. Additionally, participants were asked if the information presented in the education sessions was helpful in having these discussions. Responses to these three questions are summarized in Table 31.

Approximately 62% of respondents reported talking with someone else about the care that individual would like if that person was not capable of making such decisions at some time in the future. The persons they cited most frequently as those they had spoken with were: spouse, friend or other relative (i.e., not their spouse, parent or child). In addition, the majority of individuals who reported having these discussions said that the information presented in the education session was helpful to these discussions.

Table 31 ACP Discussions Involving Others Care

Since the session, have you talked with anyone about what care they would like if they were not capable of making decisions about their personal care or health treatment some time in the future?		If yes, percent (and number) of times each of the following individuals was reported as they individual that the participant had spoke with (N=67)	
No	29.4% (32)	Your spouse	44.8% (30)
Yes	61.5% (67)	Your parent(s)	25.4% (17)
		Your child or children	20.9% (14)
		Another relative	29.9% (20)
		A friend	35.8% (24)
		Another individual	17.9% (12)
		Did the information presented in the education session help you with talking about these issues?	
		No	6.0% (4)
		Yes	86.6% (58)

* Percentages may sum to greater than 100% because more than one response could be provided.

Participants who had **not** talked about their care wishes or the wishes of someone close to them were asked if they planed to have these discussions in the future. A follow-up question asked them to explain why they had not had these discussions. Results are summarised in Tables 32 and 33.

Table 32 Plan for ACP Discussions

If you have not talked about your care wishes or the wishes of someone close to you, do you plan to talk to someone in the near future?	Percentage (Number) of Respondents
No	5.5% (6)
Yes	50.5% (55)

Table 33 Reasons for Lack of ACP Discussions

<ul style="list-style-type: none"> ▪ feel they are too young still (2) ▪ working on it- is creating a list of preferences (1) ▪ husband awaiting bypass; refuses negative talk (1)

Finally, participants were asked for any additional comments they would like to make about the ACP sessions they had attended. Responses are summarized in Table 34.

Table 34: Feedback on ACP Education Sessions

<ul style="list-style-type: none">▪ Positive feedback; “wonderful session” (17)▪ Should advocate this info to public (7)▪ Want more sessions (2)▪ Encouraged discussion (2)▪ Would like more details (2)▪ Getting started (1)▪ Sorry, procrastinating (1)▪ Chose NH so don’t burden relatives (1)▪ Brought info to church group, now want session for them (1)▪ So important (1)▪ Useful, was prepped for wife’s death shortly after session (1)▪ Wonder if futile, what will health care offer when its time (1)▪ Was misinformed re: topic of session, this was already known, not useful (1)▪ Difficult b/c in middle of needing it right now (1)▪ Depressing (1)▪ Informative but boring (1)▪ Many were disappointed, already have POA, small part of ACP, looking for other info, and some info was inaccurate, will not invite this group in again (1)▪ Feel government should [advertise] to the elderly and baby boomers to make aware burden of choices, to decrease health care dollars and family stress (1)▪ Session was double talk, too repetitive (1)
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