

Advance Care Planning in community dwellers – A constructivist grounded theory study of values, preferences and conflicts

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Advance Care Planning – A prelude to breaking barriers

Guide to Interview Sessions

This is a guide to the semi-structured interviews that will be conducted for the study. In keeping with standard practices in qualitative research, the probes will be refined iteratively throughout the data collection in response to the changing understanding of the phenomenon being investigated.

The session will start with the confirmation that the participants have read the Letter of Information and signed the consent form. Participants will be reminded that they can refuse to answer any questions or stop the interview at any time. If participants appear to be uncomfortable or upset by the topics of the interview, the interviewer will ask whether they would like to pause or end the interview.

Introduction (for interviewer): Thank you for taking the time to meet with me today. The purpose of this interview is to find out how healthy elders think and talk about the types of care they would like to receive in the event that they experience a life-threatening illness or injury. I realize that it may be distressing to talk about the possibility of needing critical medical care, and while you have consented to take part in this recorded interview, you may decline to answer any questions or stop the interview at any time.

There is a list of questions that we will discuss today. However, if important ideas come up that are not directly assessed by these questions then we will take time to explore those ideas.

Interview Questions:

1. Today we want start with Advance Care Planning (ACP).

ACP is making choices now, while you are capable, about how you wish to be cared for in the future. It is also about giving someone you trust the information and authority to act on those wishes for you in case you are not capable of making decisions. This person is called the **substitute decision-maker**.

What kinds of conversations, if any, have you had with your family members or loved ones about Advance Care Planning? Can you tell me about these conversations?

- Suggested probes:
 - What prompted you to develop an ACP? Was it the doctors/family/prior experience with a friend or family member?
 - How would you describe the process of developing your Advance Care Plan? How much time would you say that you spent on thinking about and discussing this matter? Did it take a lot of thinking/discussion with loved ones? Could you describe those conversations to me?

- Here is a list of treatments that can be provided in the hospital. Did any of these treatments come into the conversation when you were developing your ACP? ([APPENDIX H](#))
 - Did you seek any available resources (such as the internet, brochures) to develop your ACP?
- Suggested probes for participants who say they do not have ACPs:
 - Are you planning on completing your ACP? How long have you been thinking of doing it?
 - Could you explain / describe why you have not developed your Advance Care Plan? Is there anything holding you back?
 - What kind of information or assistance might help you to start an Advance Care Plan?
2. What kinds of conversations have you had with family members or friends about who would make decisions for you if you are unable to make decisions about your care or communicate your wishes?

Do you have a SDM or POA? (Offer plain language definition of SDM and POA) (See [APPENDIX G](#))

A **substitute decision maker (SDM)** is someone who makes decisions on your behalf if you become incapable of making decisions or communicating your wishes on your own.

Power of Attorney (POA) is a legal document that gives someone else the right to act on your behalf.

Do you remember what it felt like to have this conversation? Can you tell me about that?

- Suggested follow-up questions for those who have a SDM:
 - Did your SDM/significant others take part in the decision making process?
 - What did you share with them about your wishes? Did you discuss the need for any of these ICU treatments with them? ([APPENDIX H](#))
 - Do you think they (your SDM) clearly understood the issues? Were they supportive of your decisions?
 - Did you or your SDM feel that they required further information or clarification to make the ACP?
 - Would your SDM be able to respect your wishes even if they were different from their own?

- If no SDM:
 - Have you ever thought about the need for designating an SDM?
3. Do you know if you are an SDM for someone else?
 - Describe to me how you found out or what that conversation entailed?
 - Was it a difficult process? Do you think that your loved one has made an informed decision?
 - Were you able to have an open conversation about this with them?
 - Are you concerned about making the right decisions for them when the time comes? Have you put much thought into it?
 - How has this experience shaped your thinking about advance care planning?
 4. Have any of these impacted your approach to making decisions about your own medical care? How?
 - Conversations / experience with healthcare professionals / hospitals
 - Experience with friends/family
 5. How would you describe your decision planning strategies for personal health care? Are you someone who likes to consult doctors or other professionals, makes decisions together with family members, or someone who would want to make their own decisions?
 6. Tell me what you think about the Intensive Care Units in our hospitals (Offer a plain language definition) (APPENDIX G)

An **Intensive Care Unit** is part of the hospital that cares for patients who are very sick and usually require life support.

How do you think you formed this impression?

7. Have you heard of the concept of a 'Do Not Resuscitate' Order or DNR? What does that mean to you?
8. Tell us what someone may be concerned about when they think of end-of-life. What would you be concerned about when you think of prolonging life through medical means? Have you ever considered treatment options such as life-support. Can you share more on how you came to choose various treatments?

9. Is there anything else related to your experiences with Advance Care Planning that you would like to share with me?

Demographic Information

- Age / Sex
 - Highest Education
 - elementary school
 - some high school
 - some college
 - college degree
 - some university
 - university
 - postgraduate education
 - Where were you born?
 - If you are not originally from Canada, how long have you lived in Canada?
 - Would you identify yourself as belonging to an ethnic group or groups? If so, what is your ethnic identity?
 - Would you say that you are a member of a religious group or that you have a religious practice? If so, which one(s)?
 - Do you consider yourself frail? Where do you think you fit in here?
- (APPENDIX I)

Concluding statement (for interviewer):

I would like to thank you for taking the time to have this interview today. Your contribution is valuable. The information you shared with us today will improve education for health care professionals taking care of patients in the Intensive Care Unit and allow us to respect your choices.

This envelope contains support information that you may need.

Supplementary Table: Decision aid for life-sustaining interventions

Name of Intervention	Description	Implications
Life support	Treatments such as breathing tubes and machines (ventilators /respirators)(<i>see below</i>). It may also involve other treatments such as artificial feeding, dialysis, sleepy medications, and painkillers. All these are artificial means to restore and/or continue life.	Without life support, it may not be possible to survive. The need for continuing life support varies depending on many factors. Long-term life support (2-3 weeks or longer) in the elderly may be associated with decreased chances of returning home and living independently.
Breathing tube	A plastic tube that is placed from the mouth and into the windpipe (the trachea). The procedure is called intubation .	The person is usually kept sleepy and pain free while receiving this treatment so that the ventilator (<i>see below</i>) can do the breathing for the person. This can be a short or long term treatment.
Ventilator/Respirator	A machine that helps a patient breathe through the breathing tube when they cannot breathe adequately on their own.	The person is generally kept sleepy and comfortable so that the machine can do the breathing for the person. This may be required for a short period of time or longer.
Cardiopulmonary Resuscitation (CPR)	Medical procedures used to restart your heart if it stops. CPR can involve mouth-to-mouth breathing, chest compressions and electric shocks that restart the heart. It also involves ventilators /respirators (<i>see above</i>).	Most people who have had CPR need to be treated on a ventilator in an Intensive care unit (ICU) to recover. Very few of such people, who receive CPR, survive to reach home and live independently.
Shock	A medical emergency in which the organs and tissues of the body are not receiving enough blood flow and oxygen. Shock can result in serious damage to the body or even death.	Approximately 30% of people who are in shock due to severe infection and need life support may die before hospital discharge.
Artificial feeding (intravenous/ feeding tubes / PEG)	A way to feed someone who can no longer swallow food.	Most commonly a feeding tube will have a tube inserted into their stomach through

		the nose. Feeding can also take place through special tubes that can be inserted in the body.
Dialysis	A medical procedure that cleans your blood when your kidneys can no longer do so.	Long-term need for dialysis depends on return of the patient's own kidney function. Dialysis sessions may be needed 3-4 times a week.
Do-Not-Resuscitate (DNR)	A written medical order that documents a patient's decision regarding his/her desire to avoid CPR. DNR refers to life threatening situations and should not be mistaken as 'do not treat'.	Usually patients admitted to the hospital have to decide whether they want to be DNR or not. Patients and their SDMs can change their minds about this at any time.

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There is a list of questions that we will discuss today. However, if important ideas come up that are not directly assessed by these questions then we will take time to explore those ideas.

Interview Questions:

10. Today we want to talk about Advance Care Planning (ACP).

ACP is making choices now, while you are capable, about how you wish to be cared for in the future. It is also about giving someone you trust the information and authority to act on those wishes for you in case you are not capable of making decisions. This person is called the **substitute decision-maker**.

1. What was it like for you discussing this topic of ACP in the previous interview?

- Did you come away with new, changed or any, different feelings about ACP?
- Can you tell me a little about what you discussed in the interview you had with the other researcher? About your wishes?

2) Did the last interview and the nature of discussions therein cause you any anxiety / distress?

- If **yes**: How did you feel? What about the interview or parts of the interview were you distressed or anxious about? What do you think made you anxious or distressed? How did you deal with it and how was it for you?

If **no**: Why was this the case?

3) Have you done anything about your ACP since the last meeting? Have you had any further thoughts? Have you sought more information about this topic and how (internet, media, lawyers, doctors, health care workers)? Can you describe how this has been for you?

- If **yes**, what did you do? Can you tell me a little bit more about what you did?
 - What made you do the things you did?
 - What motivated you to do those things?
 - Where do things stand for you now?
 - Have any of your plans or wishes changed?
 - [Note to interviewer to probe for opportunities where participant thought about, learned about, made decisions, talked about, or recorded any actions they have taken]
 - Did you speak to your SDM or have an opportunity to explore these changes further with them? [Depends on what changes or actions they have taken]
- If **no**, what has prevented you from thinking about or making decisions about your ACP?
 - Is there anything specific impeding your thinking or decision making?
 - What could be done to support you in making an ACP (if they have not) or thinking about this more?
 - Do you think this feasible or advisable for you?

4) Have you changed your mind in any way about how you thought about ACP after the last meeting? Has your overall thinking about ACP changed since our last meeting?

5) As an interviewer, I do not know if you had already had any conversations with your SDM about ACP prior to our last meeting? Was this the case?

Do you have a SDM or POA? (Offer plain language definition of SDM and POA) (See APPENDIX G)

A **substitute decision maker (SDM)** is someone who makes decisions on your behalf if you become incapable of making decisions or communicating your wishes on your own.

Power of Attorney (POA) is a legal document that gives someone else the right to act on your behalf.

Suggested probes for those who say yes to the above question:

- What kinds of conversations, if any, have you had with your SDMs, family members or loved ones about ACP since our last meeting? Do you remember what it felt like to have this conversation? Can you tell me more about that?
- Was it difficult or awkward to hold the discussion this time around? If yes, why? Did it take a lot of thinking and effort to bring up this topic with your loved ones? Could you describe those conversations / feelings to me?

- Did your SDM take the time to listen to you? Did they have any questions? What did they have to say about it? Are you sure they understood your wishes and would be able to respect them?
- Did you show them the information (table) we had provided to you? Why or why not?
- Did they suggest to you that you needed to speak to someone else (such as your clergy, GP, specialist/other) about it?
- Do you have any further plans to implement or decisions to make in regards to ACP?

Suggested probes for participants who say no to the above question:

- Why do you think you have not been able to do this? Can you describe those thoughts / reasons for me? Or do you think it not really important? If you don't think so, what could be the other reasons for you not to have pursued this?
- Do you have plans or intentions to discuss them with this? How would you go about it? What sort of thoughts or plans would you share? How would you go about it?
 - If no SDM at all (including the last meeting):
 - Have you ever thought about the need for designating an SDM?

6) Are you an SDM for someone else?

- If yes, did our last interview change your thoughts about what being a SDM involves? Could you please describe that to me?
- If no, would you be willing to have this responsibility? Why do you feel this way?

7) When you think about advance care planning and someone being ill, where do you think these decisions for care made are made? When you think about end of life decisions, what setting or environment are they taking place in?

An **Intensive Care Unit** is part of the hospital that cares for patients who are very sick and usually require life support and similar treatments.

- Do you remember this Table?
 - If yes: Did you have any questions about the different options and choices since last time you saw this?
 - If no: Would you to look at it, so that you could refresh your memory. Does this ring any bells? Have you had any further thoughts on this?
- Have you had any further thoughts or questions about any of these treatments? How has knowledge of these made you feel? Now that you have had some time to think about them, what do you want your SDM to know about these treatments?
- Do you feel like you can make choices about whether or not you would want any of these treatments? Or does it depend on something else?
 - What is it that would make you able to decide?

10) Now that we have interviewed 20 people about their ACP, we would like to make sure that we question the assumption that everyone should have one. Do you think there are any ways in which it is harmful to do ACP or reasons not to do it?

- Do you think it is important that people should have an ACP?
 - If yes, when do you think is the most appropriate time to have people complete an ACP?
 - In no, why not?
- Who should be involved in helping with ACP?
- Can you think of any reasons why people would not want to discuss ACP, or make plans for their future care?
- Are you satisfied with the amount of advance care planning you have done to this point?

11) **OPTIONAL FOLLOW-UP QUESTION** [Give speak up book] Have a look over this please, do you feel that you are able to answer these questions?

12) Is there anything else related to your experiences with Advance Care Planning that you would like to share with me?

Concluding statement (for interviewer):

I would like to thank you for taking the time to have this interview today. Your contribution is valuable. The information you shared with us today will improve education for health care professionals taking care of patients in the Intensive Care Unit and allow us to respect your choices.

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