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Does implementation matter if comprehension is lacking? A qualitative investigation into perceptions of advance care planning in people with cancer

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Does implementation matter if comprehension is lacking? A qualitative investigation into perceptions of Advance Care Planning in people with cancer

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Abstract

Purpose

While advance care planning holds promise, uptake is variable and it is unclear how well people engage with or comprehend advance care planning. The objective of this study was to explore how people with cancer comprehended Advance Care Plans and examine how accurately advance care planning documentation represented patient wishes.

Methods

This study used a qualitative descriptive design. Data collection comprised interviews and an examination of participants' existing advance care planning documentation. Participants included those who had any diagnosis of cancer with an advance care plan recorded: Refusal of Treatment Certificate; Statement of Choices; and/or Enduring Power of Attorney (Medical Treatment) at one cancer treatment centre.

Results

Fourteen participants were involved in the study. Twelve participants were female (86%). The mean age was 77 (range: 61-91) and participants had completed their advance care planning documentation between 8 and 72 weeks prior to the interview (mean 33 weeks). Three themes were evident from the data: Incomplete advance care planning understanding and confidence; Limited congruence for attitude and documentation; Advance care planning can enable peace of mind. Complete advance care planning understanding was unusual; most participants demonstrated partial comprehension of their own advance care plan, and some indicated very limited understanding. Participants' attitudes and their written document congruence was limited, but advance care planning was seen as helpful.

Conclusions

This study highlighted advance care planning was not a completely accurate representation of patient wishes. There is opportunity to improve how patients comprehend their own advance care planning documentation.

Keywords

Advance care planning, advance directives, end-of-life, preferences, wishes, statement of choices, refusal of treatment certificate, medical treatments

Introduction

Advance Care Planning (ACP) is a process whereby a person, in consultation with health care providers, family members and important others, makes decisions about their future health care, should they become incapable of participating in medical treatment decisions or providing informed consent.[1] ACP involve active contemplation by a person about their values and wishes, and also engagement with relevant stakeholders including loved ones, carers and health practitioners, and documentation of these values and wishes for future reference. Key components of ACP include choosing a substitute decision maker, identifying personal values, communicating with substitute decision-makers and clinicians, and documenting wishes, values and preferences for future medical care.[2]

Several studies have explored the benefits to ACP. A paper reporting on a randomised controlled trial found that in a cohort of elderly patients, ACP was associated with improved end of life care and higher family satisfaction when opportunities to talk through concerns, decisions, preferences and choices were provided.[3] Reviews of the literature reported that ACP is beneficial to patients, health care providers and families, through increasing the use of palliative care, increasing patient quality of life, increasing patient satisfaction, improving patient-clinician communication, and reducing hospital admissions.[4-6] Another systematic review, focusing on whether ACP documentation increased timeliness of end of life discussions, found there was insufficient evidence that the documentation enhanced the timeliness or effectiveness of end of life communication.[7]

While ACP is being increasingly implemented in oncology settings, several barriers to routine implementation exist. Despite policy imperatives, there are issues with uptake and implementation of ACP,[8, 9] and there ~~are~~ may not always be systems or processes in place to facilitate the development of advance care plans.[10] Challenges include the desire to sustain hope in cancer patients, a lack of consensus about who in the clinical team should initiate discussions, complexities of prognostication and the process of decision making in ACP, and health professional, patient and caregiver time constraints.[11]

Although intervention studies aiming to increase ACP documentation and adherence have been conducted,[12, 13] it is still unclear how well patients engage with, and understand ACP. Not all patients have the health literacy (defined as the ability to seek, understand and utilise health information[14]) to reflect on their wishes, communicate and record them and update them as needed. A previous qualitative study found that seven of 18 patients guessed or assumed ACP involved planning for future illness; and one incorrectly defined it as an outpatient follow up.[11] A recent American study found discordance between Physician Orders for Life Sustaining Treatment forms and current treatment preferences.[15]

The objective of this study was to explore the comprehension of ACP in people with cancer who have current advance care plans. ~~how people with cancer comprehended advance care plans.~~

Specifically, the aims of this study were to explore how patients interpreted and understood their current advance care plans and explored the congruence of advance care plan documentation with patient wishes.

Methods

This study used a qualitative descriptive design. Qualitative description provides a comprehensive summary of phenomena and can incorporate grounded theory techniques.[16, 17] The research approach included single telephone interviews with people with cancer who have ACP documentation in place, and reviewing of existing advance care planning documentation. This study was approved by local human research ethics committees at Deakin University (approval number 2015-288; 16 November 2015), Eastern Health (E20-2015; 30 October 2015) and Cancer Council Victoria (IER1508; 29 September 2015). Informed consent was obtained from all individual participants included in the study. The consolidated criteria for reporting qualitative research (COREQ) checklist was adhered to [18] although transcripts were not returned to participants for comment or correction at the completion of the interview. Data collection occurred between December 2015 and May 2017.

Participants

Participants had a diagnosis of cancer (solid or haematological, of any stage) with an advance care plan recorded with the health service (specifically, Refusal of Treatment Certificate, Statement of Choices and/or Enduring Power of Attorney [Medical Treatment]). ACP documentation was either completed at this site or completed elsewhere and lodged with the health service. Participants were over the age of 18, able to read and speak in English to provide informed consent and participate in a telephone interview. Sampling was purposive with a focus on participants with a range of ACP documents approached for participation.

Data Collection

Potential participants were recruited from a single health service, identified by trained clinical staff involved with ACP. Once identified, a member of the clinical team made contact to ask whether the patient would be interested in participating in a study involving an interview. If the patient approved, their phone number and name were passed to the interviewer (CB) who contacted the patient to explain participation requirements and answer any questions. If interested, a participant information sheet was posted and the telephone interview scheduled. At the beginning of the interview, the interviewer confirmed that the participant had read the participant information form and consent was recorded in the form of recorded verbal agreement to participate prior to commencing the interview. Participants consented to both participation in the interview and to having their advance care plan documentation forwarded to the researchers. Interviews were tape recorded and transcribed verbatim. The research team were forwarded a copy of ACP documentation of participants from the site at the end of data collection.

Interviews were conducted over the telephone. An interview schedule is presented in Table 1. Demographic and clinical details were recorded by the clinical team.

Analysis

In this study, grounded theory techniques included inductive, cyclic and comparative analysis. Qualitative description was used to examine participants' ACP interpretation and understanding. ATLAS/ti qualitative data management software supported data analysis.[19] A document was also created to support correlation of participants' understanding of their wishes and their recorded ACP documentation in local health service records. These data were also compared with ACP definitions

adopted for this study, including Statement of Choices, Refusal of Treatment Certificate and Medical Enduring Power of Attorney (Medical Treatment) (Table 2).

The audio-recorded interviews were transcribed and analysed as follows: coding (text segments ascribed with researcher created labels); category development (labels created to represent comparable code groups); and thematic development (labels created to represent comparable groups of categories and their codes). CO conducted the initial analysis. To achieve rigour, a data analysis document was created and inter-rater reliability strategy integrated. AU examined the data and analysis and then discussed the findings with CO who was in agreement. CB also examined and agreed with the findings. The analysts are experienced qualitative researchers.

Results

Twenty-two participants were identified as eligible and were approached by the health care team to schedule an interview. Four did not participate stating that family members did not want them to participate, two refused (n=1 did not want to be interviewed for up to an hour; n=1 did not provide a reason) and one consented but did not schedule an interview. A total of 14 (64%) interviews were conducted. Interviews lasted between 19 minutes and 53 minutes (mean 33 minutes). Participants had completed their ACP documentation between 8 and 72 weeks prior to the interview (mean 33 weeks).

Twelve of the fourteen participants were female (86%). The mean age was 77 (range: 61-91) years. Four participants reported a diagnosis of gastrointestinal cancer (29%), four reported haematological cancers (29%), three had breast cancer (21%), two had melanoma (14%) and one had a gynaecological cancer diagnosis (7%).

Three themes were evident in the data: Incomplete ACP understanding and confidence; Limited Congruence for Attitude and Documentation; Advance care planning can enable peace of mind. Themes are presented with supporting quotes, with P1-P14 representing the participant number.

Incomplete Advance Care Planning Understanding and Confidence

Participants' comprehension about what ACP comprised widely varied. Complete ACP understanding was unusual; most participants provided partial explanations, and four indicated very limited understanding. For example, one participant believed that ACP was when, "you get to the stage where you have got to go into palliative care because you can't look after yourself" (P11). A further participant equated ACP with "assisted dying" (P12). One participant reflected on some documents she remembered signing, arranged with a hospital and asked, "Would that be the advanced care?" (P6).

While many participants were optimistic that their own advance care plans would be actualised, and confident that family would uphold their wishes, others were concerned about a lack of application, noting they were not sure whether their documentation would be correctly used if needed. This was highlighted if they had witnessed a close person's poor quality end of life care experience. One participant stated: "I lost my sister in Canberra, and she had all those – not to be resuscitated documents et cetera, et cetera. But the hospital didn't have them, did they? So they kept resuscitating her." (P6)

One participant was uncertain whether her wishes would be acted on as she had not heard back from clinical staff who helped her complete the documents, adding that they could be “forgotten”. (P2) Another stated, “There’s no way to know whether the hospital would actually go through that process [of contacting Enduring Power of Attorney (Medical Treatment)]”. (P10). A further participant stated that they were confident about the healthcare system’s role in fulfilling advance care plans, until:

“I was in hospital and I was sick the doctor came and said to me, ‘I want to talk about something. Have you got written down you don't want CPR (cardio pulmonary resuscitation)?’ and I said, ‘Yes’, and she was horrified that I'd done that and I thought – I couldn't understand why she was worried about it and I thought to myself then, I wonder if the doctors would just ignore it.” (P10).

While most did not think that ACPs should be overridden, many speculated about when they could be. Additionally, many participants were unsure about the legality of various components of their advance care plans.

Limited Congruence for Attitude and Documentation

Overall, the congruence between participants’ ACP related attitudes and their written document was limited. Only five ACP written statements concurred with descriptions of participants’ plans. This included a participant who had no recollection of creating a plan; which had been created 30 weeks ago. She stated, “This is the first time I sort of have been questioned, or even thought about it”. (P4) Nonetheless, wishes expressed in her interview concurred with her documentation.

Three participants’ (21% of the sample) written advance care plans did not concur with their wishes. Two of these participants had completed their advance care plans over a year ago; one had completed the documentation 13 weeks ago. These included a participant who indicated they “wanted CPR” in the documentation, but stated, “I've told my daughter, you know, if anything happens and I'm - you know, got something serious and I am non-compos or whatever, just let me go.” (P11). Additional interview content not stated in her documentation included the desire for a nursing home if needed and no family visitors if “a vegetable”. Participant 13, who also did not remember completing an ACP, stated her wish to be “filled” with morphine and “let go” if seriously unwell whereas her documentation requested that doctors decide whether to administer life prolonging treatments. Her ACP documentation also included no limb amputation, yet in the interview P13 stated that treatment for amputation would be desired if needed. Further, P9 indicated in the interview that she wanted to donate organs and that CPR was not wanted, whereas her documentation did not include a desire for organ donation, and also indicated, “Yes” for “wants CPR” and “No” for “does not want CPR”. Like a number of others, this participant also erroneously completed this section through not signing one box as requested.

Six of the participants’ ACP documents (43% of the sample) only partially reflected ACP statements made in the interview, with many adding wishes not recorded in their ACP documentation. Participants’ 12 and 2 stated that their bodies were assigned to a University for the purposes of scientific research but this was not indicated in the ACP documentation.

Advance Care Planning Can Enable Peace of Mind

Most participants reported creating an ACP document was helpful by enabling them to work through what they wanted, and/or to feel empowered, peace of mind, secure, calmer, and/or relieved that their wishes are known. When questioned on whether there was anything to be gained from having an ACP, one participant however stated that having the ACP documentation was not helpful but “just something I think people should have”. (P11) She added, “The only thing I think - you know, like maybe when it was put to me, I just thought, well, like, legally is it better to have one? Because I mean, my family know how I feel.” (P11).

Some participants considered ACP advantageous because it removed difficult decision-making from family members. One participant said that ACP has “given me peace of mind that my children don't have to make those decisions because it's not fair on family to make those decisions” (P3), and another said that having ACP documentation meant that, “my family doesn't have to do anything” (P14). Similarly, another stated, “I think it's wise to have it written down, because it – it helps the patient. Like it would help me. And moreover, it would help my family, because they could say, ‘Oh, thank God, mum's made the decision, we don't have to make a decision for her’” (P13). The abrogation of doctors from decision-making was also considered a positive outcome from ACP: “It has helped because we've made decisions that ... the medical staff don't have to make” (P3).

Discussion

This study aimed to understand the comprehension of ACP in people with cancer who have current ACP documentation. Comprehension was incomplete and at times preferences and attitudes were not accurately represented within ACP documents. Despite this, ACP was seen as positive by many participants. Three participants had ACP documentation that did not concur with wishes and was considered inconsistent. A further six participants made statements and wishes that were not covered in their documentation. This would suggest that ACP was frequently not an accurate representation of patient's current wishes, ACP was inadequate to capture values, or wishes may change over time.

In the third theme it was evident that some participants reported that creating an Enduring Power of Attorney (Medical Treatment) created peace of mind for themselves. Other studies have reported that ACP can help families prepare for the death of a loved one, enhance relationships and resolve conflicts.[20] In a randomised controlled trial, family members had higher levels of satisfaction and lower levels of morbidity post-patient death when the patient was in the ACP arm of the trial.[3] However recent research suggests there may also be negative aspects to being a substitute decision maker. A qualitative study consisting of focus groups with older people and caregivers found that some caregivers who had acted in a substitute decision maker role previously experienced distress related to their decisions.[21] Similarly, another recent qualitative study with patients and their substitute decision-makers, found substitute decision-makers can have different views to patients, and efforts to promote ACP may be most successful if patient and substitute decision-maker beliefs are addressed.[22] Past research also found that some caregivers could make subsidiary plans and not necessarily follow patient advance care plans.[23] These findings, and-with the results from the study, highlight the importance of ensuring that substitute decision-makers understand patient views, and substitute decision-makers must feel equipped to represent patient wishes as distinct from their own. This understanding is central to effective ACP, and conversations about end of life preferences need to include this important group.

This research found a lack of concordance between documentation and preferences. ACP attempts to record patient views into a usable clinical document that fits within the law to preserve patient autonomy. Exploring ways to make sure this documentation meets legal and organisational requirements, yet represents patient wishes, is accessible and able to be updated will be paramount to the ongoing success and rollout of ACP. Much of the ACP literature focuses on ensuring high levels of implementation and uptake[12, 13, 24] but results of this study would suggest that comprehension is also important. A systematic review of interventions to improve participants understanding of informed consent for research found that multimedia interventions had limited success in improving patient comprehension, whereas having someone available to talk one-on-one to patients appeared to be more successful.[25] Our research would suggest that there is a need for more studies to trial strategies such as these to improve ACP comprehension as well as implementation, as there is a lack of evidence based approaches to measure and improve comprehension. For this study, recruitment occurred from a health service with dedicated ACP staff, and participants could have ACP documentation completed at the health service or any other health care or community setting. Research and policy must focus on ~~strategies exploring approaches~~ to ensure these records are accurate, accessible and well understood by both participants and health professionals. Given that some participants in our study had either forgotten doing an advance care plan, or had different attitudes to those on their original advance care plans, we suggest that future research could examine an ACP one-on-one reminder strategy with accompanying invitation for an advance care planning review.

Participants in this study were diverse in terms of how long ago they had completed ACP documentation; ranging from approximately two months to over a year. Further research should examine whether this is a relevant factor in reduced concurrence of wishes and documentation. The potentially long time between advance care plan completion and interview could mean that patients experienced problems with recall; however, regardless of the reason, incongruence between wishes and plans is problematic. Although this was a small sample, two of the three participants who had a lack of concurrence between their wishes and their documentation completed their plans over a year ago. Reviewing and updating documentation is seen as a critical part of ACP.[26] These findings suggest there is importance in strategies and systems that allow patients, their caregivers, family and substitute decision-makers, and clinicians to update and revise these plans as needed. There is not specific evidence as to when ACP decisions should be revised, however, potentially this should be routinely updated as personal or clinical circumstances change.[27] Even in the absence of a change of circumstances, the findings from this study would suggest regularly revisiting content including discussions with family and clinicians, and ensuring that any updated documents are registered with relevant sites for use if required.

This study is limited by a small sample size and single site. ~~The sample is also~~ is diverse for type of advance care plans and time between completion of plans and the interview ~~for this study~~ (ranging between eight and 72 weeks). A further limitation is that ACP documentation was only retrieved from the health service where participants were identified; documentation lodged or stored at other sites or with general practitioners was not explored. Future research could adopt a similar data collection strategy and explore comparison between existing documents to understand comprehension in different settings, including different healthcare organisations and also states or countries where there is different legislation. Quantifying this process and collecting data in a survey format could allow for a larger sample size and predictors of concurrence could be identified.

Expanding this methodology could allow for recommendations about the specific aspects of ACP that require improved description and communication, which could assist in the development of strategies to improve concurrence and comprehension. Recommendations about, and an approach to, reviewing and updating ACP documentation is also likely to improve the relevance and utility of these documents. These results, along with others,[11, 21, 22] also demonstrate the important contribution of qualitative research in understanding how ACP can be optimised.

Ensuring people with cancer comprehend and engage with ACP is paramount to ensure people receive the type of health care they want to receive if they became ill or injured and unable to articulate what they want. However patient comprehension appears to be lacking and there can be a lack of concurrence between patient wishes and documentation. In this study, ACP documentation was frequently not a completely accurate representation of patient wishes. In some cases, the documentation incorrectly represented participant views.

While there is a policy and research focus on improving implementation of ACP, the outcomes from this study would suggest that it is also important to explore strategies to improve comprehension and ensure concordance of documented preferences with patient wishes. ACP documentation is limited if it does not represent patient wishes.

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Conflict of Interest

This project was funded by a Deakin University Faculty Research Development Grant. Anna Ugalde is supported by an Alfred Deakin Postdoctoral Research Fellowship. The authors declare they have no conflicts of interest.

The authors note the data reported in this study cannot be made available due to ethical requirements.

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TABLE 1: Interview Schedule

<i>These first questions focus on what advance care planning means to you:</i>
1. What is your understanding of your current health situation?
2. What is your understanding of the term ‘advance care planning?’
3. How did you come to have an advance care plan (ACP)?
4. How has the ACP helped you, if at all?
5. When considering important decisions about health, some people like to think about the decision on their own or with doctors, some people like to share decisions with their families or others. How do you tend to make decisions about your health?
<i>The following questions are to explore your advance care planning wishes and to understand your ACP documentation.</i>
6. If you become seriously unwell in the future and are not in a position to make decisions for yourself, what is important to you regarding your future care?
7. Can you tell me more about your advance care plan?
8. How well do you think your ideas (paraphrase from question 6) are expressed in your written advance care plan?
9. How confident are you that your written advance care plan will be acted upon if necessary?
<i>The next questions will focus on your understanding of advance care planning. There is a lot of different terminology used for advance care planning, with different meanings, which is not always clear.</i>
10. There are several ways to participate in advance care planning. You have spoken about [paraphrase from question 7: statement of wishes, medical power of attorney, refusal of treatment certificate]. Are you aware of other parts to an ACP?
11. What is your understanding of Enduring Medical Power of Attorney (medical treatment)?
12. What is your understanding of statement of choices?
13. What is your understanding of refusal of treatment certificate?
14. Can you please tell me under what circumstances do you believe that doctors can override any parts of a person’s advance care plan, if at all?
15. Do you believe that a family member can ever override your advance care plans?
16. Some people are willing to talk about advance care planning but don’t want to have any ACPs documented. Do you have any thoughts on why that might be?
17. Do you have any ideas for how to help others talk about advance care planning?

TABLE 2: Summarised definitions of terms used in the study

TERM	DEFINITION	Authority
Refusal of Treatment Certificate	A certificate that an adult (18 years or older) with decision-making capacity can complete to refuse treatment for a current medical condition. The Refusal of Treatment Certificate applies at all times, unless revoked or suspended, including after the person loses capacity to make their own medical decisions. It is unlawful for medical practitioners to provide to a person any treatment that they know has been refused in a Refusal of Treatment Certificate.	<i>Medical Treatment Act 1988 (Victoria)</i>
Enduring Power of Attorney (Medical Treatment)	A legal document under which a person appoints another person (or 'agent') to make medical decisions on their behalf should they lose capacity to make their own decisions in future. At the time the research was conducted the Enduring Power of Attorney (Medical Treatment) was the only substitute decision-maker in Victoria empowered to <i>refuse</i> treatment on the principal's behalf.	<i>Medical Treatment Act 1988 (Victoria)</i> <i>Guardianship and Administration Act 1986 (Victoria)</i>
Statement of Choices	A written record of a person's preferences in relation to future medical treatment and care to guide decision-making for them should they lose the ability to make or communicate their own decisions. It can record people's values, life goals and preferred outcomes, or directions about care and treatments. If the person loses capacity, their substitute decision-maker and healthcare team should refer to and respect (so far as reasonably possible) the statement of choices in making medical decisions for them. The legal status of the Statement of Choices has been unclear in Victoria in the context of the existing statutory framework.	Advance Care Planning Australia

Note: These definitions are specific to Victoria and are correct at the time the research was conducted and at publication. Advance care planning legislation, and terminology differ from state to state in Australia and between countries; the following definitions may not be the same in other jurisdictions. These are abridged definitions; please refer to the original sources for more detail.