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How Can Advance Care Planning Support Hope in Patients with Advanced Cancer and Their Families: A Qualitative Study as Part of the International ACTION Trial

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Abstract

Purpose: Clinicians' fears of taking away patients' hope is one of the barriers to advance care planning (ACP). Barriers to ACP were extensively studied, however, research on how advance care planning potentially supports hope is scarce. The concept of hope in the terminally ill is context-specific and difficult to operationalize. This study aimed to explore aspects of hope supported by structured ACP conversations.

Methods: In an international qualitative study using in-depth interviews we explored ACP experiences of patients with advanced cancer and their personal representatives (PRs) within the cluster-randomized control ACTION trial.

An established sensitizing concept of hope in terminal illness (with several themes such as facilitating control, interpersonal relationships etc.) served as a point of reference in identifying attributes of hope supported by ACP conversations. A thematic analysis was performed on segments of text relevant to answer the research question.

Results: Twenty patients with advanced lung or colorectal cancer and 17 personal representatives from Italy, the Netherlands, Slovenia and the United Kingdom were interviewed after participation in structured ACP conversations. Three potential mechanisms through which hope may be supported were recognized for patients and their PRs: (I) achieving a greater sense of empowerment for the future; (II) experiencing participation in ACP conversations as an act of mutual care; (III) strengthening shared confidence and partnership. In addition, our results suggest that participants' hopes for cure or longevity persist after ACP conversations.

Conclusion: We identified various potentially hope supporting mechanisms of ACP conversations cultivating agency, mutuality and interdependency between people involved.

Introduction And Background

Advance care planning (ACP) enables patients to define goals and preferences for future medical treatment and care, to discuss these preferences with family and health-care providers, and to record and review them if appropriate (1).

Hope in patients with a life-threatening illness may be defined as being global in nature, moving from, or alongside, hopes for longevity or cure, to hopes embedded in relationships (2). Patients are usually hoping for comfort, quality of life, spirituality, supportive relationships, positive expectations for the time left and positive character traits (2-6). Hope is an expression of agency in the face of significant challenges (7).

Hope is widely considered to be essential to well-being and quality of life and even to life itself (8, 9). There is evidence of hope being sustained in palliative and dying patients (3, 10-12). Patients receiving palliative care feel that hope is a vital coping resource against despair - giving them resilience to carry on (10). Worry of health care professionals that ACP may take away hope is one of the main recognized barriers in initiating ACP (13-15). ACP conversations include sensitive topics, such as asking patients about their preferences for care if they become unable to make their own decision. Clinicians often perceive such questions as incompatible with promoting hope and maintaining normality in patients' remaining lifetime (16). Quantitative studies have indicated that engaging in ACP does not diminish hope or increase hopelessness (17-19) nor does ACP disrupt

hope for a cure in most patients and their loved ones (20). ACP may even enhance hope through provision of timely appropriate information (21).

Findings from qualitative and concept analysis studies (2, 3, 8, 10, 11, 21) provide us with a sufficient understanding of the concept of hope and themes that foster hope in the context of palliative care, but we lack an understanding of potentially effective mechanisms of supporting hope in the context of ACP. The aim of this study was to explore how ACP conversations support different attributes of hope as conceptualized in the medical and nursing literature.

Methods

As part of the cluster-randomized controlled ACTION trial evaluating the ACTION Respecting Choices (RC) ACP intervention in six European countries (22), we carried out a qualitative study in four of these countries (Italy, Netherlands, Slovenia, United Kingdom) to explore how patients and their personal representatives (PR) experienced taking part in the ACTION RC ACP intervention. This study reports on how taking part in the ACTION RC ACP intervention may support hope.

The ACTION RC ACP intervention is an adapted and integrated version of the RC ® First Steps and Advanced Steps RC facilitated ACP conversation (more details can be found at www.respectingchoices.org). It consists of three components: 1) The ACP conversations between the patient and, if they wish, his/her relative, and a certified facilitator; (2) the My Preferences form, and (3) information leaflets.

In the RC facilitated ACP conversations, certified facilitators use conversation guides to support patients and their relatives in exploring the understanding of their illness, in reflecting on their goals, values, beliefs and hopes and in discussing their preferences for future treatment and care.

Ethical approval

Ethical committee procedures have been followed in all countries and institutions involved, and approval has been provided.

Sampling and recruitment

Patients with a diagnosis of lung cancer (stage III or IV) or colorectal cancer (stage IV or metachronous metastases) and, if involved, the person the patient nominated as their PR, were invited to participate in the ACTION RC ACP intervention and in subsequent semi structured qualitative interviews. For details about the inclusion criteria, recruitment strategy and the ACTION RC ACP intervention, we refer to the ACTION project article and the research protocol (23-25). Data for the qualitative interviews were collected between January 2017 and July 2018.

Data collection and analysis

Semi structured interviews which followed the ACTION RC ACP intervention were based on topic guides with questions about current health circumstances, experiencing the ACP conversations, nominating and involving a person as their PR and outcomes of the ACP conversations. The ACP conversations and the interviews were audio recorded and transcribed verbatim.

We did not ask participants directly about how ACP supports their hope or narrow our search on the word "hope" in the interviews, as hope can be less consistently understood across participants. We used Johnson's rich conceptualization of hope in terminally ill patients (2) to sensitize ourselves to features of data indicating attributes of hope. Johnson described ten essential attributes of hope: positive expectations, personal qualities, spirituality, goals, comfort, help, interpersonal relationships, control and life review (2). For example, Johnson argued that having some degree of control, especially about making decisions, and having honest relationships contributes to patients' hopes.

Johnson's concept analysis was recognized as a notable work in terms of explicating a wide scope of aspects of hope from the perspective of the terminally ill and is in accordance with qualitative studies examining strategies to enhance hope (26). Our analytical approach (Flow-chart 1) involved researchers from each participating country examining participants' accounts of how they experienced ACP conversation and identifying relevant interview segments (see Supplementary Material 1 for more information about identifying relevant segments) indicating facilitation of hope attributes described by Johnson (2). It has been demonstrated that sensitizing concepts can be effective in suggesting directions along which to look in the initial analysis, a place to start inquiry, not to end it (27, 28).

Additionally to the interview segments, we analyzed parts of the ACP conversations where patients reflected on their hopes as a part of the intervention. We did so to check whether recognized hope-enhancing aspects were in some way related to patients' explicitly stated hopes. Analysis and data were discussed during regular meetings and email correspondence between researchers from all teams.

Results

Twenty patients, including 17 patients with their PR, participated in interviews following the intervention; four from Italy, five from Slovenia and the Netherlands and six from the United Kingdom. Sixteen patients had advanced lung cancer and four had advanced colorectal cancer. Patients were aged from 50 to 88, with mean age 66. Eleven patients were men and nine were women. Twelve PRs were partners of patients and five were adult children. Fourteen patients engaged in two interviews and six in a single interview. Twenty-one interviews were undertaken jointly with the patient and PR together (Table 4).

Hope in the context of ACP

When asked directly about hope during the ACP conversation, participants expressed hope for longevity or even a possible cure. Other themes of hope mainly addressed close relationships, comfort and quality of life. Patients hoped not to suffer and not to be a source of problems for others.

In the interviews following the ACP conversations, participants reported oscillating between states of being more aware of their illness versus normal living with low levels of awareness. One participant claimed that the ACP conversation had a short-term effect in a sense of raised distress.

At first, I was not happy about it [ACP conversation]*, quite the opposite; I had a moment where I thought to myself, "Damn, there are so many things to fight right now, and the sadness. We would be better off without this." Well, it became clear with time, after a few days had passed and feelings have faded that this is good, you take the information you need and you move on* (PR 4, 1st Interview, Italy).

Participants described actively creating a positive and constructive mind-set or imagining that the discussed issues related to the distant future, which helped them to maintain some degree of emotional distance in relation to ACP.

So that brought an opportunity for us to open up a little bit more and talk about it. And because we've got such a positive mind, whatever was said, we were able to kind of, respond to it… we're not at the upset stage… (PR 1, 1st interview, UK).

When asked about the ACP conversation, participants referred to some attributes of hope in the palliative care setting as suggested by Johnson (2), such as sense of control, inner strength and interpersonal relationships, as being enhanced or strengthened by the ACP conversation. Exploring these statements further, we described three ways in which ACP may support hope for patients and their PR: (1) Achieving a greater sense of empowerment. (2) Experiencing participation in ACP conversations as an act of mutual care. (3) Strengthening shared confidence and partnership.

1. Achieving a greater sense of empowerment for the future

ACP helped some participants to explore ways to cope with the scenario of health decline, which for some seemed unimaginable. A sense of agency and/or control, which is a key attribute in most conceptualizations of hope, was fostered in some by gaining more information, enabling self-expression, and by engaging others, who were available to support them through decision-making process and reaching mutual agreements for the plan of care at the end of life (Table 1).

Table 1. *Achieving a greater sense of empowerment*

Representative quotes
Being informed
It was helpful. Of course. We can talk about it at home, but you get a professional perspective from a conversation like this. Before, you didn't even think about certain things. Little details can open you up. You start to think in a different way, but not in a radical way. In a way that might be good, I could do that too. It helped a lot (Patient 1, 1st interview, Slovenia).
Building a capacity to participate in care
…to understand the disease better, what kind of behaviour one should have, how to communicate with doctors in a clearer way, because if one knows a little more one can ask better questions (Patient 1, 1st interview, Italy).
Engaging others
[to the PR] *I'd like you to fulfil that role, of course in close collaboration with my children. And thereby respecting my strong wishes, that's most important to me* (Patient 2, 1st interview, The Netherlands).
An enhanced capability to act in favour of the patient
…for me it's really helpful to know that I'm able to make the right choices for her, the moment she is not able to do this herself (PR 3, 2nd interview, The Netherlands).

A few patients reported, “taking care of ACP” or “putting it in writing” gave them “peace of mind” or “unburdened them” because “things are now clear”.

2. Participating in ACP is experienced as an act of mutual care

Participants’ explicitly stated hopes during the ACP conversation commonly revolved around care for their loved ones. Relationships are recognized as paramount to hope. Engaging in ACP could be a way to express caring and support, especially through the PR or facilitator confirming availability to address patient’s needs and wishes (Table 2).

Table 2. *Mutual care*

Representative quotes
Being heard
… to give people who are in a state of vulnerability and dependency, the feeling of being accepted, heard, and for those around them to feel less lost … It is important because of the feeling that I share these issues with another human being and the fact that he participated [in ACP] (Patient 2, 1st interview, Italy).
Well-being of loved ones
…, it’s given me the opportunity to think about everything, prepare everything, sort of make sure everything is stable for everybody, then they don’t have so much hassle in the future (Patient 1, 1st interview, UK).
ACP as a form of support
… you can share your feeling with someone else… it is, however, a form of support. A support in a sense that you can share your experiences, not only with your partner (PR 4, 2nd interview, the Netherlands).

3. Shared confidence and partnership may be strengthened

Engaging in ACP sometimes meant entering a new and often difficult territory together; this could allow further strengthening of open and honest communication. Some participants claimed they would not have discussed end of life (EOL) matters otherwise. Facilitating such discussions, however challenging these may be, enabled some of them to relate to emotional aspects of the process and allowed a greater sense of partnership and shared responsibility in facing potential illness progression; some perceived ACP as an act of courage, a willingness to confront fears and vulnerabilities together.

Table 3. *Building shared confidence and partnership*

Representative quotes
Enhancing open communication and shared responsibility Researcher: *Do you think that your conversation with the facilitator in any way influenced the conversations you have with each other?* Patient: *Yes, it freed them. I did not allow crying in my presence I said [to my wife] if you want the best for me, do not cry. However, we did not talk. My son also told her not to cry. After the conversation, we started talking.* *PR:* *It is a lot easier now that we talk openly. We are not hiding anything. It feels good to talk… I feel as if all the responsibility and suffering is not on my shoulders.* (Patient and PR 1, 2nd interview, Slovenia). **Being more prepared** *But because it creates more kind of, ideas in your head around, okay, this is, it's like, not pushing things away… it's out in the open, and let's talk about it and make us more stronger as well, and prepared… It's preparing your mind set, really, so yeah, it was useful…"* (PR 1, 1st interview, UK). *…maybe you could see it as a kind of our general repetition, during which was confirmed that we are in full agreement and that we won't have a problem with that and that everything can be talked about openly and well, done* (Patient 2, 1st interview, the Netherlands).

Table 4. *Sample characteristics*

Participant	Sex (P)	Age(P)	Country	No. of ACP discussions	No. of Interviews	PR's relation to P	Cancer	Treatment
P1	M	71	IT	2	2	-	Colorectal	CT & TT
P2 & PR2	F	58	IT	2	$2^{(s)}$	ex-partner	Colorectal	CT & TT
P3 & PR3	F	55	IT	2	$2^{(s)}$	son	Colorectal	CT
P4 & PR4	M	69	IT	1	1	daughter	Lung	CT & TT
P5 & PR5	M	51	NL	1	2	wife	Lung	CT & RT
P6 & PR6	F	64	NL	2	1	partner	Lung	CT & RT
P7 & PR7	F	53	NL	2	2	husband	Lung	TT
P8 & PR8	M	73	NL	2	2	wife	Lung	TT & IT
P9 & PR9	M	77	NL	1	2	wife	Lung	CT
P10 & PR10	M	63	SI	1	2	wife	Lung	RT
P11 & PR11	F	55	SI	1	2	son	Lung	RT & IT
P12 & PR12	F	55	SI	2	$1^{(s)}$	daughter	Lung	TT & CT
P13 & PR13	F	88	SI	1	1	daughter	Lung	TT
P14 & PR14	M	63	SI	2	2	wife	Lung	CT & RT
P15 & PR15	M	62	UK	1	2	wife	Lung	CT
P16	M	86	UK	1	2	-	Lung	IM
P17 & PR17	M	75	UK	1	2	Wife	Lung	RT & IT
P18 & PR18	M	81	UK	1	1	wife	Lung	CT
P19 & PR19	F	50	UK	1	1	Husband	Lung	PC
P20	F	78	UK	1	2	-	Colorectal	PC

Note. M and F are used to represent male and female, respectively. P and PR indicate patient and personal representative. Abbreviations are used to indicate countries and treatments: IT (Italy), NL (the Netherlands), SI (Slovenia), UK (the United Kingdom), CT (chemotherapy), TT (targeted therapy), RT (radiation therapy), PC (palliative care). $^{(s)}$ indicate separate interviews for patient and personal representative

Discussion

Hope is frequently defined as the expectancy of something good in the future and a question arises on how ACP conversations that include sensitive topics, such as end of life care, could support elements of hope? To answer this question we acknowledged hope in patients with advanced illness as being multi-faceted and achievable no matter how poor one's prognosis (2). Patients and their family members in our study harbored a range of hopes. Usually hope for living a “normal” life as long as possible prevailed. Other themes of hope mainly addressed close relationships, comfort and quality of life. Additionally, we used a sensitizing concept to draw our attention to instances of hope attributes in participant's accounts of how they experienced ACP. We did so to find a variety of hope-supporting mechanisms within the experience of ACP we would otherwise have overlooked, such as enhancing control, personal qualities (namely courage) and strengthening relationships. Our results show that for some participants, ACP has the potential to enhance hope through promoting a proactive stance and helping to feel empowered to act in the present out of concern for self and others. Furthermore, hope can be supported through containing thoughts, feelings, wishes and expressing mutual care during ACP conversations, and through strengthening shared confidence and partnership in meeting the demands of possible illness progression.

Clinical experiences of working with dying patients and their families show that hope can be fostered through relational actions, not only by a preferred outcome (29). Our results confirm that participants value ACP as a relational process that emphasizes engagements between patient, PR and healthcare professional over time.

Health care professionals’ effort to understand how patients and family members respond to ACP is important; especially because their understanding guide their practice. For example, their perceptions of what is good for patients and a desire to protect them and themselves are directly connected to decisions about initiating discussions about EOL care or not (30, 31). This is especially relevant in cultures where ACP is not part of mainstream patient-centered care and introducing ACP at earlier stages of illness is frequently avoided (32).

While ACP might intensify somewhat unpleasant emotions linked to focusing on scenarios related to EOL (33), participants in our study reported having shifts in their attention as they changed context, with strong preferences to retain a focus on continuing to live a “normal life”.

Our findings support a relational approach to ACP (33, 34). From this perspective, it can provide an opportunity for patients and their significant others to explore subjective worlds and unknown territories together. Papadatou (35) refers to “growth” in the context of palliative care as something that “occurs between people in the context of relations that become personal” and our findings show that ACP has a potential to support intimacy and honesty.

Though the facilitated ACP RC intervention was standardized, participants engaged individually with different expectations and objectives, e.g. acquiring information about their illness, engaging a family member or making advanced treatment decisions. Understanding the goal of ACP as a means by which patients exercise control over treatment choices at the EOL is too narrow, as studies have shown (33, 36). Some more fundamental and complex relational and emotional needs may be addressed in the process of ACP, which should be taken into account when discussing hope in relation to ACP. For many, agency is put in the service of caring for others; for example, to act on patient’s behalf to secure desired outcomes or to spare a family

member the difficulties related to decision-making. Growing intimacy and open communication were reported by some participants as a result of the intervention which is important in the light of (6) notion that new targets of hope in patients with life-threatening illness are likely embedded in their intimate relationships. There is evidence of the crucial significance of relational dimensions in patients' hoping in the context of palliative care (4, 37, 38).

Our findings contribute to an analysis of the value of ACP beyond outcomes such as completion of advance directives or preferences for future care. We suggest that supporting hope in the context of ACP refers to enabling a collaborative space where agency for the case of illness progression is supported and intimate and sometimes difficult thoughts and emotions are contained. From this interpersonal realm, shared confidence may emerge. Hope for a cure or longevity is usually held simultaneously with other hopes. ACP engagement can be an affirmative act promoting fortitude, intimacy and a sense of shared reality for some patients and their family members.

Strengths and limitations

Our findings extend observations from previous studies on hope in the context of ACP and contribute international data to this literature. It is important to note that ACTION RC ACP conversations avoid the predominantly biomedical model of discussing end-of-life care preferences and are taking into account emotional, psychological and social aspects in such planning as well. Bearing in mind that participants' understanding of hope in relation to ACP could be limited or hard to grasp if asked directly, we decided to search cues in their spontaneous talks about the intervention in order to explore more subtle aspects of ACP in supporting hope. However, whereas using this conceptual framework on hope did alert us to a range of important aspects, it might also direct our attention away from some other potentially important aspects.

Our approach of analyzing parts of data explicitly on hope in ACP conversations and searching for the various aspects of hope according to Johnson model in the subsequent interviews, allowed us to confirm the relevance of identified hope-supporting mechanisms for participants' explicitly stated hopes, which often addressed close relationships and quality of life.

We make no claim for generalizability of our findings. This study was done in a cancer population and our findings may not be relevant for all populations requiring palliative care.

Conclusion

Despite the challenges of ACP processes for patients with advanced cancer and the difficulties and resistance participants sometimes felt in imagining the future, our study suggests that structured ACP conversation, addressing clinical, emotional, psychological and social aspects of patients' experience might support some hope-enhancing attributes. It is important to bear in mind that whereas ACP has a potential to support hope, this is not always the case and we cannot make conclusions about how meaningful the ACP intervention was for participants' lives based on our results.

By exploring areas within control and promoting a proactive stance, some patients and their family members can achieve a greater sense of empowerment for their future. ACP is often perceived as an act of mutual care. Shared confidence and partnership may emerge during ACP conversations or they may be strengthened. This

study confirmed that frequent fears of “taking away hope” by initiating ACP conversations, when facilitated in a structured way and with good general communication skills are not founded.

Declarations

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Availability of data and material: The datasets generated and/or analyzed during the study are not publicly available, but are available from the corresponding author on reasonable request.

Code availability: Not applicable.

Authors’ contribution: We made great efforts to work collaboratively at each stage. HKČ and UL conceptualized the study. Eventually, all authors discussed and agreed with the main focus and design of this study. FB, GC, MK, GM, JS, AT, MZ and KP screened data extraction strategy document and conducted data input. HKČ and UL took the lead in analysis and interpretation of data. With many helpful comments, all authors were involved in interpretation of data. HKČ drafted the manuscript. All authors provided critical feedback and helped shape the manuscript. All authors approved the version to be published and have participated sufficiently in the work to take public responsibility for the content.

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Consent to participate: Informed consent was obtained from all individual participants included in the study.

Consent for publication: Participants signed informed consent regarding publishing their data.

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Figures

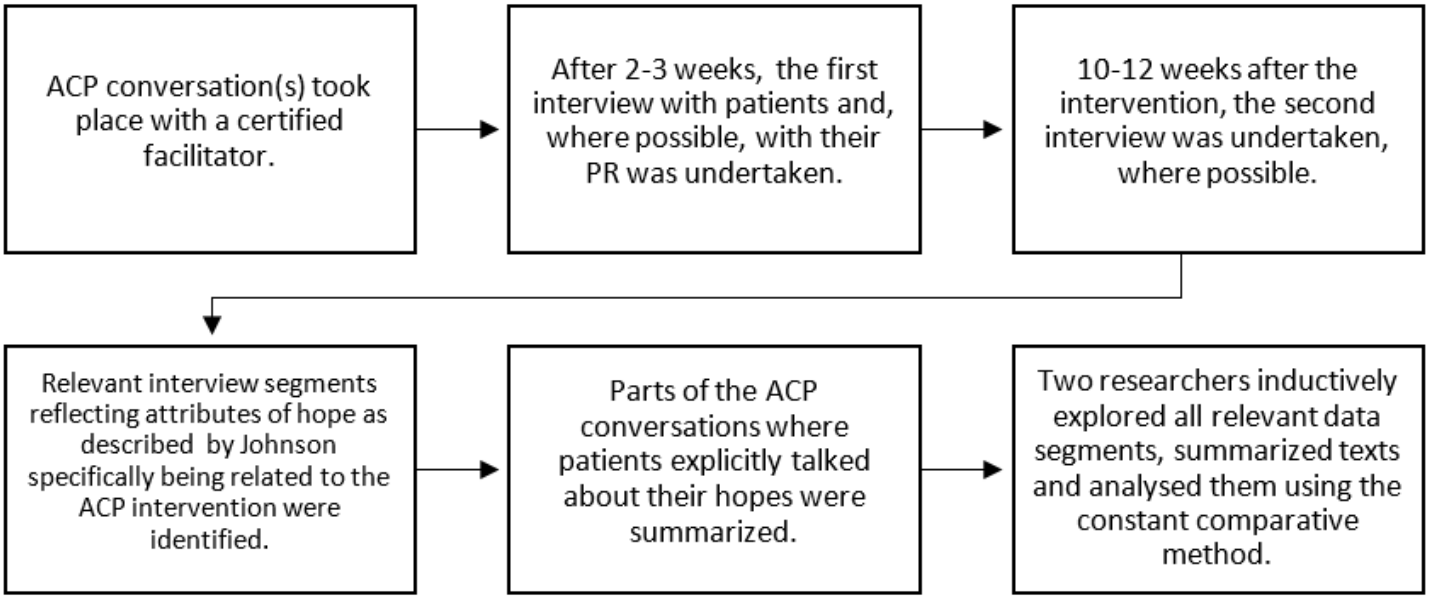

Figure 1

Flow-chart of data collection and analysis procedure

Supplementary Files

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- SupplementaryMaterial1ACTIONHOPEIdentificationform.docx