

This is the peer reviewed version of the following article: Walczak A1, Henselmans I, Tattersall MH, Clayton JM, Davidson PM, Young J, Bellemore FA, Epstein RM, Butow PN. A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program. *Psychooncology*. 2015 Mar;24(3):287-93. Which has been published in final form at, doi: 10.1002/pon.3635. This article may be used for non-commercial purposes in accordance with Wiley Terms and Conditions for Self-Archiving.

Title: A qualitative analysis of responses to a question prompt list and prognosis and end-of-life care discussion prompts delivered in a communication support program

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Research Support: This research was supported by funding from the National Health and Medical Research Council of Australia (Project Grant: 571346)

Conflict of Interest: The authors declare no conflicts of interest.

Originality: This manuscript represents original work and has not been accepted for publication elsewhere in part or in whole

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Running head: Response to end-of-life QPL & discussion prompts

Keywords: oncology, cancer, end-of-life communication, qualitative research, advance care planning, prognostication

Abstract:

Objective: Discussing end-of-life (EOL) care is challenging when death is not imminent, contributing to poor decision-making and EOL quality-of-life. A communication support program (CSP) targeting these issues may facilitate discussions. We aimed to qualitatively explore responses to a nurse-led CSP, incorporating a question prompt list (QPL – booklet of questions patients/caregivers can ask clinicians), promoting life expectancy and EOL-care discussions.

Methods: Participants met a nurse-facilitator to explore an EOL-focussed QPL. Prognosis and advance care planning (ACP) QPL content was highlighted. Thirty-one transcribed meetings were analysed using thematic text analysis before reaching data saturation.

Results: Thirty-one advanced cancer patients (life expectancy <12 months) and 11 family caregivers were recruited from 6 medical oncology clinics in Sydney, Australia. Intent to use the QPL related to information needs, involvement in care and readiness to discuss EOL-issues. Many participants did not want life expectancy estimates, citing unreliable estimates, unknown treatment outcomes, or coping by not looking ahead. Most displayed interest in ACP, often motivated by a loved one's EOL experiences, clear treatment preferences, concerns about caregivers or recognition that ACP is valuable regardless of life expectancy. Timing emerged as a reason not to discuss EOL-issues; many maintaining it was too early.

Conclusion: Patients and caregivers appear ambivalent about acknowledging approaching death by discussing life expectancy, but value ACP. Given heterogeneity in responses, individualised approaches are required to guide EOL discussion conduct and content. Further exploration of the role of prognostic discussion in ACP is warranted.

Introduction

Cancer progression, health decline and death are somewhat predictable. Knowing one's life expectancy and planning care may afford opportunities to prepare for the end-of-life (EOL) and ensure care is consistent with personal values. Timely doctor/patient communication about prognosis and EOL issues is vital. Such discussions may reduce aggressive EOL medical care and associated costs [1], increase early hospice referral [2], increase satisfaction with care and improve quality-of-life and survival [3,4].

Many health policies and guidelines [5,6] advocate Advance Care Planning (ACP) discussions include life expectancy dialogue, reasoning that knowing life expectancy is short encourages and enables patients to form cogent future care plans. Such discussions present many challenges. Doctors' avoidance of life expectancy discussions is common [7], often fearing destruction of hope or therapeutic relationships [8]. Patients' readiness for discussions is variable, depending on factors including exposure and adjustment to disease, coping style and spirituality [9]. Consequently, doctors and patients may "collude" to avoid EOL preference discussions [10]. These often first occur near death during acute hospital admissions [11] when critical chemotherapy or life support decisions may already have been made. Indications as few as 14% of doctors know patients' pain management or place of death preferences [12] and many palliative chemotherapy recipients misunderstand its non-curative intent [13] suggest poor quality communication.

External prompts normalising and placing EOL issues on the consultation agenda may be beneficial. Providing cancer patients with pre-consultation question prompt lists (QPLs – evidence-based booklets containing questions patients/caregivers can ask clinicians) can facilitate question asking, specifically about topics like prognosis [14]. QPLs are valued for showing the range of discussion topics, assisting question formulation and highlighting

clinicians' willingness to discuss all subjects [15-17]. QPLs have been shown to facilitate palliative care setting EOL discussions [16], however guidelines recommend such discussions happen earlier in the disease trajectory [18]. Acceptability and potential efficacy of an EOL QPL in the oncology setting is unclear.

This paper presents a qualitative analysis of patient/caregivers responses to nurse-facilitated delivery of an EOL-focussed QPL within a Communication Support Program (CSP) for oncology patients with a prognosis of less than one year. Data was drawn from participants in the intervention arm of a broader RCT evaluating the CSP [19]. Primary intervention goals were assisting patients/caregivers in meeting their life expectancy and EOL-related information needs and promoting ACP discussions. This analysis aimed to explore patient/caregiver response to the QPL and their openness to discussing prognosis, EOL-issues and ACP.

Methods

Participants and procedure

English-speaking adult oncology patients with advanced, incurable heterogeneous cancer diagnoses and an oncologist-assessed 2-12 month life expectancy and their English-speaking adult primary informal caregivers gave informed consent for participation.

Consecutive patients and caregivers were identified by oncologists at six treatment centres in Sydney, Australia, were informed that the study was evaluating strategies to help with the difficult discussions and decisions they may face in the future and were recruited by research assistants.

Participants completed demographic questionnaires and were randomised to receive CSP or standard care. CSP sessions were audio-recorded and transcribed verbatim. Sampling

of CSP session content from the intervention arm of the trial [19] continued until data saturation (no new themes). Patient age and gender and which nurse facilitator delivered the session were monitored to avoid overrepresentation of any group.

Ethical and governance approvals were granted by Sydney South West Area Health Services Ethics Committee and governance officers for Royal Prince Alfred, Royal North Shore, Concord Repatriation General and Campbelltown Hospitals.

The communication support program

The communication support program (CSP) [19] was informed by the self-determination theory of health-related behaviour change [20,21], and aimed to increase 'autonomous motivation' to discuss prognosis/EOL-care preferences and 'competence' to undertake such discussions. Two nurses were trained to deliver the intervention, consisting of 1) a face-to-face meeting and 2) a follow-up phone call. Patients (and their participating caregiver) attended a 60-90 minute face-to-face meeting at their treatment centre approximately 1 week before a follow-up oncology consultation. Nurses established rapport and introduced a previously developed and piloted QPL for patients with advanced, incurable cancer and their caregivers [22]. It included questions regarding prognosis, treatment options/decisions, palliative care, lifestyle, patient/family support, ACP and caregiver-specific issues. The QPL was explored in depth, focussing on prognosis/EOL-care content, and participants were encouraged to choose questions for their next consultation. This analysis examined responses to the QPL and life expectancy and ACP content during the face-to-face meeting.

Analysis

The research team reviewed and interpreted the data using thematic text analysis with an inductive, data-driven approach [23-25], managed with NVivo [26]. Transcripts were explored with respect to patient/caregiver responses to: 1) the QPL in general, 2) prompting to discuss life expectancy and 3) prompting to discuss ACP. Ten transcripts were initially analysed by two researchers (AW and IH) to form a preliminary code tree, which was applied to 6 further transcripts to refine codes and establish agreement. Remaining transcripts were individually coded. Through iterative reading, recurrent themes and illustrative examples were established. Successive rounds of discussion and resolution of code names/definitions and themes and review of coding procedures by investigators not directly involved in developing the coding framework ensured methodological rigor [27].

Five-point Likert scales of a) intent to use the QPL, b) engagement with exploring the QPL/selecting questions, c) resistance to exploring the QPL, and d) emotional response to the QPL were completed by AW and IH for each transcribed session, based on manualised definitions. Numeric ratings were only completed for patients as caregivers' presence and involvement were highly variable, making consistent application problematic. Responses were collapsed into 3 reporting categories to improve descriptiveness. Patients' willingness to discuss life expectancy and ACP was also rated (yes/no/unclear). Twenty transcripts were double-coded. Cohen's Kappas ranged from .744 to 1, indicating moderate to high inter-rater reliability.

Results

Data from the first 31 patients and 11 corresponding caregivers to receive the CSP were analysed, representing 50.8% of intervention arm patients in the wider trial at publication. Participants included in this analysis did not differ from corresponding participants in the

care as usual arm of the trial. See Table 1 for patient/caregiver characteristics and patient Likert ratings.

Insert Table 1 here

General response to QPL

Approximately 55% of patients displayed strong intent to use the QPL immediately or in the future (n = 17; rating 4/5), 3 some intent (rating 3) and 11 little or no intent (rating 1/2). A little under half were highly engaged in the session (n = 15; rating 4/5), 6 somewhat engaged (rating 3) and 10 hardly/not engaged (rating 1/2). While most displayed no signs of resistance to QPL exploration and selecting questions (n = 20), some exhibited annoyance, uneasiness or disinterest with this process (n=11). In 3 cases, resistance appeared considerable (rating 3/4), however none refused to continue. QPL exploration evoked clear negative emotions in 4 participants (sadness), while possible emotional responses were apparent in another four.

Patients and caregivers with higher information needs (e.g. identified multiple unanswered QPL questions), who appeared more involved in their care (e.g. had previously brought question lists to consultations) and who appeared ready to discuss EOL-issues (e.g. frankly discussed imminent death in the face-to-face meeting) responded more positively to the QPL. Some with very high involvement or information needs had already asked QPL-like questions or received relevant information and were less likely to use the QPL.

SID: 7, female, 54 years – Previously asked questions

Nurse: Were there any questions in the booklet that interested you or that you think you would like to ask?

Patient: I already asked all of them to my doctor... they already answered them.

Nurse: ...Were there any in section eight that interest you?

Patient: ...nothing really... we're all prepared... we've done everything up to the funeral.

SID 21, male, 38 years, - High involvement in care

Patient: ...We do come in with a load of questions. Actually while we're doing this I should write down...

Nurse: Do you normally write a list of stuff before you go and see your oncologist?

Patient: Yes... the two of us work really well... She'll make sure we've got questions going in to make sure that it's happening... (Patient shows example list) there's our last one.

Readiness to discuss EOL-issues appeared influenced by 1) appropriate timing and 2) personal coping style. Some participants stated they coped with illness by being realistic and not avoiding what was to come. Such participants were more likely to be ready for discussions and respond positively to the QPL.

SID 21, male, 38 years – Realism and non-avoidance

Patient: ...when it came down to that point and he said, "Do you really want to know and how much do you want to know?" He said, "Is there a point that you want me to hold back? Do you want the soft or the hard version? ...it's always going to be hard but how do you want it?"

Nurse: What was your answer to that?

Patient: "I want every bit of information you can give me and as detailed as possible." I mean there's no point pussy footing around.

Others maintained that whilst discussing EOL issues may be worthwhile in principle, it was too early to consider them in their present circumstances.

SID 15, male, 70 years – Not ready to ask

Patient: ...there's probably... a lot of questions, but I'm not prepared to ask them yet... I don't want to go down that track; I'm not ready for that...

Further, some indicated that they coped by consciously choosing to live day-by-day and focus on positive information rather than considering negative future outcomes.

SID 8, female, 64 years – Focus on the present

Caregiver: ...you can look at the whole picture and honestly tomorrow the whole picture can be so different... that's pretty much how I think we see our future. We just take a step at a time.

SID 5, female, 77 years – Prefer not to think about negative outcomes

Patient: I don't think I'm going to die that quick... I'm not thinking I'm going to live a hundred years, I'm thinking I still have time really... You have to die one day, nobody can live forever [but] I feel better if I'm not thinking about it

Response to Life Expectancy content/prompts

When presented with QPL questions and prompts to discuss life expectancy, almost half of patients explicitly indicated they did not wish to discuss this during consultations or receive estimates (n = 14 clearly no interest, 6 clear interest, 11 unclear about interest).

Caregivers appeared similarly un-interested. Beliefs about the futility of asking such questions often underpinned this preference. Patients felt life expectancy estimates were too uncertain to be meaningful given ongoing treatment, and that available treatment options might offer many additional years of life.

SID 4, male, 63 years – Answer depends on treatment

Patient: At this time I'll just wait for the treatment to keep going and see how it goes and then we'll start looking at [life expectancy].

Some believed their doctor lacked skills or methodologies to calculate meaningfully accurate estimates or was unable or unwilling to provide one. Others felt their oncologist's discomfort in discussing life expectancy would hinder such discussions, though this was not necessarily unacceptable to patients and caregivers.

SID 28, male, 64 years – Answers inaccurate

Patient: ...I've always known I could ask [DOCTOR] what the prospects are, but in a sense I just thought that was kind of an unfair question... with the anti-cancer diet people... they keep harping on that this person... they'd told they had six months, six weeks to live and they survived it all through by changing their diet...

SID 18, male, 65 years – Answers inaccurate

Patient: ...they can't tell you how long – how long's a piece of string? They can't guarantee; if they say you're going to live 10 years... and your 10 years come up... are you going to die?

SID 2, male, age unspecified – Doctor discomfort

Caregiver: They don't want to approach the topic. I think they're scared, so silence is the easiest way to deal with it... and not knowing, that's the way we deal with it

Finally, several patients thought prognostic information would not be beneficial, as they would live their lives the same regardless of this knowledge.

SID 22, male 61 years – Answer not useful

Patient: I probably ask more... technical questions, not questions about how long I'm going to live and this type of stuff... I just don't think there's an answer there... it doesn't matter that much because one would just sort of trudge on and drop dead, where other

people would be looking at doing things and seeing family and friends overseas and trying to travel round and get their bucket list and tick all those things off.

Response to ACP content/prompts

QPL content and prompts to discuss ACP were well received by most patients (n = 19 clearly interested, 3 clearly un-interested and 9 un-clear about interest). Caregivers appeared similarly positive. Some patients indicated they had already made EoL care arrangements. Half of patients interested in exploring ACP also identified and marked related QPL questions to ask their oncologist (n = 9).

Some were motivated to consider ACP by having experienced the progressive illness and death of a friend or family member. Many cited traumatic experiences resulting from a lack of planning or articulation of preferences. Others described experiences where ACP resulted in better EOL quality-of-life.

SID 4, male, 63 years – Bad EOL experiences

Patient: It's something I have considered a bit... we've spoken about a couple of things, especially things like life support... After seeing my brother, I know that it's just not worth it once you get to a certain stage...

SID 27, female, 55 years – Good EOL experiences

Patient: ...with my friend... I was at her bedside when she died and looked after her with the palliative care nurse for the week before... no body function whatever, but she died at home, she died in her own room, in her own bed, well almost her own bed, they had to bring a bed in... I think dying at home is so much more beautiful if you possibly can...

Several patients recognised that lack of ACP could cause their loved ones significant burden and trauma.

SID 4, male, 63 years – Concern for caregiver

Patient: ...I don't want [WIFE] stuck between 'I can't let him go' ...it's not what I want anyway and it's best if she just accepts and it's something we'll have to talk to someone about, especially from [WIFE]'s point of view, because she's going to be the one left here. I assume I'm going first [laughter].

Other patients held firm EOL-care preferences and sought ACP to ensure their wishes were known and acted upon.

SID 19, female, 59 years – Clear preferences

Patient: We'll find out what happens with this chemo... then we can talk, well as I said to [DOCTOR], I won't have intervention... definitely NFR... I don't want to be kept, so analgesia, maybe hydration ... If I want water, give me water, if I need an IV I'll have that, but I won't have PEG feed, I won't be force fed that way

Finally, many patients and caregivers recognised the benefits of ACP regardless of illness. Several caregivers indicated they would undertake ACP in the future, despite being currently healthy.

SID 8, female, 64 years – Value regardless of health

Caregiver: I need to make one as well... something could happen to me. I suppose my question would be should [PATIENT] make an appointment for medical decisions on his behalf. That would go for both of us really. I should have something done for me as well... I think that's really important.

Discussion

This analysis aimed to describe oncology patient and caregiver reactions to a CSP incorporating an EOL-focussed QPL and prompts to discuss life expectancy and ACP with their oncologist. Similar to earlier findings [22,28], most responded positively to the QPL and prompts to discuss EOL issues. Approximately two-thirds intended to use the QPL in future consultations and did not resist exploring its content. Approximately one-third were less interested, seemingly due to low information needs, very high or very low involvement in care or lack of readiness to discuss EOL-issues. Some may also have resisted due to slow or repetitive QPL exploration.

As expected given the emotional impact of life threatening illness, discussion of the QPL, life expectancy and ACP appeared to sadden a handful of participants. While none were sufficiently distressed to warrant session termination or referral to support services, intervention design should account for the potentially confrontational nature of EOL-focussed communication. A trained nurse-facilitator introducing these topics allowed timely and adequate response to distress.

Interest in ACP was substantial amongst many participants, despite few wishing to discuss life expectancy with their oncologist. Many health policies and guidelines [5,6] advocate that ACP discussions include life expectancy dialogue, reasoning this enables patients to form cogent plans for future care. While awareness of their short life expectancy may encourage patients to undertake ACP sooner, the current findings suggest anchoring ACP to life expectancy discussion could be undesirable, distressing or obstructive for individuals who place little value on life expectancy information. Indications that patients held appropriate EOL-care preferences without wanting life expectancy information supports the contention that hope for cure may not hinder ACP [29].

Participants' willingness to discuss ACP appeared influenced by experiencing friends' or family members' overtly good or bad EOL outcomes, clear established EOL-care preferences or caregiver burden-related concerns. Exploring these experiences, pre-existing EOL-care preferences or concerns may facilitate such discussions. Indeed, evidence suggests such experiences motivate ACP [30]. Further, presenting ACP as a relevant process regardless of health status was well received, particularly by healthy caregivers, and could be used to introduce ACP into the consultation agenda.

Patients' desire for prognostic information is considered relatively ubiquitous [31], however many participants placed little value on this information, a finding not unique to this sample [32]. Some indicated they were not interested in life expectancy estimates, while most reasoned their oncologist would not be able or willing to provide an answer. Some lacked confidence in their oncologist's ability to provide accurate estimates generally or in light of uncertain treatment outcomes. Further, some perceived the oncologist might be afraid or reluctant to provide prognostic estimates or initiate such discussions. This may reflect defence mechanisms suggested by death anxiety theories [33-35] such denial [36] or avoidance of information (blunting) [37]. Patients' recognition of prognostication skills deficits and oncologists' un-willingness to initiate these discussions is noteworthy and deserves further exploration, potentially informing strategies to open prognostic discussions. Our findings suggest meta-communication about the possibility and challenges of prognostic disclosure may be useful.

Participants' intent to use the QPL appeared in part dependent on readiness to discuss EOL issues, with some indicating it felt too early. Guidelines suggest that EOL discussions be offered without pressure at transition points including referral to palliative care, revised treatment regimen or where the patient's life expectancy limits become clear and present

[18]. The importance of timing and readiness for these discussions was apparent, though lack of a clear, agreed-upon time-point where discussing life expectancy and ACP was considered appropriate reinforces that individualised approaches are needed.

It remains unclear whether participants' intent to use the QPL will yield greater question asking, higher quality discussions or whether positive responses to ACP content result in ACP process engagement. Future CSP evaluation will analyse patient and caregiver behaviour during oncology consultations and examine patients' medical records for evidence of ACP completion.

Several methodological strengths and weaknesses warrant consideration. Having been conducted with English-speaking Australians only, responses may not be cross-culturally representative. Indeed, evidence suggests substantial differences in EOL-related communication between cultural backgrounds [38-40]. As QPL and discussion prompts were observed rather than hypothetically reviewed in an interview, thoughts and opinions could not be explored in depth. This design afforded an opportunity to observe natural responses rather than opinions regarding an abstract scenario and may have revealed different findings to interview or questionnaire methodologies. Indeed, negative responses to life expectancy QPL content were not as prominent in a previous study where patients with comparable disease and prognostic profiles provided feedback in focus groups and individual interviews [22] suggesting the current methodology may have provided useful additional insight into how recipients use and value it.

In conclusion, the EOL-focussed QPL was largely well received. Intent to use it in future consultations seemed dependent upon information needs, involvement in care and readiness to discuss EOL-issues. Results suggesting potential benefits from separating

ACP and life expectancy discussions and insights into patients' perceptions of futility in discussing life expectancy and willingness to discuss ACP are noteworthy but require further exploration due to our small sample. The QPL appears to be a promising tool to facilitate EOL discussions and discussion prompts and exploration of its content during the CSP may enhance its effectiveness.

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Table 1: Patient and Caregiver Characteristics and Patient Likert Ratings		
	Patients (n = 31)	Caregivers (n = 11^a)
Age		
Mean	63.0	62.2
Range	33.3 – 84.7	36.2 – 74.8
	n (%)	n (%)
Gender		
Male	17 (54.8)	2 (20)
Female	14 (45.2)	8 (80)
Education		
<Year 10/elementary/some high school	5 (16.1)	4 (12.9)
Year 12/HSC/GED/high school graduate	5 (16.1)	2 (6.5)
Professional qualification/some university/college	14 (45.2)	4 (12.9)
Undergraduate degree	3 (9.7)	
Postgraduate degree	4 (12.9)	
Primary tumour site		
Bladder	2 (6.5)	
Bowel/anus	1 (3.2)	
Breast	6 (19.4)	
Cervix	1 (3.2)	
Kidney	1 (3.2)	
Lung	5 (16.1)	
Mouth/nose/throat	2 (6.5)	
Ovaries	2 (6.5)	
Pancreas	3 (9.7)	
Prostate	5 (16.1)	
Soft tissue	2 (6.5)	
Stomach/oesophagus	1 (3.2)	
Treatments received		
Chemotherapy	30 (96.8)	
Radiotherapy	17 (54.8)	
Surgery	19 (61.3)	
Medical/Allied Health Training	8 (25.8)	1 (3.2)
Relationship to patient		
Spouse		7 (22.6)
Child		1 (3.2)
Parent		1 (3.2)
Friend		1 (3.2)
Intent to use QPL		
Strong intent	17 (54.8)	
Some intent	3 (9.7)	
Little/no intent	11 (35.5)	
Engagement in face-to-face session		
Highly engaged	15 (48.4)	
Somewhat engaged	6 (19.4)	
Hardly/not engaged	10 (32.2)	
Resistance to exploring QPL		
Little/No resistance	20 (64.5)	
Considerable resistance	11 (35.5)	
Refusal	0 (0)	
Negative emotional response to QPL		
Clear emotion	4 (12.9)	
Possible emotion	4 (12.9)	
No emotion	23 (74.2)	
Life expectancy discussions interest		
No interest	14 (45.1)	
Clear interest	6 (19.4)	
Unclear interest	11 (35.5)	

Advance care planning discussions interest	
No interest	3 (9.7)
Clear interest	19 (61.3)
Unclear about interest	9 (29.0)
^a participant characteristics not available for n=1 caregivers	