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Quality versus quantity in end of life choices of cancer patients and support persons: a Discrete Choice Experiment

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ABSTRACT

Objectives: To explore in a sample of medical oncology outpatients and their nominated support persons (SPs): (1) the relative influence of pain, consciousness, and life extension on end-of-life choices using a Discrete Choice Experiment (DCE); (2) the extent to which SPs can predict the choices of index patients; and (3) whether having a previous end-of-life discussion was associated with dyad agreement.

Methods: Adult medical oncology patients and their SPs were approached for consent to complete a survey containing a DCE. Participants chose between three unlabelled care scenarios characterised by three attributes: pain (mild, moderate or severe), consciousness (some, half or most of time) and extension of life (1, 2 or 3 weeks). Respondents selected: 1) most-preferred and 2) least-preferred scenarios within each question. SPs answered the same questions but from patient's perspective.

Results: A total of 110 patients and 64 SPs responded overall (42 matched patient-SP dyads). For patients, pain was the most influential predictor of *most-* and *least-preferred* scenarios ($z=12.5$ and $z=12.9$). For SPs, pain was the only significant predictor of *most* and *least-preferred* scenarios ($z=9.7$ and $z=11.5$). Dyad agreement was greater for choices about *least-* (69%) compared to *most-preferred* scenarios (55%). Agreement was slightly higher for dyads reporting a previous EOL discussion (68% vs 48%; $p=0.065$).

Conclusion: Patients and SPs place significant value on avoiding severe pain when making end-of-life choices, over and above level of consciousness or life extension. People's views about end-of-life scenarios they most as well as least prefer should be sought.

INTRODUCTION

Eliciting patient preferences for end-of-life care can assist clinicians to align care with what is most important to the patient. It is often assumed that people wish to avoid death no matter what the alternatives[1]. However, studies exploring people's views of what is most important at the end-of-life suggests that maintaining quality of life is often equally or even more important than life extension[1-3]. Fewer people choose life-sustaining treatments when the expected outcome is functional or cognitive impairment than when the expected outcome is death [2]. Seriously ill people have also rated living with particular health states, such as incontinence (69%), relying on breathing tubes (67%) or feeding tubes (55.6%) and depending on others for care all the time (54%), as worse than death[1]. Concerns for loved ones, having the opportunity to say goodbye and maintaining independence may have also been reported to influence patient end-of-life care choices[4].

Family and friends of patients often have a critical role in making end-of-life decisions, especially if the patient experiences a loss of capacity at the time of decision-making[5]. This is particularly pertinent to cancer patients who experience a rapid or unexpected decline in functioning. However, studies have shown that judgements about end-of-life issues do not always accord between cancer patients and their support persons (SPs)[6-8]. A systematic review of 16 studies highlighted that SPs incorrectly predict patients' end-of-life treatment preference in one third of cases[9]. Others report that when asked what contributes to a 'good death', SPs more frequently selected life extension (80%), quality of life (70%), dignity (70%), and presence of family (70%) compared to patients (35%–55% across indicators) [10]. When SPs views do not reflect patients' true preferences, higher rates of distress and unwanted medical treatments may occur[11, 12].

While practice guidelines recommend using patient values to guide end-of-life decisions and care, recent studies suggest that using specific value statements in situations where trade-offs are required (e.g. life extension may require enduring greater pain) may be challenging[13]. The extent to which specific value statements predict patient preferences for the use of life-sustaining treatments has also been called into question [13]. For instance, Heyland and colleagues found that 15% of patients who stated that 'to be kept comfortable' was their most important value also indicated a preference for all life-sustaining measures, including cardio-pulmonary resuscitation (CPR)[13]. These findings suggest that improvements in the methods used to elicit values are needed, so that a range of potential consequences of end-of-life choices can be explored and trade-offs between different consequences clarified [13]. One potential method is discrete choice methodology, which is a quantitative approach to measuring the strength of an individual's preferences and exploring how

different attributes contribute to decision making[14, 15]. In a discrete choice experiment (DCE), the individual is presented with a set of two or more hypothetical scenarios composed of a number of attributes. The levels of the attributes vary across the scenarios, and the individual is asked to select which scenario out of the set they prefer[16, 17]. There are a number of advantages to DCEs in the context of EOL care. Firstly, DCEs allow investigation of patient preferences across a number of attributes within a single question, which can significantly reduce the number and complexity of survey items. Secondly, the forced response of DCE reduces the occurrence of yes-response bias;[18, 19] and reduction of subjectivity related to the response labels used in Likert-type rating scales. Thirdly, it provides an assessment of the trade-off respondents are willing to make between attributes.[19, 20] DCEs also show evidence of internal validity and consistency.[18] Despite the potential benefits, few studies to date have explored end-of-life care using this approach[21-25].

AIMS: To explore in a sample of medical oncology outpatients and their nominated support persons perceptions of:

- (1) the relative influence of pain, consciousness, and life extension on end-of-life choices using a Discrete Choice Experiment (DCE);
- (2) the extent to which support persons are able to predict the end-of-life choices of their index patients;
- (3) whether previous end-of-life discussions predict patient-support person agreement.

METHODS

Sample and procedure: The sample and procedure for this cross-sectional survey study have been published elsewhere[6, 26]. Briefly, adult medical oncology outpatients and their nominated support persons were approached for consent in the waiting room of an outpatient clinic in a single tertiary referral centre in New South Wales Australia by a trained research assistant (RA). Patients were included regardless of stage of disease or estimated life expectancy. The patient was given a recruitment package to pass on to their support person if that person was not present in the clinic at the time of recruitment. Consenting participants completed a pen-and-paper survey at home and returned it directly to the research team in a reply paid envelope.

Development of Discrete Choice Experiment. Under a heading that specified “*What you would want if you were facing the end of your life*”, medical oncology outpatients were asked for a response to the statement “*If I needed end-of-life care, I would be worried about*”: (a) *being in pain* (b) *loss of dignity* (c) *being alone when they die* (d) *not being at peace* (e) *not being able to*

recognise family/friends (f) family/friends seeing me in pain (g)family/friend being full-time carers (g) doctors not providing sufficient information about treatment options (h) receiving a treatment I do not want. Responses were recorded on five point Likert scales ranging from ‘strongly agree’ to ‘strongly disagree’. The highest rated items were selected for inclusion in the DCE. The format and presentation style of the DCE was reviewed by an advisory panel which included health behavioural scientists, psychologists and cancer care providers. This review continued until consensus on the content and format of items was reached. Items and format were further tested with a convenience sample of 20 medical oncology outpatients.

Ethics approvals: The University of Newcastle Human Research Ethics Committee (H-2014-0411) and the ethics committee of the participating health service approved the study (14/11/19/4.04).

Outcome measures

Best-Worst Discrete Choice Experiment: Each DCE consists of three attributes, with three statements (referred to as levels) for each attribute. The attribute pain included three levels defined by a score out of 10, with a higher score indicating greater pain. These levels included mild pain (3 out of 10), moderate pain (5 out of 10) or severe pain (8 out of 10). The attribute consciousness (i.e. being mentally aware of people and/or surroundings) included three levels defined by amount of time. These levels included: some of the time, half of the time, or most of the time. The attribute length of life included three levels defined in terms of number of additional weeks life would be extended. These levels included one week, two weeks and three weeks.

The DCE was presented in the following format

SCENARIO

A patient has been told that they have incurable cancer and only have about a month to live. The doctor tells the patient there are three types of care they can have. Each type of care will be different in terms of how it affects their length of life, how much pain they will feel and how much of the time they will be conscious (i.e. mentally alert). The person must choose one of the three care types (Care A, B or C).

If you were the one being asked to choose between Care A, B or C, which would you:

- **Most prefer** for yourself.
- **Least prefer** for yourself.

	Care A	Care B	Care C
Patient will feel	Mild pain (3 out of 10)	Moderate pain (5 out of 10)	Severe pain (8 out of 10)
Patient will be conscious <i>(i.e. mentally aware of people and surroundings)</i>	Some of the time	Half of the time	Most of the time
Patient's length of life will be extended by:	Two weeks	One week	Three weeks
I would MOST PREFER <i>(PLEASE TICK ONE BOX in this row):</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I would LEAST PREFER <i>(PLEASE TICK ONE BOX in this row)</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Previous discussion of EOL issues: was measured using the item “*Have you already discussed the type of end-of-life care you would want to receive with your support person?*”. Response options were ‘yes’ or ‘no’.

Statistical analysis

Initial analyses focussed on summary statistics for the demographic variables, and frequency and contingency tables for the choices. Agreement within patient-carer dyads was assessed with contingency tables, calculated separately for choices about *most* and *least-preferred* options. The influence of end-of-life attributes on choices were investigated using cumulative link models to predict choices (separately for *most* and *least* choices) using attribute levels as predictors. A probit link function was used, corresponding to a Gaussian assumption for a random utility model of preferences. The relative influence of different attributes on choice was quantified by the standardised coefficients estimated in these models (z-scores, also known as beta coefficients).

RESULTS.

Sample

Of the 203 patients and 120 support persons approached, a total of 110 patients and 64 support persons returned a survey (54% and 53% respectively). Of these, 42 were matched patient-support person dyads. Table 1 presents the characteristics of the matched dyads.

What attributes influence patients end-of-life choices?

Patients' choices for most-preferred scenario were most strongly influenced by level of pain ($z=12.5$), followed by level of consciousness ($z=5.9$). The other attribute (i.e. life extension) did not have a statistically significant effect. Patients choices for least-preferred scenarios were also most strongly influenced by level of pain ($z=12.9$); followed by level of consciousness ($z=3.2$). All three interactions were significant and important ($z=7.5-8.6$). Choices were in the direction expected (i.e. increased consciousness and decreased pain preferred).

What attributes influence support persons choices?

Support persons' choices for most-preferred scenario were strongly influenced by pain, but little else ($z=9.7$; all others $z<1.8$). Similarly, support persons' choices for the least-preferred scenarios were strongly influenced by pain ($z=11.5$). The other two main effects (i.e. consciousness and life extension attributes) were not significant predictors of choices. All three two-way interactions were significant, in the expected directions (e.g. increased pain was not favoured if consciousness or length of life was also increased; increased length of life was favoured only with increased consciousness).

Agreement within patient-support person dyads about preferred scenarios.

Overall, 63% of dyads had discussed end-of-life care together. The majority of dyads agreed on whether or not they had discussed EOL care (85%). In three cases the SP said "no" and the patient said "yes"; in three other cases the SP said "yes" and the patient said "no". Overall, there was 55% agreement between dyads regarding the most-preferred scenarios; and 69% for least-preferred scenarios. There was slightly better agreement (68%) about the most-preferred scenario among dyads who had discussed EOL care, compared to dyads who said they had not had a discussion (48%) ($\chi^2(df=1)=3.4$, $p=.065$). Agreement on the least-preferred scenario was high for dyads who had discussed EOL care (77%) as well as those who had not (65%) was not significantly different ($\chi^2(df=1)=1.1$, $p=.29$).

DISCUSSION

This is one of the first DCEs to quantitatively demonstrate the trade-offs patients with a life-threatening cancer diagnosis and their support persons make in their preferences about end-of-life care. The preferences of patient respondents in this study favoured end-of-life care that allowed them to avoid severe pain and to a lesser extent confusion. This was regardless of the impact that care had on life extension. Our findings are consistent with previous studies which emphasise the importance of maintaining quality of life to seriously ill people, even when it means they may not live as long[1-3]. Up to 75% of advanced cancer patients will have sufficiently severe pain that they will require opioid analgesia; while up to 80% of those admitted to palliative care unit will develop delirium[27]. Despite the detrimental impact that uncontrolled pain and confusion have on the quality of life of both cancer patients and families, studies suggest that some people are uncertain about the likelihood that they will experience these symptoms. Fear of opioid addiction or other adverse side effects, and a perception that these symptoms are inevitable (i.e. fatalism) are also common among patients[28]. As avoidance of these symptoms appears to significantly influence the type of care people might choose, patients and families must have realistic expectations about the potential consequences of each treatment option being offered. Open and honest communication is required to ensure informed decisions about care can be made [29].

While there is variability among patients, many express a desire to receive information about the possible risks and benefits associated with end-of-life care from their treating team[30]. Many also want to be involved in decisions about care, and to have their support persons involved as well. Processes for establishing patients' preferences for information and choosing between end-of-life options can be supported by introducing tools such as decision aids, especially when choices are preference-dependent[31, 32]. However, the potential value of these tools may be hindered when general values that are likely to influence patient choices, such as aspects of quality of life and burden on families, are not incorporated[32]. DCEs offer an alternative means of introducing conversations to clarify people's preferences and end-of-life values, including the value placed on life expectancy and goals of treatments[21, 22]. The advantage of this approach is that information can be presented about a range of physical, emotional, social and/or practical consequences of different care options simultaneously, so that the person's most important values can be determined in relation to each other. Where necessary, the attributes included in DCEs can be tailored to reflect the risks and/or likely outcomes associated with the particular treatment options being offered to the individual at the time.

There is also increasing recognition of the important role that support persons play in end-of-life decision making. For SPs in this study, pain was the most significant predictor of most and least-

preferred scenarios. Even choices that included the greatest life extension (i.e. extend life by 3 weeks) were not favoured by respondents if it was paired with an increase in pain severity. In contrast to patients, SPs did not consider the patient's level of consciousness as important when choosing care. While many families find it distressing when patients are confused or agitated at the end-of-life[27, 33], it appears that this is a less confronting concern than uncontrolled pain. Higher levels of grief, worse bereavement adjustment and depression are more prevalent among family members who perceive a loved one experienced uncontrolled pain[27]. SPs in our study were more accurate in predicting the end-of-life care scenarios that patients would least want when compared to choosing scenarios that patients would most want. Even so, only half of the dyads agreed on the *most-preferred* scenario, and two-thirds on the *least-preferred* scenario. This is a significant gap, given that poor dyad agreement may lead to conflict between family members and/or treating teams, poorer bereavement outcomes for family members or delivery of unwanted medical care to the patient[34].

Promoting earlier and ongoing end-of-life discussions between cancer patients, their support persons and clinicians is a recommended strategy for improving the accuracy with which SPs (and clinicians) are able to predict patient choices. In this study, there was a trend for dyads who had discussed end-of-life wishes to report higher agreement, compared to dyads who had not discussed EOL preferences together. This finding requires confirmation in a larger sample size. Only 63% of dyads had discussed EOL care with each other, highlighting that there is room for improvement. In many cases, conversations only begin to occur when people become very ill or are admitted to hospital[4, 35]. Furthermore, they do not always involve support persons.

Implications for research, policy and practice

Our study suggests that DCEs are a good way to elicit preferences from patients and their support persons. This in no way suggests that DCEs should replace end-of-life discussions between patients, support persons and healthcare providers. Much of the literature has highlighted the need for more complex, system-based changes to occur to achieve improvements in end-of-life outcomes, such as compliance with patients' EOL wishes, satisfaction with care and the experience of death and dying [4, 36-38]. However, the challenges associated with trying to make informed decisions about end-of-life care without having had time to reflect on the potential benefits and risks of options and most important values and priorities highlights opportunities for DCEs to be integrated within larger multi-component approaches [39-41]. For instance, DCEs can be used by researchers to help understand preferences in complex decisions with multiple factors that tradeoff. DCEs may also be used to help patients and families consider what is important to them prior to having end-of-life conversations with providers. DCEs can be tailored to reflect choices about specific treatments or to elicit more

general values to help guide more nuanced decisions [13]. Other tools, such as question prompt lists, have achieved modest success in promoting and improving the quality of end-of-life conversations[42]. The feasibility of using DCEs as part of a larger strategy for improving end-of-life care discussions in routine practice could be explored. Furthermore, the extent to which such an approach can lead to improvements in end-of-life outcomes, such as quality of communication and decision-making, patient and/or family distress and anxiety or concordance between perceived and actual end-of-life care should be tested.

Study limitations

Findings must be interpreted with caution given the low response rates. Like many studies in this field, participants included those for whom end-of-life scenarios did not reflect their specific circumstance[9, 43]. Longitudinal data is needed to establish the extent to which agreement between patient and support person perceptions improves or decreases over time. Due to the limited sample size, only three attributes were included in this DCE. These attributes were included based on patients' reports about what would worry them most about the end-of-life. However, other attributes may also influence choices should be explored. Due to sample size and design considerations, interaction effects between attributes and dyad socio-demographic variables could not be examined.

Conclusions

The DCE approach is a feasible means for eliciting end-of-life preferences of cancer patients and their support persons, with the potential for wide applicability. Patients and their support persons placed significant value on avoiding severe pain when making end-of-life choices, over and above level of consciousness or life extension. Support persons are more accurate in predicting the end-of-life care scenarios that patients would least want, when compared to scenarios they would most want. The potential impact of care choices on indicators of quality and quantity of life should be explored with patients and support persons, with views sought about scenarios they most and least prefer.

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Conflict of interest

None declared.

Table 1: Patient socio-demographic and clinical characteristics

	Patient sample n (%)
Sex	
Male	18 (42.9%)
Female	24 (57.1%)
Age (Mean = 64.9 years)	
Less than 60 years	11 (26.2%)
60 years and over	31 (73.8%)
Cancer Type	
Breast	17 (40.5%)
Prostate	3 (7.1%)
Lung	1 (2.4%)
Colorectal	8 (19.0%)
Other	13 (31.0%)
Patient perceived cancer status	
Curable	23 (54.8%)
Incurable	18 (42.9%)
Missing	1 (2.4%)
Estimation of patient life expectancy	
2 years or less	4 (9.5%)
More than 2 years	13 (31.0%)
Don't know	24 57.1%)
Missing	1 (2.4%)
Quality of life	Score out of 10
Mean (SD)	7.5

Table 2: Support person socio-demographic and clinical characteristics

	SP sample n (%)
Sex	
Male	15 (35.7%)
Female	27 (64.3%)
Age (Mean 58.6 years)	
Less than 60 years	19 (45.2%)
60 years and over	23 (54.8%)
Relationship to patient	
Spouse/partner	24 (57.1%)
Other (including: parent, sibling, offspring, and other)	18 (42.9%)
Missing	-
Living with patient	
Yes	29 (69.0%)
No	13 (31.0%)
Time spent caring per week	
< 20 hours	22 (52.4%)
20 to 40 hours	6 (14.3%)
More than 40 hours	5 (11.9%)
Unsure/do not provide any care	8 (19%)
Missing	1 (2.4%)
Quality of life	Score out of 10
Mean (SD)	8.1

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