



NOVA

University of Newcastle Research Online

nova.newcastle.edu.au

**Waller, A., Sanson-Fisher, R. & Brown, S. D. et al (2018) Quality versus quantity in end-of-life choices of cancer patients and support persons: a discrete choice experiment. *Supportive Care in Cancer*, 26 (10) 3593–3599**

Available from: <http://dx.doi.org/10.1007/s00520-018-4226-x>

This is the peer reviewed version of the following article: 'Quality versus quantity in end-of-life choices of cancer patients and support persons: a discrete choice experiment.' which has been published in final form at <http://dx.doi.org/10.1007/s00520-018-4226-x>.

Accessed from: <http://hdl.handle.net/1959.13/1385374>

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

**Authors:**

Amy Waller, PhD<sup>1,2</sup> [amy.waller@newcastle.edu.au](mailto:amy.waller@newcastle.edu.au)

Rob Sanson-Fisher, PhD<sup>1,2</sup> [rob.sanson-fisher@newcastle.edu.au](mailto:rob.sanson-fisher@newcastle.edu.au)

Scott D. Brown, PhD<sup>3</sup> [scott.brown@newcastle.edu.au](mailto:scott.brown@newcastle.edu.au)

Laura Wall, BPsych<sup>3</sup> [laura.wall@uon.edu.au](mailto:laura.wall@uon.edu.au)

Justin Walsh BSc<sup>1,2</sup> [Justin.walsh@newcastle.edu.au](mailto:Justin.walsh@newcastle.edu.au)

**Affiliations**

<sup>1</sup>Health Behaviour Research Group, Priority Research Centre for Health Behaviour, University of Newcastle, University Drive, Callaghan, NSW 2308, Australia

<sup>2</sup>Hunter Medical Research Institute, New Lambton Heights, NSW 2305, Australia

<sup>3</sup>Department of Psychology, The University of Newcastle, University Drive, Callaghan, NSW 2308, Australia

**Corresponding author**

Dr Amy Waller

Health Behaviour Research Group

University of Newcastle

Hunter Medical Research Institute

Callaghan NSW 2308

Ph: +61 2 40420708

Email: [amy.waller@newcastle.edu.au](mailto:amy.waller@newcastle.edu.au)

ORCID: 0000-0002-0987-9424

Word count: 2813

## 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
<b>Patient will feel</b>	Mild pain (3 out of 10)	Moderate pain (5 out of 10)	Severe pain (8 out of 10)
<b>Patient will be conscious</b> <i>(i.e. mentally aware of people and surroundings)</i>	Some of the time	Half of the time	Most of the time
<b>Patient's length of life will be extended by:</b>	Two weeks	One week	Three weeks
<b>I would MOST PREFER</b> <i>(PLEASE TICK ONE BOX in this row):</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>I would LEAST PREFER</b> <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  $z_s < 1.8$ ). 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.

### **Acknowledgements:**

The authors acknowledge research support from Lucy Boyd, Judy Hollingworth and Natalie Dodd. This research was supported by a National Health and Medical Research Council Partnership grant with the Cancer Council NSW (1059760), a Strategic Research Partnership Grant (CSR 11-02) from Cancer Council NSW to the Newcastle Cancer Control Collaborative (New-3C), and infrastructure funding from the Hunter Medical Research Institute. AW is supported by an Australian Research Council DECRA (150101262). Our thanks to hospital staff, patients and families for their contribution to this research.

**Conflict of interest**

None declared.

**Table 1: Patient socio-demographic and clinical characteristics**

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

Table 2: Support person socio-demographic and clinical characteristics

	<b>SP sample n (%)</b>
<b>Sex</b>	
Male	15 (35.7%)
Female	27 (64.3%)
<b>Age (Mean 58.6 years)</b>	
Less than 60 years	19 (45.2%)
60 years and over	23 (54.8%)
<b>Relationship to patient</b>	
Spouse/partner	24 (57.1%)
Other (including: parent, sibling, offspring, and other)	18 (42.9%)
Missing	-
<b>Living with patient</b>	
Yes	29 (69.0%)
No	13 (31.0%)
<b>Time spent caring per week</b>	
< 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%)
<b>Quality of life</b>	<b>Score out of 10</b>
Mean (SD)	8.1

## References

1. Rubin EB, Buehler AE, Halpern SD. States Worse Than Death Among Hospitalized Patients With Serious Illnesses. *JAMA Intern Med.* 2016;176(10):1557-9.
2. Fried TR, Byers AL, Gallo WT, Van Ness PH, Towle VR, O'Leary JR, et al. Prospective study of health status preferences and changes in preferences over time in older adults. *Arch Intern Med.* 2006;166(8):890-5.
3. Heyland DK, Dodek P, Rocker G, Groll D, Gafni A, Pichora D, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *CMAJ.* 2006;174(5):627-33.
4. Bernacki RE, Block SD. Communication about serious illness care goals: a review and synthesis of best practices. *JAMA Intern Med.* 2014;174(12):1994-2003.
5. Raymont V, Bingley W, Buchanan A, David AS, Hayward P, Wessely S, et al. Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet.* 2004;364(9443):1421-7.
6. Waller A, Hall A, Sanson-Fisher R, Zdenkowski N, Douglas C, Walsh J. Do medical oncology patients and their support persons agree about end of life issues? *Internal medicine journal.* 2017.
7. Bukki J, Unterpaul T, Nubling G, Jox RJ, Lorenzl S. Decision making at the end of life--cancer patients' and their caregivers' views on artificial nutrition and hydration. *Support Care Cancer.* 2014;22(12):3287-99.
8. Hwang IC, Keam B, Kim YA, Yun YH. Factors Related to the Differential Preference for Cardiopulmonary Resuscitation Between Patients With Terminal Cancer and That of Their Respective Family Caregivers. *Am J Hosp Palliat Care.* 2016;33(1):20-6.
9. Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. *Arch Intern Med.* 2006;166(5):493-7.
10. Meier EA, Gallegos JV, Thomas LP, Depp CA, Irwin SA, Jeste DV. Defining a Good Death (Successful Dying): Literature Review and a Call for Research and Public Dialogue. *Am J Geriatr Psychiatry.* 2016;24(4):261-71.
11. Conflict in the care of patients with prolonged stay in the ICU: types, sources, and predictors. *Intensive Care Medicine.* 2003;29(9):1489-97.
12. White DB, Ernecoff N, Buddadhumaruk P, Hong S, Weissfeld L, Curtis JR, et al. Prevalence of and Factors Related to Discordance About Prognosis Between Physicians and Surrogate Decision Makers of Critically Ill Patients. *JAMA.* 2016;315(19):2086-94.
13. Heyland DK, Heyland R, Dodek P, You JJ, Sinuff T, Hiebert T, et al. Discordance between patients' stated values and treatment preferences for end-of-life care: results of a multicentre survey. *BMJ Supportive & Palliative Care.* 2017;7(3):292-9.
14. Ryan M. Discrete choice experiments in health care. *Bmj.* 2004;328(7436):360-1.
15. Louviere JJ. Choice experiments: an overview of concepts and issues. *The choice modelling approach to environmental valuation.* 2001:13-36.
16. Lancsar E, Louviere J. Conducting Discrete Choice Experiments to Inform Healthcare Decision Making. *Pharmacoeconomics.* 2008;26(8):661-77.
17. Viney R, Lancsar E, Louviere J. Discrete choice experiments to measure consumer preferences for health and healthcare. 2002.
18. Ryan M, Watson V, Amaya-Amaya M. Methodological issues in the monetary valuation of benefits in healthcare. *Expert review of pharmacoeconomics & outcomes research.* 2003;3(6):717-27.
19. Viney R, Lancsar E, Louviere J. Discrete choice experiments to measure consumer preferences for health and healthcare. *Expert review of pharmacoeconomics & outcomes research.* 2002;2(4):319-26.
20. Flynn TN, Louviere JJ, Peters TJ, Coast J. Best-worst scaling: what it can do for health care research and how to do it. *Journal of health economics.* 2007;26(1):171-89.
21. Finkelstein EA, Bilger M, Flynn TN, Malhotra C. Preferences for end-of-life care among community-dwelling older adults and patients with advanced cancer: A discrete choice experiment. *Health Policy.* 2015;119(11):1482-9.
22. Malhotra C, Farooqui MA, Kanesvaran R, Bilger M, Finkelstein E. Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment. *Palliat Med.* 2015;29(9):842-50.

23. Hall J, Kenny P, Hossain I, Street DJ, Knox SA. Providing Informal Care in Terminal Illness: An Analysis of Preferences for Support Using a Discrete Choice Experiment. *Med Decis Making*. 2014;34(6):731-45.
24. Jin X, Liu GG, Luo N, Li H, Guan H, Xie F. Is bad living better than good death? Impact of demographic and cultural factors on health state preference. *Qual Life Res*. 2016;25(4):979-86.
25. Shah KK, Tsuchiya A, Wailoo AJ. Valuing health at the end of life: a stated preference discrete choice experiment. *Soc Sci Med*. 2015;124:48-56.
26. Waller A, Sanson-Fisher R, Zdenkowski N, Douglas C, Hall AE, Walsh J. The right place at the right time: Medical oncology outpatients' perceptions of location of end of life care. *JNCCN*. 2017;in press.
27. Clark K. Care at the Very End-of-Life: Dying Cancer Patients and Their Chosen Family's Needs. *Cancers*. 2017;9(2):11.
28. Sun V, Borneman T, Piper B, Koczywas M, Ferrell B. Barriers to pain assessment and management in cancer survivorship. *Journal of cancer survivorship : research and practice*. 2008;2(1):65-71.
29. Ghandourh WA. Palliative care in cancer: managing patients' expectations. *Journal of Medical Radiation Sciences*. 2016;63(4):242-57.
30. Care: ColtQoC. Patient-Centered Communication and Shared Decision Making. *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis* Washington: National Academies Press (US); 2013.
31. Oczkowski SJ, Chung HO, Hanvey L, Mbuagbaw L, You JJ. Communication Tools for End-of-Life Decision-Making in Ambulatory Care Settings: A Systematic Review and Meta-Analysis. *PLoS One*. 2016;11(4):e0150671.
32. Cardona-Morrell M, Benfatti-Olivato G, Jansen J, Turner RM, Fajardo-Pulido D, Hillman K. A systematic review of effectiveness of decision aids to assist older patients at the end of life. *Patient Educ Couns*. 2017;100(3):425-35.
33. Finucane AM, Lugton J, Kennedy C, Spiller JA. The experiences of caregivers of patients with delirium, and their role in its management in palliative care settings: an integrative literature review. *Psychooncology*. 2017;26(3):291-300.
34. Wright AA, Zhang B, Ray A, Mack JW, Trice E, Balboni T. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300.
35. Mack JW, Cronin A, Taback N, Huskamp HA, Keating NL, Malin JL, et al. End-of-life discussions among patients with advanced cancer: A cohort study. *Annals of internal medicine*. 2012;156(3):204-10.
36. Johnson S, Clayton J, Butow PN, Silvester W, Detering K, Hall J, et al. Advance care planning in patients with incurable cancer: study protocol for a randomised controlled trial. *BMJ Open*. 2016;6(12):e012387.
37. Waller A, Dodd N, Tattersall MHN, Nair B, Sanson-Fisher R. Improving hospital-based end of life care processes and outcomes: a systematic review of research output, quality and effectiveness. *BMC Palliat Care*. 2017;16(1):34.
38. Scott I. Difficult but necessary conversations — the case for advance care planning. 199. 2013;10(662-666).
39. Frost DW, Cook DJ, Heyland DK, Fowler RA. Patient and healthcare professional factors influencing end-of-life decision-making during critical illness: a systematic review. *Critical Care Medicine*. 2011;39(5):1174-89.
40. You JJ, Downar J, Fowler RA, Lamontagne F, Ma IW, Jayaraman D, et al. Barriers to Goals of Care Discussions With Seriously Ill Hospitalized Patients and Their Families: A Multicenter Survey of Clinicians. *JAMA Intern Med*. 2015.
41. Bester J, Cole CM, Kodish E. The Limits of Informed Consent for an Overwhelmed Patient: Clinicians' Role in Protecting Patients and Preventing Overwhelm. *AMA journal of ethics*. 2016;18(9):869-86.
42. Rodenbach RA, Brandes K, Fiscella K, Kravitz RL, Butow PN, Walczak A, et al. Promoting End-of-Life Discussions in Advanced Cancer: Effects of Patient Coaching and Question Prompt Lists. *Journal of Clinical Oncology*. 2017;35(8):842-51.
43. Fagerlin A, Ditto PH, Danks JH, Houts RM, Smucker WD. Projection in surrogate decisions about life-sustaining medical treatments. *Health Psychol*. 2001;20(3):166-75.