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Preferences for life expectancy discussions following diagnosis with a life threatening illness: A discrete choice experiment

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Abstract

Purpose. To explore in a sample of adult cancer patients: (1) the relative influence of initiation source, information format and consultation format on preferred approach to life expectancy disclosure using a Discrete Choice Experiment (DCE); and (2) whether patient age, cancer type and perceived prognosis were associated with preferences within the three attributes.

Methods. A DCE survey of adult solid tumour and haematological cancer patients. Participants chose between three hypothetical scenarios about life expectancy disclosure consisting of three attributes: initiation source (i.e. doctor versus patient initiated discussion), information content (i.e. estimate presented as best-worst-typical length of life case scenario versus median survival time) and consultation format (i.e. two 20-minute versus one 40-minute consultation). Respondents selected their most-preferred scenario within each question.

Results: 302 patients completed the DCE (78% consent rate). Initiation source was the most influential predictor of patient choice. More preferred doctor deliver life expectancy information as soon as it is available rather than waiting for the patient to ask (59% vs 41% $z=-7.396$, $p < 0.01$). More patients preferred the two 20-min rather than one 40-min consultation format (55% vs 45%, $z= 4.284$, $p<0.01$). Information content did not influence choice. Age, cancer type and patient-perceived prognosis were not associated with preferences.

Conclusion. Healthcare professionals should assess cancer patients' preferences for engaging in life expectancy discussions as soon as they have this information; and ensure patients have adequate time to consider the information they receive, seek additional information and involve others if they wish.

INTRODUCTION

Many cancer patients indicate a preference for being told their life expectancy (1, 2). Accurate life expectancy information can enable patients to clarify their choices over management of their disease and treatment. However, some oncologists may avoid these discussions, or provide overly optimistic estimates (3). A recent meta-analysis reported that less than half of advanced cancer patients accurately understood their prognosis (4). Previous studies also suggest that patients with accurate perceptions of life expectancy are more likely to engage in advance care planning, which has been associated with reduced stress (5), unwanted aggressive medical care and health care costs (6, 7). Others report that life expectancy discussions strengthen the therapeutic alliance between patients and oncologists, rather than harm these relationships (1, 8). Consequently, the Institute of Medicine (IOM) and practice guidelines recommend that patients be informed of their life expectancy to support informed treatment decision-making, in line with their preferences(9, 10).

Tailoring life expectancy discussions to patient preferences is a complex task. Conversations can be initiated by either clinicians or patients (i.e. *initiation source*). However, clinicians report difficulties in knowing with whom they should initiate life expectancy discussions(11-13), often waiting for their patients to initiate conversations in order to prevent unwanted disclosure(13). There is evidence to suggest that not all patients feel comfortable and well-equipped to raise this topic(14). Tools such as question prompt lists have been developed to assist patients to initiate and participate in these discussions(15). Patients may also avoid raising the topic if they are uncertain about their doctors' willingness to discuss life expectancy(16, 17).

Clinicians also report difficulties in communicating often complex life expectancy information in a way that patients can understand (i.e. *information content*). In an observational study of patient-oncologists consultations, life expectancy information content was presented as either: the likelihood of experiencing a significant event, point estimates, or general time frames such as months or years(3). Using a hypothetical scenario, Kiely and colleagues compared patient preferences for receiving life expectancy (survival estimates) as "median survival time" (5%) versus "best case, worst case and typical survival time" (88%)(18), with the latter perceived as more helpful and reassuring by patients.

Allowing patients sufficient time to digest and reflect on information received about life expectancy has been identified as a key component of life expectancy disclosure(9, 19). There may be justification for alternative consultation styles (i.e. *consultation format*). For instance, Herrmann and colleagues examined cancer patients' preferences for either having a single, longer consultation versus having two separate, shorter consultations prior to making a decision about care(20), and found mixed patient preferences for these two approaches. To our knowledge, no study has assessed patients' preferred number and length of consultations in relation to life expectancy disclosure.

To help clinicians and patients navigate life expectancy discussions and increase the likelihood that this occurs in a manner that is acceptable, patients' views on the relative importance of each of these different aspects of life expectancy communication are needed. Discrete choice experiments (DCE) are a useful methodology for studying preference strength (21, 22). Individuals have a concept of the value (or utility) for each choice, but we do not know all the factors that might affect that choice. While there are still likely to be unobserved attributes present in real-life decisions that are not well accounted for, DCE methodology allows these utilities to be estimated by documenting the choices made. Respondents are asked to make a series of preference judgements, choosing between hypothetical scenarios (in this case, different life expectancy disclosure approaches) whilst attributes of these scenarios (in this case, *initiation source*, *information content* and *consultation format*) are systematically varied (23, 24). Responses can then be used to provide empirical support for which attributes have the strongest relative influence on overall preference judgements (24, 25). As these choices involve weighing multiple factors at the same time; DCEs simulate real-world decision-making (26) and help clarify what amount of one attribute a person is prepared to give up in order to gain more of another attribute. DCEs also enable a better investigation into heterogeneity of choice. This information cannot be obtained from traditional survey methods that rely on ranking or rating techniques such as Likert scales. For instance, simple ranking can establish that 'Option A' is more important than 'Option B', but not by how much, or whether both 'Option A' and 'Option A' are important. A DCE can also establish that changing 'Option A' AND 'Option B', but NOT 'Option C' will result in changes most in line with patient preferences.

Eliciting the perceptions of people who have been diagnosed with cancer is recommended for clinical decisions, as patients are likely to report higher utilities and stronger preferences than

lay people (27). A lay person's preferences may also change when they become a patient (27). Therefore, the aims of this study were to explore in a sample of adult cancer survivors: (1) the relative influence of *initiation source*, *information format* and *consultation format* on preferred life expectancy disclosure using a vignette style discrete choice experiment (DCE); and (2) whether patient age, cancer type or perceived prognosis were associated with preferences.

METHODS

Design: A cross-sectional survey study.

Participants. Participants were selected from a database that included patients who had previously participated in a study involving 19 cancer treatment centres across Australia and had indicated a willingness to be contacted about other research studies(28). To be eligible for this study, participants had to: have a confirmed cancer diagnosis (any type, including haematological cancers); be aged 18 years or older, be able to read and understand English(29). Eligibility was not restricted by stage of disease or estimated life expectancy.

Procedure: The procedure for this study has been described elsewhere(29). Briefly, participants listed on the database were posted a primer letter informing them of the study and giving them the opportunity to opt-out of receiving further information. Approximately 3 weeks later, participants were mailed a study information package comprising an information sheet, a copy of the survey and a reply paid envelope. Participants who had not returned a survey were mailed a reminder after 3 weeks; with a reminder phone call made to those non-responders who had provided a phone number after a further 3 weeks. Implied consent was obtained via return of the survey to the research team(29).

Development of Discrete Choice Experiment. Four different DCE topics were developed by the research team, as described previously(29). This paper presents the data from one of the four topics. Briefly, the content (attributes and levels), format and presentation style of the life expectancy 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, and attribute levels hypothesised to be associated with mild to moderate preference strength. Items and format were further tested with a convenience sample of 20 medical oncology outpatients.

Outcome measures

Discrete Choice Experiment: Each DCE consisted of three attributes, with two statements (referred to as levels) for each attribute. Attributes and levels were randomised in a full factorial design producing 56 unique combinations of 3-choice sets. Each participant was randomly assigned to one of the 56 combinations. Participants made decisions on their allocated 3-choice sets. The random assignment of choice sets occurred as a trade-off had between rigor and feasibility. It is standard practice to randomly assign a subset of all possible choice sets to patients. Asking participants to respond to a greater number of choice sets would have created too great a respondent burden in this context.

(1) The attribute '**initiation source**' included two levels defined by 'patient-initiated disclosure' (i.e. *Doctor should wait until you ask before telling you your life expectancy*) and 'doctor-initiated disclosure' (i.e. *Doctor should tell you your life expectancy as soon as he/she has some understanding of what it might be*).

(2) The attribute '**information content**' included two levels defined by 'median survival time' (i.e. *If we imagine 100 people in exactly the same situation as you , we'd expect that half of the people would live longer than 12 months and half would die within 12 months*') and 'best-worst-case scenario' (i.e. *If we imagine 100 people in exactly the same situation as you, we'd expect the: 5-10 who do best to live 3 years or longer; 5-10 who do worst to die within 3 months; middle 50 to live between 6 months and 2 years*).

(3) The attribute '**consultation format**' included two levels as defined by 'one consultation' (i.e. *the doctor tells you your life expectancy and then discusses your care options in one 40 minute visit*) and 'two consultations' (i.e. *doctor tells you your life expectancy in one 20 minute visit. You are given information about care options to take home. You have another 20 minute visit one week later to discuss these options with the doctor*).

The DCE was presented in the format shown in Figure 1.

[figure 1 here]

Demographics. Participants self-reported: age, gender, education, home post code, and employment status. Participants also self-reported the following disease and treatment variables: cancer type; perceived stage of disease at diagnosis (i.e. perceived prognosis); time since diagnosis; treatments received; and stage on the cancer treatment trajectory.

Ethics approvals. The University of Newcastle Human Research Ethics Committee (H-2015-0285) and the Australian Institute of Health and Welfare (EO2015/4/203) granted full ethics approval for this study.

Statistical analysis

Data were analysed in R version 3.4.1 using packages *eptools* (for recoding of demographic data) and *ordinal* (for the cumulative link model). Initial analyses included summary statistics of demographic variables and frequency and contingency tables for the choices. Inferences regarding the influence of the different life expectancy attributes on choice of scenario were examined using cumulative link models to predict choices (for *most-preferred* scenarios) using attribute levels as predictors. We adopted a Type I error rate of $\alpha=0.01$ throughout, to limit family-wise error. 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 standard coefficients estimates in these models (z-scores, also known as beta coefficients). Initial analyses focused on summary statistics for the demographic variables, and frequency and contingency tables for the choices. The full model with all possible two and three way interactions found a significant effect for only one of the attributes, i.e. source of initiation ($p<0.001$). Given the complexity of the full model, with three main effects and four interactions, we examined a restricted model which allows for higher statistical efficiency. This restricted model included only the three main effects (allowing for effects of source, content and timing) and no interactions. Supporting our choice, the AIC for this restricted model was marginally better than the AIC for the full model. This reduced model was then applied to six different subsets of the data split by three predefined demographic variables of interest; perceived prognosis or disease stage at diagnosis (early vs advanced or incurable), age (under 65 vs 65 years of age or older), and cancer type (haematological vs non-haematological cancer). This was to examine if the results from the full dataset were consistent across the different patient characteristics.

RESULTS

Sample

Of the 389 patients approached, a total of 302 patients returned a survey (78%). The mean age of the sample was 64.7 years (SD=12.5), 42% were male, 32% had been diagnosed with haematological cancer and 78% self-reported they either had or were currently receiving treatment with curative intent. Table 1 presents the characteristics of those who returned the survey.

[table 1 here]

What attributes influence patients' preferences for life expectancy disclosure?

Patients' choices for their most preferred scenario were most strongly influenced by source of discussion initiation ($z=-7.396$, $p < 0.001$; see figure 2). More patients (59%) preferred their doctor tell them their life expectancy as soon as they had the information, rather than wait until the patient asked for it (41%).

Patients choices were also influenced by consultation format ($z=4.284$, $p < 0.001$; see figure 2). More patients preferred that they receive the information and discuss care options in two 20-minute consultations (55%) rather than one 40-minute consultation (45%).

In contrast, the information content attribute (stacked attribute in figure 2) did not have a statistically significant effect (51% vs 49%, $p = 0.612$).

Furthermore, none of the interactions were significant at $\alpha=.01$. This implies that preferences about one attribute were not reliably changed by the levels of the other attributes. This interpretation aligns with the results of the cumulative link analysis, which supported a main-effects-only model, without interaction terms.

[figure 2 here]

Do patient characteristics influence preferences?

The preference for receiving information as soon as it was available rather than when patients asked for it did not differ by age group, perceived prognosis / disease stage at diagnosis or cancer type. Similarly, the preference for receiving information in two 20-minute consultations rather than one 40 minute consultation did not differ by age group or cancer type. The effect of consultation format (i.e. two vs one consultation) did not reach statistical significance when examining the preferences of people with advanced cancer. There was an inconsistent direction of preference for the information content attribute (i.e. median vs. 'best-worst-typical case'). Those who were older and perceived their cancer as incurable preferred the "median" option, whereas those who were younger and potentially curable preferred the "best-worst-typical case" option. However, this difference was not significant.

DISCUSSION

This study is one of the first to use DCE methodology to examine what aspects of the life expectancy disclosure process are most important to adult cancer survivors in Australia. Using this methodology to simulate real-world decision-making (26), albeit framed as a hypothetical scenario, provides guidance on which attributes of the life expectancy disclosure process are perceived as most important. Patient choice regarding life expectancy disclosure was most strongly influenced by who initiated the discussion. Specifically, more respondents favoured doctors disclosing information about life expectancy as soon as it becomes available, rather than the doctor waiting for them to request this information. This preference did not differ according to age, cancer type or stage of disease. Fears that life expectancy information might adversely impact patients, the perceived lack of time or comfort with conversations, and potential uncertainty of prognostic estimates have been cited as barriers to clinician-initiated disclosures (30). Consequently, clinicians may adopt a more reactive approach which relies on patients or family members to initiate these conversations(13). While a patient-initiated approach is also consistent with the preference of a number of respondents in this study, this assumes that patients have the necessary resources to effectively initiate conversations, and that doctors will provide information in a way that can be understood(31). Asking patients whether they want to receive information about their life expectancy prior to disclosing this information can allow those who would prefer not to discuss this topic an opportunity to defer the conversation(32). Many patients view gaining their permission as a critical first step in the disclosure process(32).

More patients reported that they would prefer to have time in-between their consultations to consider information about life expectancy (i.e. preferred two 20-minute consultations). This is consistent with recommendations made in practice guidelines to provide information in two consultations with a short time between each consultation when making treatment decisions(19, 33). The aim of this approach is to give patients the opportunity to consider the information they receive about their prognosis, talk to their family and seek additional information if desired, then confirm their understanding of the information(20). Previous studies show that patients do not remember between 40% and 80% of the information they are given in a consultation, and more than half of it is recalled incorrectly(34). Providing multiple consultations may increase satisfaction with care and improve recall and illness understanding. Augmenting this approach with tools such as written or audio-visual information, consultation audio-recordings and/or question prompt lists and a template for presentation of prognosis may enhance patient participation in the second consultation, and improve their recall and understanding of the information discussed (15, 35, 36). Despite these potential benefits, multiple consultations may not be an appropriate or feasible option for everyone. In fact, a significant proportion of patients in this study preferred a one-off consultation when receiving information about life expectancy. Multiple visits to clinics may not be practicable for patients who live at a distance to the clinic or are seriously ill.

Presenting three scenarios (i.e. best-case, worst-case and typical) for survival is advocated as a way of helping clinicians to convey realistic and honest information while still maintaining hope(37). Previous studies have found that many patients report a preference for this approach, perceiving that it would make sense, improve understanding and help them make plans for the future(38). Our study results suggest that patients' choices were not significantly influenced by information content, relative to the source of information or consultation format. Approximately half of the respondents preferred each of the two options provided. Although the DCE scenario in both studies specified a similar standardised hypothetical patient survival scenario of 12 months, this difference in findings relating to patient This difference may reflect the nature of the sample, which included a high proportion of patients with treatment with curative intent and adjuvant therapy. Further, the proportion of patients who had not completed treatment was very different compared to the sample described in the study by Kiely and colleagues(38). Our sample included a larger proportion of haematological cancer patients, but a smaller proportion of patients reporting being <12 months since diagnosis with a prognosis of advanced or incurable cancer.

Research and clinical implications

The findings from this study highlight the need for future research to prospectively assess the impact of different sources of initiation and consultation formats on patient outcomes, such as life expectancy information recall, understanding and affect. Despite being perceived as less important by patients than the consultation style or the source of the information, examining the effect of different methods for presenting life expectancy estimates on patient understanding has also been recommended in the literature(13). Patient preferences for other aspects of the disclosure process not included in this DCE, such as presence of support persons, should also be explored. The sample represented here was heterogenous in terms of both type and stage of disease. Replicating this approach with samples of patients homogenous in both type and stage of disease is important to progress the field and inform clinical practice. An advantage of the DCE method over other survey methods is that it allows manipulation and control over the choice situation, so that the attributes and levels can be tailored to the specific patient population to simulate real world decision-making. The need for complex, system-based changes to occur to achieve improvements in prognosis disclosure and treatment decision-making is widely recognised. There are opportunities for DCEs to be integrated within larger multi-component approaches to help patients consider what is important to them prior to having these conversations with providers.

Strengths and limitations

DCEs are an efficient tool where a revealed preference experiment (i.e., observed real-world choices) is difficult to observe (39). The forced response of DCEs also reduces the occurrence of yes-response bias,(24, 40) and subjectivity related to the response labels used in Likert-type rating scales(40). The findings of the study should be considered in light of a number of limitations. The cross-sectional nature of the data is a limitation as preferences about life expectancy information may change with individuals' circumstances; examination of test-retest reliability is required to clarify preference stability over time(41). While internal validity is often high in DCEs, respondents may make different choices in real-world situations than the hypothetical scenarios presented here potentially limiting external validity. Choices about a hypothetical situations do not necessarily translate to a real situation (18). However, several studies have compared actual choices with stated preferences and concluded that parameters from both were similar (42).

There was a need to limit the number of attributes describing life expectancy disclosure, as too many attributes may have hindered respondents' decision-making. Scenarios included only three attributes, even though there may be other aspects of the disclosure process that influence patient choices. The inclusion of more or differently defined levels may change the interpretation of attribute level change importance. For example, people with a strong preference for not being informed about their life expectancy may have opted for the patient-initiated source option, when in fact their true preference may be for clinician-initiated approach where they are given the right to choose not to get this information. It is also possible that some respondents' traded-off only a subset of attributes when considering their choice sets (i.e. attribute non-attendance(43)), which may have resulted in biased estimates. Asking respondents directly if they ignored characteristics has been suggested in the literature as a way of identifying non-attendance (43).

Conclusions

While there is variability among patients, many respondents in this study would prefer their clinicians to disclose life expectancy information as soon as it is available, and to adopt an alternative consultation style. This was regardless of the content of the information.

Healthcare professionals should assess cancer patients' preferences for engaging in life expectancy discussions as soon as life expectancy information becomes available; and ensure patients have adequate time to digest and consider the information provided, seek additional information and involve others if they wish.

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Conflict of interest

None declared.

Table 1. Patient characteristics (n=302)^a

	N	%
Sex		
Male	126	41.7
Female	173	57.3
Highest level of education completed		
Primary school (Year 6)	13	4.3
High school (Year 10 or Year 12)	104	34.4
Trade or vocational training (e.g. TAFE or college)	106	35.1
University degree	66	21.9
Other	5	1.7
Current employment		0.0
Full-time work	58	19.2
Part-time or casual work	54	17.9
Home duties	18	6.0
Unemployed	7	2.3
Retired or mature age pension	134	44.4
Disability pension	22	7.3
Other	2	0.7
Type of cancer		
Haematological cancer (e.g. leukaemia, lymphoma, myeloma)	98	32.5
Breast	104	34.4
Colorectal	30	9.9
Prostate	13	4.3
Lung	7	2.3
Melanoma	1	0.3
Other	28	9.3
Two or more cancers	14	4.6
Stage of cancer when first diagnosed		
Early	211	69.9
Advanced or incurable	66	21.9
Don't know	20	6.6
How long ago were you diagnosed with cancer?		
0-12 months	2	0.7
More than 1 year but less than 2 years ago	1	0.3
Between 2 and 5 years ago	152	50.3
More than 5 years	140	46.4
Treatments received		
Surgery	188	62.3
Chemotherapy	246	81.5
Radiation therapy (radiotherapy)	151	50.0
Hormone therapy (e.g. Tamoxifen, Arimidex, Zoladex)	81	26.8
Biological therapy (e.g. Rituximab, Avastin, Glivec)	42	13.9
Bone marrow or stem cell transplant	36	11.9
I haven't had any treatment, 'watch and wait' only	7	2.3
Other	6	2.0
Where are you in your cancer journey?		
I haven't had any treatment, 'watch and wait' only	15	5.0

I am receiving treatment to try and cure my cancer	31	10.3
I have completed treatment to cure my cancer and am now in follow-up	191	63.2
I was told my cancer cannot be cured and am receiving anticancer treatment	46	15.2
I was told my cancer cannot be cured and am not receiving anticancer treatment	7	2.3

^a *Not all variables add up to 302 due to missing data or non-mutually exclusive response options.*

SCENARIO

- The doctor tells a patient that he/she has been diagnosed with a life threatening disease.
- Doctors have some understanding of how this disease usually affects people’s life expectancy (i.e. length of life). However, some people might live longer than the doctor thinks, while others might have shorter length of life.
- Doctors can give information about life expectancy in different ways, and this can affect whether people have a good understanding of how the disease might influence the length of their life.
- If you were the patient in this situation, how would you like the doctor to give you information about life expectancy?

Importantly: The scenarios below describe different ways that a doctor can give information about life expectancy. Please assume life expectancy is the same (i.e. expected to live 12 months) for every scenario. If you were the one being asked to choose between Option A or B below, which type of care would you most prefer for yourself?

Example choice set. Participants read each of the options and indicate which they prefer.

	Option A	Option B
Initiation source	Doctor should wait until you ask before telling you your life expectancy	Doctor should tell you your life expectancy as soon as he/she has some understanding of what it might be
Information content	‘If we imagine 100 people in exactly the same situation as you, we’d expect that half of the people would live longer than 12 months and half would die within 12 months’	‘Typical’, ‘best-case’, and ‘worst-case’ scenario e.g. ‘If we imagine 100 people in exactly the same situation as you, we’d expect the: - 5-10 who do best to live 3 years or longer; - 5-10 who do worst to die within 3 months; - middle 50 to live between 6 months and 2 years’
Consultation format	The doctor tells you your life expectancy and then discusses your care options in one 40 minute visit.	The doctor tells you your life expectancy in one 20 minute visit. You are given information about options to take home. You have another 20 minute visit one week later to discuss these options with the doctor.
I would like MOST: Please tick one box in this row:	<input type="checkbox"/>	<input type="checkbox"/>

Figure 1: DCE formatting example

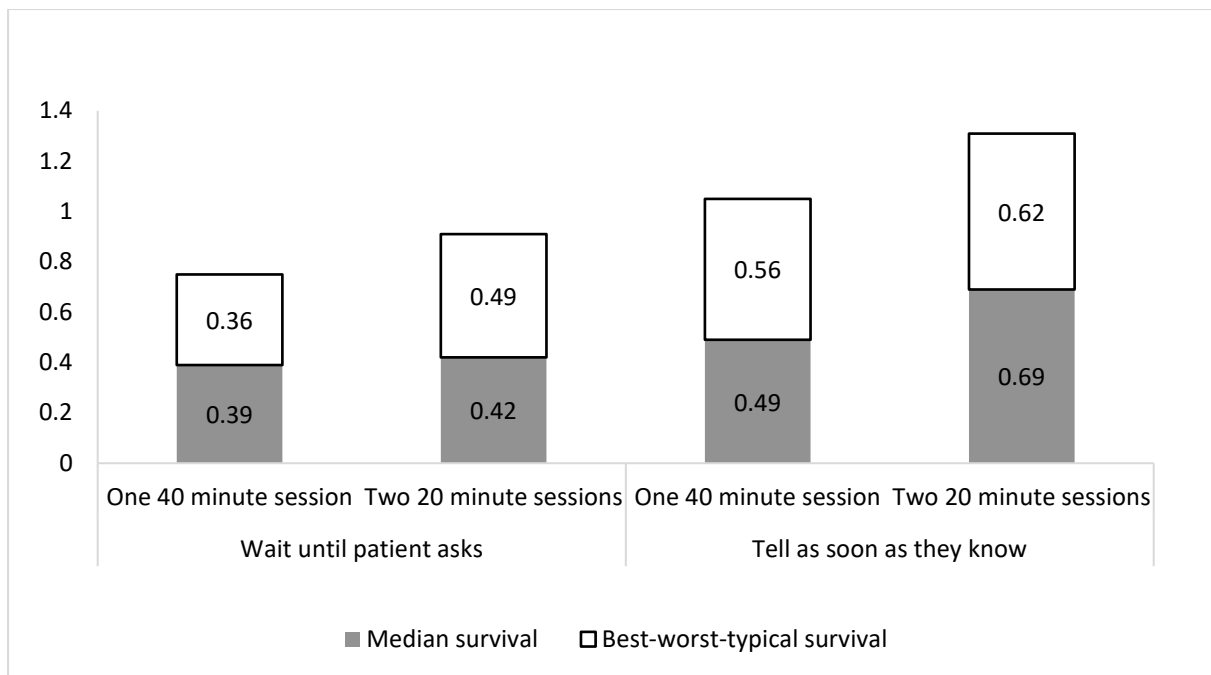


Figure 2: Proportion of 'most preferred' responses for each scenario

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