

## Original Article

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# Novel application of discrete choice experiment methodology to understand how clinicians around the world triage palliative care needs: A research protocol

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**Abstract**

**Objective.** As referrals to specialist palliative care (PC) grow in volume and diversity, an evidence-based triage method is needed to enable services to manage waiting lists in a transparent, efficient, and equitable manner. Discrete choice experiments (DCEs) have not to date been used among PC clinicians, but may serve as a rigorous and efficient method to explore and inform the complex decision-making involved in PC triage. This article presents the protocol for a novel application of an international DCE as part of a mixed-method research program, ultimately aiming to develop a clinical decision-making tool for PC triage.

**Method.** Five stages of protocol development were undertaken: (1) identification of attributes of interest; (2) creation and (3) execution of a pilot DCE; and (4) refinement and (5) planned execution of the final DCE.

**Result.** Six attributes of interest to PC triage were identified and included in a DCE that was piloted with 10 palliative care practitioners. The pilot was found to be feasible, with an acceptable cognitive burden, but refinements were made, including the creation of an additional attribute to allow independent analysis of concepts involved. Strategies for recruitment, data collection, analysis, and modeling were confirmed for the final planned DCE.

**Significance of results.** This DCE protocol serves as an example of how the sophisticated DCE methodology can be applied to health services research in PC. Discussion of key elements that improved the utility, integrity, and feasibility of the DCE provide valuable insights.

**Introduction**

In recent years, decision-making has become more complex for healthcare providers and healthcare consumers alike (Chambers, 2017; Epstein & Gramling, 2013; Kuziemsky, 2016). This is due to an ever-expanding body of scientific knowledge, combined with increased emphasis on holistic care and patient-centered design of health services. Frequently, decisions involve weighing multiple heterogeneous elements, which can lead to decision fatigue and subsequent susceptibility to systematic errors including implicit bias (Islam *et al.*, 2014; Kuziemsky, 2016).

An example of this is the triaging of patients to receive specialist palliative care (PC) services. When there is only one bed left in the palliative care unit, or only time for one more home visit, which patient should be attended to first? Is it the patient who is imminently dying or the patient with a pain crisis; the patient with severe anxiety or the patient whose caregiver isn't coping? Patients referred for specialist PC often have disparate needs and goals (Fitzsimons *et al.*, 2007; Moghaddam *et al.*, 2016). Furthermore, most triage decisions must be made without direct assessment of the patient but rather are based on information from referring non-PC health professionals or lay caregivers who may under- or overestimate urgency of need. These

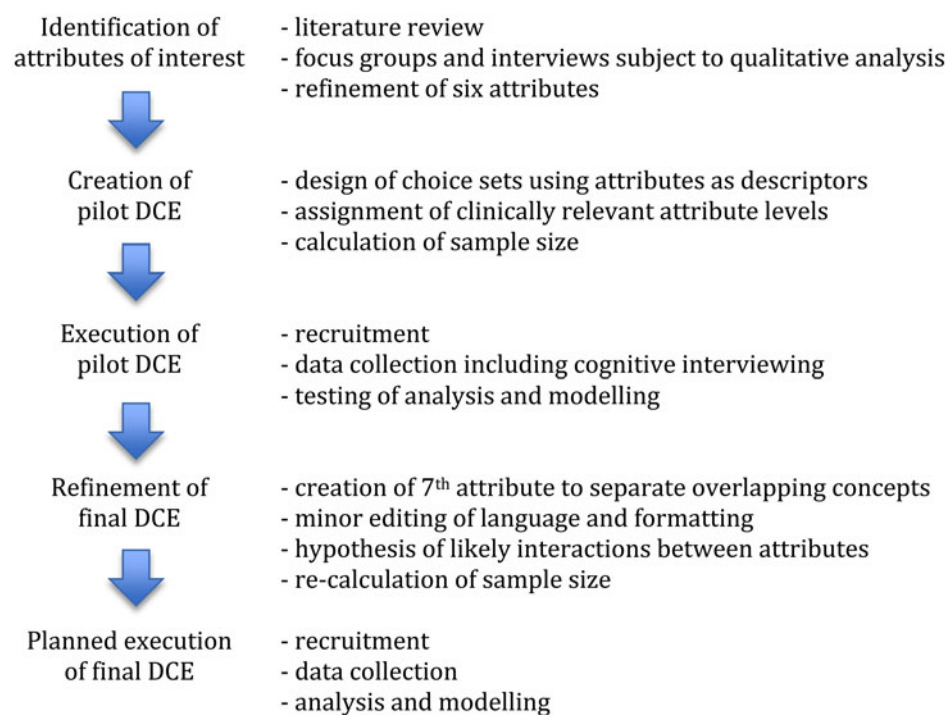


Fig. 1. Discrete choice experiment design process.

decisions are not simple and often cause consternation among PC teams as they manage waiting lists (Eagle & de Vries, 2005). Meanwhile, a growing body of evidence documents inequity of access to specialist PC, often related to sociodemographic and disease-related factors (Addington-Hall et al., 1998; Addington-Hall & Altmann, 2000; Grande et al., 1998; O'Neill & Marconi, 2001; Walshe et al., 2009). Given these factors and with the aim of making resource allocation transparent, efficient, and equitable, an evidence-based systematic approach is needed to guide the complex decision-making involved in PC triage.

Discrete choice experiments (DCEs), a quantitative methodology traditionally used in marketing and economics, are being increasingly recognized as an important healthcare research tool (Clark et al., 2014; Farrar et al., 2000; Ryan, 2004; Viney et al., 2002), and are useful for both exploring and informing complex decision-making. During a DCE, participants are presented with a series of vignettes in pairs or groups, called “choice sets,” and are required to state their preference within each set. The vignettes are described by a finite set of characteristics, or attributes. Response patterns are used to determine how participants’ preferences are influenced by the attributes and which tradeoffs between attributes they are willing to make. Statistical modeling is used to assign weights based on the relative importance of each attribute. Responses are choices rather than opinions, and these choices involve weighing multiple factors simultaneously; hence, DCEs can be used to simulate real-world decision-making.

Several DCEs have been conducted to explore patient and caregiver preferences for cancer care (Casarett et al., 2008; Herrmann et al., 2018; Kohler et al., 2015; Osoba et al., 2006; Mühlbacher et al., 2008; Wong et al., 2014) and in PC specifically (Douglas et al., 2005; Finkelstein et al., 2015, 2016; Gomes et al., 2017; Hall et al., 2014; Malhotra et al., 2015; Meads et al., 2017; Molassiotis et al., 2012) but none thus far have focused on the views of PC clinicians because they provide complex care within complex health systems. Our investigator team has embarked on a mixed-method program of research ultimately aiming to develop

an evidence-based clinical decision-making tool for PC triage. This paper presents a research protocol for the novel application of an international, online DCE—its design, pilot, and planned execution and analysis—as an example of how this sophisticated methodology can be applied to health services research in PC.

### Discrete choice experiment design process

The various stages of development of the planned DCE (Figure 1) were undertaken in conformity with international guidelines (Bridges et al., 2011; Reed Johnson et al., 2013). Ethics approval was granted by the St Vincent’s Hospital Human Ethics Research Committee [LNR/16/SVHM/42].

### Identification of attributes of interest

An initial qualitative study was conducted to explore the practices and attitudes of 20 Australian PC clinicians toward triaging PC needs and is reported in detail elsewhere (Russell et al., 2018). This study, informed by a literature review, identified six key clinical characteristics or ‘attributes’ that clinicians use to determine urgency of PC needs: (1) physical suffering; (2) psychological suffering; (3) caregiver distress; (4) unmet communication or information needs; (5) discrepancy between care needs and care arrangements; and (6) mismatch between current site of care and desired site of death when imminently dying (Table 1).

### Creation of pilot DCE

Vignettes were written using the six attributes as descriptors (Figure 2), with care taken to omit confounders such as gender, age, or disease, and to be plausible in all PC settings (inpatient, hospital consultation, and community). For simplicity, pain was chosen as an example of physical suffering, anxiety as an example of psychological suffering, and discussion of prognosis and goals of care as an example of communication and information needs.

**Table 1.** Attributes and levels used for pilot discrete choice experiment

Attribute	Description	Levels and exemplars	A priori expectations
1. Physical suffering or distress of patient	Any physical symptom experienced by the patient and causing suffering or distress. May include pain, dyspnea, nausea, vomiting, constipation, diarrhea, itch.	Unknown/nil/mild: Mrs. Smith has no pain. Moderate: Mrs. Smith is having moderate pain. Severe: Mrs. Smith is having severe pain.	Priority given to those patients with greater physical suffering is expected.
2. Psychological or spiritual suffering or distress of patient	Any psychological symptom experienced by the patient and causing suffering or distress. May include anxiety, depression, confusion, existential distress.	Unknown/nil/mild: Mrs. Smith has no anxiety. Moderate: Mrs. Smith is having moderate anxiety. Severe: Mrs. Smith is having severe anxiety.	Priority given to those patients with greater psychological suffering is expected.
3. Distress or burnout of caregiver	Any distress or burnout experienced by the caregiver. May include anxiety, depression, exhaustion, existential distress.	Unknown/nil/mild: Her caregiver is not distressed. Moderate: Her caregiver is moderately distressed. Severe: Her caregiver is extremely distressed.	Priority given to those patients with more distressed caregivers is expected.
4. Urgent and complex communication or information needs	Mismatched goals of care or understanding of disease stage may influence management decisions that lead to suffering (e.g., pursuing investigations or aggressive therapies when unlikely to affect poor prognosis). Advance care planning discussions may be pressing when a patient is deteriorating rapidly, or may soon be unable to comprehend or communicate (e.g., in the setting of a progressive neurological disease).	Unknown/no: Mrs. Smith understands her prognosis and has clear goals of care. Yes: Mrs. Smith urgently wants to discuss her prognosis and make important decisions.	Priority given to those patients with more distressed caregivers is expected.
5. Significant discrepancy between care needs and current care arrangements	Care needs may include hygiene, medication administration (including subcutaneous infusions), psychological care, and medical management. Total arrangements may include lay caregivers abilities and capacity, professional caregivers expertise and accessibility (including after hours), equipment, location (including implications for lay caregiver's transportation needs).	Unknown/nil/mild/moderate: Her care needs are being adequately met by current arrangements. Impending: Her care needs are increasing and are expected to soon exceed current arrangements. Severe: Her care needs exceed current arrangements.	Priority given to those patients with greater discrepancy between care needs and current care arrangements is expected.
6. Imminently dying in nondesired site of death	The patient is expected to die within days and is not currently being cared for in their desired site of death, which is an important patient-centered outcome for palliative care services. This is relevant even if care is adequate in the current location.	Unknown/no: She is not imminently dying. Yes: She is expected to die within days but does not wish to die within her current site of care.	Priority given to those patients who are imminently dying with mismatch between current site of care and desired site of death is expected.

Levels of intensity were assigned for each attribute (Table 1), using the minimum number of levels required to sufficiently capture the full spectrum of clinically relevant alternatives to increase the design efficiency of the DCE. For example, a patient having “nil” versus “mild” pain was thought unlikely to be a significant differentiating factor in the assessment of urgency; thus, these attribute levels did not warrant separation within the experimental design. Attribute levels were made explicit (e.g., moderate, severe) rather than using clinically authentic but ill-defined terms (i.e., debilitating, niggling, or overwhelming) that would require interpretation and thus potentially confounding results.

The six attributes, four three-level and two two-level (Table 1), gave rise to 324 ( $3 \times 3 \times 3 \times 3 \times 2 \times 2$ ) possible unique vignettes and 324<sup>2</sup> possible paired choice sets. Inclusion of all these clinical vignettes in the DCE would represent a full factorial design and

would enable the estimation of the independent importance of each attribute (main effects) and all correlations between attributes (interactions), but would not be feasible; thus, an efficient orthogonal fractional factorial design was developed based on D-efficiency and using SAS 9.2 (Macro MktEx and ChoicEff). A cognitive burden of 36 vignettes presented in 18 paired-choice sets was hypothesized to be feasible for health professional participants. Participants were not provided an option of skipping any choice sets because this would not reflect real-world clinical practice.

#### *Execution of pilot DCE*

PC practitioners who had participated in the earlier qualitative study (Russell *et al.*, 2018) were contacted by phone or e-mail

In the context of your primary role (inpatient palliative care unit, inpatient palliative care consultation or community palliative care consultation) which patient do you think has the most urgent needs?	
Patient 1	Patient 2
Mrs Smith is having moderate pain and severe anxiety. Her caregiver is extremely distressed. Mrs Smith understands her prognosis and has clear goals of care. Her care needs are increasing and are expected to soon exceed current arrangements. She is not imminently dying.	Mrs Jones is having severe pain and moderate anxiety. Her caregiver is not distressed. Mrs Jones urgently wants to discuss her prognosis and make important decisions. Her care needs are being adequately met by current arrangements. She is expected to die within days but does not wish to die in her current site of care.

Fig. 2. Example choice set from pilot discrete choice experiment.

Table 2. Pilot participant characteristics

	N (%)	Median (range)
Profession		
Doctors	4 (40)	
Nurses and allied health clinicians	6 (60)	
Place of practice		
Inpatient unit	4 (40)	
Hospital liaison	4 (40)	
Community	2 (20)	
Gender		
Female	7 (70)	
Male	3 (30)	
Age (years)		45 (42–62)
Work setting		
Metropolitan	9 (90)	
Rural	1 (10)	
Years of palliative care practice		13.5 (10–20)

and invited to complete the pilot DCE followed by a face-to-face or phone interview to clarify their interpretation of the vignettes and the rationale for their choices. Ten participants were recruited (response rate, 50%), meeting the target sample size of 5 to 15, which has been shown to reveal most critical problems within survey design (Willis, 2004). Participants provided written informed consent. Their characteristics are shown in Table 2.

The cognitive burden of 18 choice sets was acceptable to participants and the median completion time was 14.7 minutes. Interviews revealed that participants sometimes did not select the patient they believed had the most urgent needs if they thought that those needs would be better met by an alternative type of PC service to the one they offered or by referral to an emergency department. Participants also noted that achieving care in the desired site of care was a separate and distinct PC priority from achieving death in the desired site of death, but the two concepts had been conflated as one attribute in the vignettes (“mismatch between current site of care and desired site of death when imminently dying”).

The pilot DCE was also reviewed by two PC physicians from the United Kingdom and two PC physicians from North America to ensure the appropriateness of language and terminology within their differing healthcare systems.

### Refinement of final DCE

Based on the findings of the pilot DCE, instructions to participants were expanded to clarify that no alternative health services were available, with the aim of ensuring participants only considered urgency, rather than appropriateness of service type (Figure 3). Additionally the attribute “mismatch between current site of care and desired site of death when imminently dying” was separated into two attributes, “mismatch between current site of care and desired site of care” and “imminently dying,” to allow independent analysis of the concepts involved (Table 3). In response to feedback from the international reviewers, minor changes were made to the terminology used in the demographic items preceding the DCE itself.

The final DCE plan therefore incorporates seven attributes, four three-level and three two-level (Table 3), giving rise to 648 (3 × 3 × 3 × 3 × 2 × 2 × 2) possible vignette profiles and 648<sup>2</sup> possible choice sets, again making a full factorial design unfeasible. Six pairwise interactions between attributes were hypothesized to be clinically important by investigators (B.R., J.P.) (Table 4); therefore, the number of choice sets needed to be increased to enable statistical estimation of these interactions. SAS 9.2 (Macro MktEx and ChoicEff) was used to develop an efficient orthogonal fractional factorial design that would allow estimation of main effects and the hypothesized interactions. The final DCE will hence consist of 72 choice sets divided into four blocks of 18 choice sets, with each participant randomly allocated to one of the four blocks to maintain acceptable cognitive burden.

The minimum sample size required for each block was determined using the Orme (2010) equation:  $n \geq 500 \times c / (t \times a)$ , where  $t$  is number of choice sets,  $a$  is the number of choices in each choice set, and  $c$  is the maximum number of attribute levels. The minimum number of participants in each block was therefore determined to be 42 ( $n \geq (500 \times 3) / (18 \times 2)$ ), requiring total recruitment of at least 168 participants for the four blocks.

### Planned execution of final DCE

The DCE will be open worldwide to doctors, nurses, and allied health professionals who have specialist PC training or who

<p><b>In the context of your primary role (inpatient palliative care unit, inpatient palliative care consultation or community palliative care consultation) which patient do you think has the most urgent needs?</b></p> <p>These two patients have both been newly referred to you today. Thinking of the service you identified as your primary setting (inpatient palliative care unit, inpatient palliative care consultation or community palliative care consultation), imagine this is the only service available (ie no emergency department or alternative palliative care service). Which patient will you admit to your service or see first?</p>	
<b>Patient 1</b>	<b>Patient 2</b>
<p>Mrs Smith is having moderate pain and severe anxiety. Her caregiver is extremely distressed. Mrs Smith understands her prognosis and has clear goals of care. Her care needs are increasing and are expected to soon exceed current arrangements. She is expected to die within days. She is currently in her desired site of care.</p>	<p>Mrs Jones is having severe pain and moderate anxiety. Her caregiver is not distressed. Mrs Jones urgently wants to discuss her prognosis and make important decisions. Her care needs are being adequately met by current arrangements. She is expected to die within days. She is not currently in her desired site of care.</p>

**Fig. 3.** Example choice set from final discrete choice experiment.

work primarily in PC, in inpatient, hospital consultation, or community PC services. Participants will be required to be proficient in English and have 2 years professional experience in clinical PC.

PC professional organizations internationally (listed in the International Association for Hospice and Palliative Care [2018] Global Directory) will be contacted by phone or e-mail and requested to circulate recruitment invitations to their members and affiliates via e-mail, newsletter, or social media platforms. This will be supplemented by promotion on social media and via personal contacts. An internet address will be provided for potential participants to access further information or to take part. The opening page will include a participant information and consent statement.

The DCE will be an online anonymous questionnaire using the Lime Survey platform and including demographic (age, gender, location) and work-related items (profession, PC setting, years of PC experience, prior consideration of PC triage process) to allow description of the study population and potential analysis of subgroups.

The importance of each attribute and prespecified interactions will be analyzed using a mixed logit model with maximum simulated likelihood (Train, 2009). All attributes will be assumed to have random coefficients to assess whether each attribute varies among the health professionals in a significant manner. If the interactions do not significantly contribute to the fit of the model, only the main effects model will be presented. Analysis will be performed using user-written package “mixlogit” in STATA 13.1.

## Discussion

Decision-making in PC triage is complex, because multifaceted and disparate clinical scenarios compete for finite clinical resources. At a minimum, transparency is required so that rationales for triage decisions can be made explicit and examinable, thus allowing standardization and correction of systematic biases over time. Ideally, efficiency and equity would also be embedded in routine practice, such that the needs of each patient are assessed and compared against those of others in a simple and fair manner. The planned DCE described in this paper allows

for consideration of multiple factors simultaneously and thus will be a useful method for exploring how PC clinicians make triage decisions. To the best of our knowledge, this will be the first time that a DCE has been conducted with PC clinicians as participants, but it appears to be a highly appropriate methodology for a discipline in which the tension of providing tailored patient-centered complex care has potential to hamper efforts to improve standardization.

As recommended by current guidelines (Reed Johnson *et al.*, 2013), the initial qualitative work (Russell *et al.*, 2018) was essential to delineate the factors that clinicians consider important when making PC triage decisions and thus generate the attributes to be tested in the DCE. Without this rigor, key attributes may have been omitted from the DCE, leading to a clinically inauthentic final triage tool and/or trivial attributes that may have been included in the DCE, leading to an unnecessarily large and potentially unfeasible DCE.

The efforts made to carefully craft the language of the DCE vignettes will minimize error because of misinterpretation (Coast *et al.*, 2012) and make the experiment pertinent to all PC settings. Piloting the DCE was crucial, particularly in identifying the problematic nature of combining the concepts of desired site of care and desired site of death. This distinction has been documented in the literature previously (Agar *et al.*, 2008), but was not made explicit during the qualitative study, yet the interviews revealed how it had potential to confound the DCE results.

An ideal DCE is orthogonal in design, allowing vignettes that combine all of the attributes to be evaluated by study participants. The planned DCE has the recommended maximum of seven attributes, many with only two levels, but because four attributes required three levels, the number of possible vignettes increased exponentially. Hence, a tradeoff had to be made between rigor and feasibility. Here the importance of clinical input was invaluable, to refine and prune levels, query whether each attribute critically captured an independent domain of PC triage, and which interactions between attributes were important to capture within the experimental design. All this needed to be within the maximum acceptable cognitive burden (and potential fatigue) placed upon the study participants, and we are confident this is the case given the pilot data.

**Table 3.** Attributes and levels used for final discrete choice experiment

Attribute	Description	Levels and exemplars	A priori expectations
1. Physical suffering or distress of patient	Any physical symptom experienced by the patient and causing suffering or distress. May include pain, dyspnea, nausea, vomiting, constipation, diarrhea, itch.	Unknown/nil/mild: Mrs. Smith has no pain. Moderate: Mrs. Smith is having moderate pain. Severe: Mrs. Smith is having severe pain.	Priority given to those patients with greater physical suffering is expected.
2. Psychological or spiritual suffering or distress of patient	Any psychological symptom experienced by the patient and causing suffering or distress. May include anxiety, depression, confusion, existential distress.	Unknown/nil/mild: Mrs. Smith has no anxiety. Moderate: Mrs. Smith is having moderate anxiety. Severe: Mrs. Smith is having severe anxiety.	Priority given to those patients with greater psychological suffering is expected.
3. Distress or burnout of caregiver	Any distress or burnout experienced by the caregiver. May include anxiety, depression, exhaustion, existential distress.	Unknown/nil/mild: Her caregiver is not distressed. Moderate: Her caregiver is moderately distressed. Severe: Her caregiver is extremely distressed.	Priority given to those patients with more distressed caregivers is expected.
4. Urgent and complex communication or information needs	Mismatched goals of care or understanding of disease stage may influence management decisions that lead to suffering (e.g., pursuing investigations or aggressive therapies when unlikely to affect poor prognosis). Advance care planning discussions may be pressing when a patient is deteriorating rapidly, or may soon be unable to comprehend or communicate (e.g., in the setting of a progressive neurological disease).	Unknown/no: Mrs. Smith understands her prognosis and has clear goals of care. Yes: Mrs. Smith urgently wants to discuss her prognosis and make important decisions.	Priority given to those patients with more distressed caregivers is expected.
5. Significant discrepancy between care needs and current care arrangements	Care needs may include hygiene, medication administration (including subcutaneous infusions), psychological care, and medical management. Total arrangements may include lay caregivers abilities and capacity, professional caregivers expertise and accessibility (including after hours), equipment, and location (including implications for lay caregiver's transportation needs).	Unknown/nil/mild/moderate: Her care needs are being adequately met by current arrangements. Impending: Her care needs are increasing and are expected to soon exceed current arrangements. Severe: Her care needs exceed current arrangements.	Priority given to those patients with greater discrepancy between care needs and current care arrangements is expected.
6. Mismatch between current site of care and patient or caregiver's desired site of care	Facilitating patients to be cared for in their desired site of care is an important patient-centered outcome for palliative care services. This is relevant even if care is adequate in the current location.	Unknown/no: She is currently in her desired site of care. Yes: She is not currently in her desired site of care.	Priority given to those patients with mismatch between current site of care and desired site of care is expected.
7. Patient is imminently dying	The patient is expected to die within days and no acute intervention is planned or required. Typical features may include reduced conscious state, loss of swallow and profound fatigue and weakness.	Unknown/no: She is not imminently dying. Yes: She is expected to die within days.	Priority given to those patients imminently dying is expected.

DCEs are gaining popularity, but have thus far been underused in PC despite being a discipline in which many decisions and interventions are complex. Although DCEs tend to be internally valid and consistent, external validity may still be a limitation; that is, respondents may make different choices in a real-world situations than the hypothetical scenarios in a DCE (Viney et al., 2002). DCEs, however, remain an efficient research tool where a “revealed preference” experiment (i.e., observed real-world choices rather than hypothetical choices as in the present “stated preference” DCE) may not be feasible because of logistical factors, as in PC triage. In any case, limitations regarding the

study of hypothetical rather than real-world decisions may not be such a concern when participants are experienced healthcare professionals, as evidenced by the previously documented congruence between stated and revealed prescribing preferences of physicians (Mark & Swait, 2004).


In summary, we anticipate the planned DCE will be a rigorous and efficient method by which to inform the development of an evidence-based PC triage tool.

Our future research includes the execution of the planned DCE and the use of the statistical model generated to form a scoring system for items on the triage tool (Table 3), followed by

**Table 4.** Hypothesized interactions between attributes

Attribute 1	Attribute 2	Nature of hypothesized interaction	Strength of hypothesized interaction
Patient is imminently dying	Physical suffering or distress of patient	Increased propensity to assign priority	Very strong
Patient is imminently dying	Significant discrepancy between care needs and current care arrangements	Increased propensity to assign priority	Very strong
Patient is imminently dying	Mismatch between current site of care and patient or caregiver's desired site of care	Increased propensity to assign priority	Very strong
Significant discrepancy between care needs and current care arrangements	Distress or burnout of caregiver	Increased propensity to assign priority	Strong
Patient is imminently dying	Distress or burnout of caregiver	Increased propensity to assign priority	Strong
Psychological or spiritual suffering or distress of patient	Physical suffering or distress of patient	Increased propensity to assign priority	Strong
Mismatch between current site of care and patient or caregiver's desired site of care	Psychological or spiritual suffering or distress of patient	Increased propensity to assign priority	Moderate
Mismatch between current site of care and patient or caregiver's desired site of care	Distress or burnout of caregiver	Increased propensity to assign priority	Moderate
Psychological or spiritual suffering or distress of patient	Distress or burnout of caregiver	Increased propensity to assign priority	Moderate
Mismatch between current site of care and patient or caregiver's desired site of care	Significant discrepancy between care needs and current care arrangements	Increased propensity to assign priority	Moderate
Distress or burnout of caregiver	Physical suffering or distress of patient	Increased propensity to assign priority	Moderate
Patient is imminently dying	Urgent and complex communication or information needs of patient or caregiver	Increased propensity to assign priority	Moderate
Urgent and complex communication or information needs of patient or caregiver	Psychological or spiritual suffering or distress of patient	Increased propensity to assign priority	Moderate
Urgent and complex communication or information needs of patient or caregiver	Distress or burnout of caregiver	Increased propensity to assign priority	Moderate
Significant discrepancy between care needs and current care arrangements	Psychological or spiritual suffering or distress of patient	Increased propensity to assign priority	Moderate
Urgent and complex communication or information needs of patient or caregiver	Significant discrepancy between care needs and current care arrangements	Increased propensity to assign priority	Weak
Significant discrepancy between care needs and current care arrangements	Physical suffering or distress of patient	Increased propensity to assign priority	Weak
Patient is imminently dying	Psychological or spiritual suffering or distress of patient	Increased propensity to assign priority	Weak
Urgent and complex communication or information needs of patient or caregiver	Mismatch between current site of care and patient or caregiver's desired site of care	No effect	—
Urgent and complex communication or information needs of patient or caregiver	Physical suffering or distress of patient	No effect	—
Mismatch between current site of care and patient or caregiver's desired site of care	Physical suffering or distress of patient	No effect	—

validation of the final tool. It would also be beneficial to conduct a parallel program of research with patients and the public to investigate their priorities for PC triage, and thus develop triage strategies directly informed by those who access, who fund, and who may in future be recipients of, PC services.

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