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Barbara Gomes, PhD, MSc, BSc, Maja de Brito, MSc, BSc, Vera P. Sarmento, MD, MSc, Deokhee Yi, PhD, MPH, BS, Duarte Soares, MD, MSc, Jacinta Fernandes, MD, Bruno Fonseca, MSc, Edna Gonçalves, MD, MSc, Pedro L. Ferreira, PhD, Irene J. Higginson, OBE, BMedSci, BM BS, FFPHM, PhD, FRCP

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Valuing attributes of home palliative care with service users: a pilot discrete choice experiment

Running title: Home palliative care discrete choice experiment

Barbara Gomes¹,², PhD, MSc, BSc, Maja de Brito³, MSc, BSc, Vera P Sarmento⁴, MD, MSc, Deokhee Yi⁵, PhD, MPH, BS, Duarte Soares³, MD, MSc, Jacinta Fernandes⁴, MD, Bruno Fonseca⁵, MSc, Edna Gonçalves⁶, MD, MSc, Pedro L Ferreira⁷, PhD, Irene J Higginson², OBE, BMedSci, BM BS, FFPHM, PhD, FRCP

¹ University of Coimbra, Faculty of Medicine, Coimbra, Portugal
² King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, London, UK
³ Northeast Local Health Unit (Unidade Local de Saúde do Nordeste – ULSNE), Hospital Unit Bragança, Palliative Care Department, Bragança, Portugal
⁴ Northeast Local Health Unit (Unidade Local de Saúde do Nordeste – ULSNE), Home Palliative Care Unit Planalto Mirandês, Miranda do Douro, Portugal
⁵ Matosinhos Local Health Unit (Unidade Local de Saúde de Matosinhos – ULSM), Home Palliative Care Team, Matosinhos, Portugal
⁶ Saint John’s Hospital (Hospital de São João HSJ), Palliative Care Service, Porto, Portugal
⁷ Centre of Health Studies and Research of the University of Coimbra, Coimbra, Portugal

Corresponding author: Barbara Gomes, King’s College London, Cicely Saunders Institute, Department of Palliative Care, Policy and Rehabilitation, Bessemer Road, London SE5 9PJ, United Kingdom, Phone: 0207 848 5516, Fax: 0207 848 5517, barbara.gomes@kcl.ac.uk

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ABSTRACT

Context: Discrete choice experiment (DCE) is a quantitative method that helps determine which service attributes are most valued by people and consequently improve their well-being.

Objectives: To test a new DCE on home palliative care (HPC).

Methods: Cross-sectional survey using the DCE method with adult patients and their family caregivers, users of three HPC services in Portugal. Service attributes were based on a Cochrane review, a meta-ethnography, and the few existing DCEs on HPC: 1) team’s availability, 2) support for family caregivers, 3) homecare support, 4) information and planning, and 5) waiting time. The experimental design consisted in three blocks of eight choice sets where participants chose between two service alternatives that combined different levels of each attribute. We piloted the DCE using cognitive interviewing. Interviews were analysed for difficulties using Tourangeau’s model of information processing.

Results: The DCE was conducted with 21 participants out of 37 eligible (10 patients with median Palliative Performance Scale =45, 11 caregivers). Most participants found the DCE easy (median 2 from 1-5), though 2 patients did not finish the exercise. Key difficulties related to comprehension (e.g. waiting time sometimes understood as response time for visit instead of time from referral to care start) and judgement (e.g. indecision due to similar service alternatives).

Conclusion: The DCE method is feasible and acceptable, but not all patients are able to participate. In the main study phase we will give more attention to the explanation of the waiting time attribute.

Keywords: home care services, palliative care, patient preference, caregivers, economics, discrete choice experiment
INTRODUCTION

In today’s healthcare systems a considerable effort is focused on the efficient allocation of scarce resources. In the field of palliative care, the need for home support is growing as the number of deaths is rising (1, 2) and home remains where most people prefer to die and where most spend their last months of life. (3) A Cochrane review demonstrated that receiving home palliative care (HPC) doubles the odds of dying at home and is associated with fewer symptoms for patients with advanced illness, compared to usual care. (4) Some attributes of HPC appear to be associated with increased benefits for patients and family caregivers (e.g. case conferencing with general practitioner (GP), 24/7 availability of the HPC team, provision of support for family caregivers, practical and advanced technical support at home). (4-7) However, it remains unknown what attributes are most valued by HPC users.

There is growing interest in the discrete choice experiment (DCE) as a quantitative method for eliciting user preferences when modelling healthcare services. (8-10) Participants are asked to elicit preferences considering different dimensions of a service (attributes with different levels). They voice their preferences by making choices between alternatives of hypothetical but realistic descriptions of a service (scenarios). These stated preferences are, therefore, not based on observation of real behaviour (revealed preferences). Consequently, the value of DCE is in providing information on preferences in fields where real behaviour is difficult or impossible to observe.

Few have used this methodology in palliative care. In the US, a DCE (5) including 300 patients with advanced cancer found that alternative supportive care services (voucher for practical assistance at home, transportation, peer support, meal delivery, case management, family care) were more valued than traditional hospice care services (nurse, counsellor, home health aid, respite care, chaplain). In Australia, (6) a DCE including 168 family caregivers of people receiving HPC revealed a preference for current services over hypothetical alternatives; most valued attributes were daily nurse home visits, 24-hour phone advice, doctor home visits weekly, personal care assistant visits and home respite care. Most
recently, two DCE studies conducted in Singapore with over 500 advanced cancer patients, their

caregivers, and community-dwelling older adults, showed that services working towards supporting
death at home are in line with the preferences of all three participating groups. (11, 12)

DCE can yield misleading results when not well-designed.(10) To ensure rigour in the development of the
scenarios used (service attributes and their levels) a qualitative approach is recommended.(13) The
optimal number of choice sets depends on the complexity of the choices(10) and this should be informed
by pilot results. A pilot phase is also needed to ensure the choice sets are appropriate to the specific
context in which the DCE will be applied.

Further investigation of the reasoning process behind the choices made in a DCE is necessary, to better
understand its feasibility and results. However, this is rarely done. A systematic review of DCEs in health
published in 2014 reported that only 41% of DCE studies (73/179) used qualitative approaches to pre-test
the questionnaire and only 8% (14/179) used debriefing techniques to increase understanding of the DCE
process and results.(10) Usually, researchers used think-aloud techniques to understand reasons for
choosing/rejecting an attribute.(14) Rarely have they conducted cognitive interviews to identify
difficulties emerging during the administration of a DCE.

This pilot study aimed to test a new DCE to determine which attributes and models of HPC are most
valued by service users, i.e. patients with advanced illness and family caregivers under HPC, with a view
to inform the modelling of future HPC services. The objectives were to test the DCE design and patients’
and family caregivers’ understanding of the DCE, and identify sources of possible response errors.

METHODS
Study design

The study was a cross-sectional survey using the DCE method with service users of HPC. After defining the attributes of HPC and their levels (stage 1), we developed the experimental design (stage 2), and used cognitive interviewing techniques to identify and address problems that could arise in the process of eliciting preferences (stage 3). In this paper we focus on the second and the third stage. For the clarity of the study, we first briefly describe the stage of developing the attributes. The study is described according to ISPOR good research practices for conjoint analysis application in health.

Stage 1: Defining attributes and levels

HPC attributes and levels were developed based on results from a Cochrane review, a meta-ethnography and two DCEs on HPC that existed at the time the study was developed.

The Cochrane review on HPC showed that reinforcing services with a specific component of support for family caregivers (brief psycho-educational intervention) reduces caregiver’s distress with patient’s symptoms and increases feelings of rewards from caregiving; findings also suggested that 24/7 availability may play an important role. In addition, an RCT examining comparative effectiveness suggested that adding case conferencing with the GP to standard HPC reduced hospitalization and better maintained patient’s performance status. Based on this, we identified the provision of support for the family caregivers, the availability of the team, and information provision/care planning as important attributes for the DCE.

We also conducted a meta-ethnography, a systematic method for synthesising qualitative evidence, focusing on what was known about patients and family caregivers’ experiences with HPC services, to inform the choice of attributes in the study. The synthesis of 19 studies showed that the concept of ‘security’(feeling developed through trusting the team to be there for support, prevention and relief of
suffering)(7) is central to understanding the mechanisms of action and outcomes of HPC services. We
found that ‘presence’ (team’s 24/7 availability, prompt response and visiting patients and caregivers at
home)(7) and ‘competence’ (providing effective symptom control and communicating skilfully)(7) are key
components of HPC to patients and family caregivers. Important features were identified from this
evidence for the DCE that led to the definition of attribute levels; these include easily accessible 24/7
team with prompt response; home visits with practical help and advanced technical support; and
anticipatory guidance to handle illness progression, symptoms, and decision-making.

Attributes in the other two DCEs on HPC were also taken into account, including the importance of
respite care (for which there were contradictory findings).(5, 6) These studies reinforced the relevance of
the attributes already identified and highlighted the importance of the HPC team’s quick response and
delivery of various levels of care at home.

Based on the evidence described above, we therefore defined five attributes: 1) team’s availability, 2)
support for family caregivers, 3) homecare support, 4) information and planning, and 5) waiting time.
Once these were identified, we looked for specific features within each of them in order to define their
levels. As a result, three of the attributes (availability, homecare and waiting time) have three levels,
while the remaining two (support for family caregivers, and information and planning) have four levels.
All are listed in Table 1. The attributes were described in a way they would be realistic in the current
healthcare system and considered necessary and desirable by the patient and/or caregiver. The number
of attributes (five) is the mean in DCEs in health (9) and is deemed appropriate for our population.
Using the Statistical Analysis System (SAS®), we developed a forced-choice block design; this means that participants are presented a fixed number of alternative responses and asked to choose one. We designed three blocks of eight choice sets, each choice set with two service alternatives for participants to choose one from. An example of a choice set can be seen in Figure 1. This design reduced the 432 possible choice sets (3 X 3 X 3 X 4 X 4) to 24 (with the optimal statistical efficiency of the design based on D-efficiency(19)). Each participant was randomly assigned to one of the three blocks of eight choice sets - this kept the exercise simple, while securing the efficiency of the design (maintaining balance between response efficiency and statistical efficiency). Scenarios (descriptions of an HCP service) were randomly paired. To control for any potential ordering effect, the order of presentation of the attributes in each choice set varied randomly.

[Figure 1]

**Stage 3: Survey piloting with cognitive interviewing techniques**

The DCE was piloted using cognitive interviewing. This set of techniques aids access to how participants understand and answer to survey questions and check if the materials are understood as intended by the researchers.(19) The techniques focus on the cognitive processes (overt and hidden) that participants use to answer to survey questions. We used a hybrid model of think-aloud, concurrent and retrospective probes, including: How did you arrive at the answer? Was that easy or difficult to answer? I noticed you hesitated, what were you thinking? We probed after each of the eight DCE choice sets because the processes involved in the decision of a specific choice set were still fresh. We also probed retrospectively at the end of the DCE, where we asked participants to grade the level of difficulty (from 1 - very easy to 5 - very difficult) and to identify which factors influenced their choices in the DCE.

**Setting and participants**
Portugal is a country with 10.3 residents and only generalised PC provision within public and private sectors.\(^{21}\) The public sector represents the majority of the existing services and provides HPC free of charge at the point of delivery. Although Portugal has seen an increase in HPC teams, only a minority of patients have access to these services. According to the Portuguese PC Observatory, in 2016 there were 22 HPC teams in the country, all providing care with no costs for patients at point of delivery except three that are privately paid for.\(^{22}\) This means there is one HPC team per 470 000 residents in Portugal when guidelines from the European Palliative Care Association recommend one HPC team per 100 000 residents.\(^{23}\) Criteria for referral of a patient to HPC vary from service to service but usually include a patient having an incurable, advanced and progressive disease, being unable to attend out-patient clinic, presence of need for monitoring and/or symptom management that exceeds the resources of the primary palliative care provider and availability of informal caregiver.

In this study, we included patients and family caregivers in three public HPC services in the North region of Portugal (one rural, two urban) from March to June 2015. Patients were considered eligible if they had an advanced illness and were being followed by the HPC team. The family caregiver was nominated by the patient as the person providing most help with care. Reasons for exclusion were: age <18 years; residence outside the North region; inability to understand or communicate in Portuguese, incapacity to provide informed consent; and being too ill, stressed or overwhelmed. We also excluded patients with initial assessment only or with only one follow-up HPC visit as they had limited experience of the service.

Given that this was a pilot and our aim was to test the method and identify problems, we considered guidelines for sample size in cognitive interviewing research. According to Willis,\(^{20}\) conducting 5 to 15 cognitive interviews reveals the most critical problems.

**Data collection**
DCE questions were administered face-to-face by interviewers with background information and instructions. After explaining the DCE, we presented to the participant a ‘key-card’, which contained a description of all attributes and its key components. The ‘key-card’ (Figure 2) was an A3 colour-printed hardcover card with text in large font size and symbols to explain all the attributes and the key components that combined to create different levels within each attribute. After reading aloud the description of the attributes one by one and making sure the participants understood all, a warm-up exercise followed. In this exercise we asked participants to describe their own HPC service in terms of each attribute, with the help of the ‘key-card’. This aimed to improve participants’ understanding of the attributes and their levels, and it also showed how well they knew the characteristics of the service they were on. There was also a warm-up example with annotations.

The second part of the interview consisted of the application of the DCE, where each participant was asked to look at each of the eight choice sets individually (example in Figure 1) and choose one of the two service alternatives (A or B) they preferred the most. This means that each participant was asked to make eight choices. The ‘key-card’ was held close by in case they needed to recall the meaning of the attributes or components referred to in each attribute level.

After the DCE was completed, the participants responded to socio-demographic questions (including gender, age, nationality, educational level, and working status) and completed the following measures of health status, palliative care outcomes and symptoms: the EQ5D (completed for both the patient and family caregiver), the Palliative care Outcome Scale (POS) and the POS-Symptom scale (completed for the patient). All measures have been validated in Portugal.[24, 25] The researchers completed a measure of patient’s performance status (Palliative Performance Scale - PPS)[26] based on observation.

We interviewed patients and caregivers separately to capture individual perspectives and experiences.

The interviews were conducted by four researchers who participated in a training session involving
readings and practice through role-play. If the participant consented, the interview was recorded and transcribed for analysis.

Analysis

Two researchers (BG and MdB) who were involved in the interviews listened to all the interviews and read the transcripts, applying codes to the difficulties identified following Tourangeau’s model of information processing, the most established in the field. According to this model, a person goes through four stages of cognitive processing when answering a survey question: comprehension and interpretation of the question, retrieval of information (from memory) needed to answer the question, making a judgement about the relevance and accuracy of the answer; and formulating the response. In each of these stages, cognitive errors that compromise the validity and accuracy of the answer may occur.

The two researchers examined cognitive processing problems during the interview, consistencies and inconsistencies in response processes and patterns across the interviews. They also reviewed the questionnaires and interviewers’ notes and measured interview length. Cognitive difficulties, missing data, expressions of uncertainty, distress or burden were identified. Furthermore, participants’ understanding of the descriptions of the attributes and levels, the DCE and the layout of the materials were examined. An interim analysis was conducted after eight dyads were interviewed.

Ethics and approvals

All participants provided written consent to participate in the study. In case of illiteracy or incapacity to read due to the disease, the consent was read aloud and a thumbprint was used if participants could not sign their name. The study was approved by the researchers’ institution research ethics committee, the Portuguese data protection authority, and local ethics committees of all participating clinical centres.
RESULTS

Sample characteristics

Out of 37 eligible individuals, a total of 10 patients (7 males) and 11 family caregivers (2 males) participated in the pilot. Therefore, in total the response rate was 57% (21/37); 56% for the patients (10/18) and 58% for the caregivers (11/19). Reasons for loss of the eight patients were: symptomatic on the day of the interview (e.g. breathlessness, headache, fatigue) (n=4), deterioration of health condition (n=1), death (n=1), caregiver feeling there were already too many unknown people entering the family space at a very sensitive time and refusing participation in the name of both (n=1), patient refusal with no reason provided (n=1). Reasons for loss of eight caregivers were: too exhausted to participate (n=4), caregiver hospitalized (n=1), not feeling comfortable to do the interview in the house of the patient and accepting no alternative (n=1), refused participation due to having too many unknown people entering the family space (n=1), not feeling comfortable to participate in research interview due to being an unknown situation (n=1).

Cognitive interviews lasted from 26 to 120 minutes. The median age of patients was 75.5 (min. 51 - max. 91) and of family caregivers 58 (min. 48 - max. 81). Most patients had cancer as primary diagnosis (7/10) and the median PPS score was 45 (min. 10 - max. 80). Patients’ median health status on the interview day measured using the EQ5D visual analogue scale, was 30 (min. 10 – max. 70), while caregivers’ median was 70 (min. 0 – max. 100). Most caregivers were spouses (6/11) or daughters (3/11). One was a mother taking care of a son and one a daughter-in-law caring for her mother-in-law. Of all participants, most were married and retired, and had a low education level (Table 2).
Difficulty of the DCE

Self-reported median difficulty with the DCE was 2 ("easy") for both patients and family caregivers, ranging from 1 (min.) to 5 (max.). The ease experienced by most participants is illustrated in the following comments:

“No, no, it’s … It’s not arduous, it’s easy” (female caregiver, 75 years, basic education)

“I found it easy to understand. Didn’t think it was difficult.” (female caregiver, 57 years, bachelor’s degree)

However, two patients indicated level 4 ("difficult") and two other completed only two out of the eight choices sets. Both were symptomatic (breathlessness and fatigue); one said there were too many packages and the other expressed tiredness.

Stages and difficulties in information processing

Questions and response categories worked well for most participants. However, through cognitive interviewing we identified some difficulties (Table 3). These were mainly related to comprehension and judgement problems, and less with retrieval of information and response formulation. This is now explained in more detail and Table 3 shows the solutions that were implemented afterwards.

[Table 3]

Comprehension
Comprehension problems were the most common. We identified several difficulties, such as misunderstanding terms or requests for clarification. The HPC attribute Waiting time proved to be most prone to misunderstanding. At times, participants requested a confirmation of understanding:

Caregiver: “... Waiting time, this means since it [HPC] is activated until the ... ?” [looks at the interviewer] (female, 48 years, graduate degree)

Interviewer: “Yes, [time] between referral and the first visit, first contact.”

After the third DCE card was presented, another patient said:

“... this package has less days to wait ... I don’t understand well these days.” (male, 91 years, basic education)

Some participants understood this attribute as the response time for each individual HPC visits/contact and not the time they would wait for the start of HPC after referral (as intended). One patient expressed this by saying:

"... [This service package] has fewer days of waiting. I like when they [the HPC team] come." (male, 91 years, basic education)

Problems were resolved when the interviewer clarified the meaning and emphasized it related to the first contact and not each visit.

Confirmation of understanding was also asked for the attributes Support for family caregivers and Information and Planning. One caregiver requested clarification about the attribute Respite Care:
Caregiver: “I interpret this as … the team provides someone that takes care of the patient, for me to go …” (female, 54 years, basic education)

Interviewer: “Yes, it’s exactly that. It’s someone from the team that stays here, so you can rest or go and do some things that need to be taken care of. Go to the bank, supermarket, pharmacy, anything.”

One caregiver, when referring to the case conference with the GP (in attribute levels for Information and Planning), was unsure to what extent is the GP present in the provision of HPC:

Caregiver: “This meeting with the GP … It’s important at a first … when the person enters palliative care ok? From there on, I understand that the GP steps a bit out of the area, because he stops participating in the care of the patient. He [the GP] is only aware of the situation, but doesn’t … let’s say … do anything, because who will then “encompass” the patient, let’s put it this way, is palliative care mostly. So … I don’t know if by including this [case conference with the GP] you mean that he [the GP] is always present? Or if it’s at the beginning only.” (female, 48 years, graduate degree)

Interviewer: “The idea of the case conference with the GP is to have a meeting with the presence of the GP where the coordination of care with the existing team is discussed, because they [GPs] have access to the nurses from the [continuous care] network.

Caregiver: “Yes.”

Interviewer: “The GP may not be directly involved, but is present.”

Caregiver: “Yes, it’s true, the GP has [access to] nursing [care] that has to manage the information and sometimes [they] talk [exchange information] between them.

One caregiver had difficulties understanding how the GP could be integrated in current care as, based on their situation (the patient’s HPC team was hospital-based), she did not see that as feasible.
Caregiver: “This meeting with the family doctor, I don’t see very well what is the purpose of it, unless the family doctor is integrated in home visits. ... [looking at the DCE card] Here is standard information and planning, this meeting with the GP ... I don’t understand very well how this [inclusion of the GP] is organized. It can be, but as I see it ... I don’t see ... Because if palliative care would be organised within the health centre, the primary care nurses would provide the care. But it’s not like that. Since there is no such link [between the services] and I hire a private company [to provide nursing care], the GP ... from the health centre is automatically ... the whole primary care service is automatically out. Because when my mother needs a doctor, she will go to palliative care and when she needs nursing care, she will go to a private company. I don’t see ... do you understand?” (female, 58 years, master degree)

In the example above, the interviewer then explained further the attribute; however, thinking about their experience, the caregiver concluded she did not see any additional value of having a case conference with GP involvement.

Another caregiver (female, 50 years, basic education) mixed up two attributes on the second DCE card because the order they show on each choice card varied. She assumed that the attribute Support for family caregivers would always be presented first, as in the first card. The error was spotted by the interviewer who brought attention to the different attribute order and summarized again the levels of both attributes to make sure they are well understood in the following choices cards.

Retrieval of information

Problems retrieving the information were not very common, but occasionally participants struggled to remember what a service package, attribute or attribute level encompassed. The key card was often used as a memory aid to remember attributes and their levels (e.g. Advance care planning). In addition, participants used the choice cards to remember all attributes and levels involved in a given service
package. Error in recall was identified twice when a caregiver (female, 74 years, basic education) and a patient (male, 91 years, basic education) could not answer, in retrospect, why they had preferred a certain service package. This patient commented: “It’s not difficult [to do this exercise], but one is forgetful.”

Judgement

It was common for both patients and caregivers to feel indecisive between the two service packages. Sometimes this was due to difficulty integrating and considering all the information together, which was annotated as an interviewer’s observation in field notes at two occasions. Other times the uncertainty was due to difficulty deciding between very similar service packages. This was most evident when participants could not find in their preferred service package something they felt they needed the most (e.g. 24/7 availability or advanced technical support) or when the care aspects most valuable to them were distributed between the two service packages (having extended team’s availability hours in one package and the psychoeducational intervention in the other, but valuing both). As one patient (female, 75 years, basic education) put it simply "Everything is needed when the time comes.", which implies both packages offer support that is needed and valuable.

Participants expressed some worry about whether they were giving us the correct answers. In field notes, we recorded several observations about the patients asking us at the end of the interview to confirm whether their answers had been the same as those of the caregiver. Also, one caregiver expressed her worry about whether she was following the same line of thought throughout the choices she made:

Caregiver: “I think it’s this one.”

Interviewer: “Package A.”

Caregiver: “I think ... I do not know if I’m following more or less the same line ...” (female, 54 years, basic education)
The interviewer explained there was no system to answering the questions and made sure the participant understood there are were no right or wrong answers and that the interest was on their opinions.

Difficulties in judging the choice options had sometimes origin in previous stages of information processing. For example, the caregiver (female, 58 years, master degree) who had difficulties understanding GP’s role within the service package had later on difficulties deciding which service alternative she preferred. This caregiver also felt divided between applying a general principle or personal experience regarding the attribute Waiting time.

Caregiver: “There’s three and nine days [looking at the two service packages on the card]. I, well, when my mother was referred … I thought the sooner the better … Normally, nine days would be perfectly acceptable. But when you refer a person with metastases … waiting for the first complication to refer [the patient to PC] … it’s a bit too late. So, the nine days would have been more than enough, but, like it happened [to us], even three days means the person was afflicted.”

One caregiver (female, 74 years, basic education) looked for some response validation from the interviewer when making the first out of the eight choices as she felt unsure which service package to choose. The interviewer made it clear there were no right or wrong answers and summarized the service packages presented in the card. In response to this, the caregiver easily decided for one of the two alternatives. Another caregiver (female, 70 years, basic education) explained she was counting symbols to help her decide which service she considered better, with the reasoning the best service was the one that provided more care (”As it [the service package] has more symbols, I think it [the service package] has more support.”). This was the most extreme example of simplification of the DCE.

Response formulation
Problems formulating the response were very rare. One caregiver (female, 48 years, graduate degree) perceived the combination of two attribute levels as non-plausible (Advanced technical support and Availability 24/7), which made it difficult for her to respond which service she preferred.

Caregiver: “There is some kind of contradiction here. ‘Cause if I had the advanced technical support, automatically it could never be from Monday to Friday [availability of the team]. Right? Maybe I’m exposing a problem here. Because it’s like, imagine the situation you’ve presented me here. Transfusion or something that requires the presence of medical staff. This kind of support would require weekend coverage. If I had this level of support …”

Interviewer: “What we are saying is that you have this level of support [advanced technical support] on working days, from 9am to 5pm.”

Caregiver: “Yes, but usually when you have this type of support there is no distinction of Saturday and Sunday. [laughing] This almost prevents hospitalization. It’s like hospital antibiotics, they would need to come home and do it here. Automatically, they would have to come and do the treatments on Saturday and Sunday as well, right?”

After consulting with health professionals within our team, we decided to maintain the combination of attributes because most advanced technical support can be provided within a weekday schedule.

Other relevant difficulties

One caregiver said the service packages did not correspond completely to their specific situation and that they would need to change some things (the patient had a degenerative developmental condition). Two patients bounded preferences to their personal experience of services: one (male, 91 years) did not choose an alternative that offered a conference with the GP because he had no GP and one (male, 91 years) asked which package was “from his doctor”. The interviewer explained the services presented were hypothetical and did not refer to a specific existing team.
One caregiver (female, 70 years, basic education) reacted emotionally to the attribute level *Advanced care planning*. Although the description of the attribute does not speak explicitly of dying, the caregiver started to cry, as this reminded her of her husband’s imminent death as one of the future scenarios for which she said she did not feel ready for. The interview was stopped and the interviewer inquired with empathic presence whether she had shared this with the HPC team. The caregiver said she talked about this issue with the HPC nurse on the previous day and spontaneously continued responding to the question about the type of information and planning offered by their HPC team.

It’s worth noting the HCP teams gave us positive feedback after visiting their patients and family caregivers following our interview. We were informed that caregivers in particular expressed satisfaction, saying the conversation was pleasant. Some caregivers said they felt relieved after the interview; two asked the nurse if we were to visit them again. We sent all participants thank you letters at the end of their participation.

**DISCUSSION**

This paper describes the results of a systematic and thorough qualitative approach to test and improve a new DCE on HPC with patients and family caregivers. There is a limited number of DCE studies about this topic. Our study is one of the first to include patients followed by HPC services, and to our knowledge, the first to report in detail the results of cognitive interviewing. As such, the paper contributes to the literature on DCE development and specifically on the systematic process of testing the acceptability and feasibility by means of cognitive interviewing.

The DCE was built based on published quantitative and qualitative literature, from where attributes and levels were defined. A constant iterative qualitative approach is recommended for attribute derivation. This study shows that in the event of constraints in conducting studies with
patients and families at the end of life, other rigorous approaches such as meta-ethnography,(7) can provide the required evidence, maximising use of the existing data.

Our pilot study demonstrates that a DCE conducted with patients and family caregivers in the HPC context is acceptable and feasible. In general, the application of the DCE worked well, the attributes are relevant and attribute levels appropriately differentiated. Only minor changes were needed to achieve better explanation and consequently greater understanding of the attributes and levels. The participants were able to make trade-offs comparing the alternatives. The number of choice sets (eight) seems acceptable for most participants. Based on the pilot, we expect that not all patients will be able to participate fully.

At times the participants found it helpful that the interviewer summarized the choice set and followed along. We believe this strategy helped them in considering all the information while deciding what service they preferred. However, interviewers should be cautious and summarize the service package in a way that is as neutral as possible, not to influence the participant’s choice.

The difficulties identified were mostly related to comprehension and judgement. All these difficulties can be reduced with additional explanation, description, concrete examples or use of the key card. We consider some of the requests for clarification (e.g. trying to understand better the role of the GP) as caregiver’s effort to engage in the exercise with attention, in order to make informed choices. Judgement difficulties were considered as positive feedback as we feel these are a reflection of the nature of DCE and indirectly show the choice sets were well constructed (involving trade-offs).

Nevertheless, important findings have emerged from the struggles participants had in connection with the retrieval of information and formulation of the final response. We have checked if all the attribute levels are compatible and realistic and we have learned the value of a thorough explanation and knowing well how the participating HPC teams work. Simplification of the exercise (counting symbols) and failure
to recall the final response could be the most worrying cognitive difficulties we have encountered as they might mean the participants did not understand the DCE and the stated choices were merely guesses. However, they could also reflect more basic ways of making choices, which should be as respected as much as the more elaborate reasoning.

This is one of the rare studies that used cognitive interview in DCE (and one of the rare papers showing the thoroughness of the steps leading to the administration of a DCE). We found cognitive interviewing was very useful for mapping difficulties in the design and contents of our DCE. Furthermore, it proved to be a helpful approach in refining the materials used, as it gives voice to study participants to share their opinion with the research team. Also, observations that result from cognitive interview techniques offered us insight into the heuristics the participants use while stating their preferences for HPC. Kohler et al(27) used this approach when constructing a DCE for eliciting preferences for early cancer detection with 20 healthy women, but from their published work it is not clear if they applied any formal approach to the analysis. They concluded that the interview approach ensured comprehension of the attributes and levels, images and helped identify the problem areas. Based on our findings, we agree and conclude the cognitive interview is a valuable tool for improvement of a DCE in the context of HPC.

Although frequent probing of the rationale for the choices made can be a potential trap as it can backfire with participants perceiving this as the interviewer not being satisfied with the choices made or suggesting the response is not a correct one, we believe that with a sensitive approach to interviewing and taking into account characteristics of the interviewee this can be overcome.

**Strengths and limitations**

We used think aloud and probing techniques in order to maximise the possibilities of gaining insight into difficulties while participating in the DCE survey and to minimise interviewer-imposed bias. Although the DCE is a well-structured and standardized method, it offers participants manoeuvring space for trading
off within the framework they choose (whether it is thinking on the current or the future needs in health
deteriorating circumstances). Looking through a merely quantitative perspective, we see only part of the
reasoning patients and caregivers express in a DCE. We examined qualitative data from cognitive
interviews,(20) coding exhaustively to identify problems within each of all four stages of information
processing.(15) This analysis was performed by two researchers to increase the rigour.

Although we reached the recommended number of the interviews,(20) it is still subject to discussion
what is a sufficient sample for cognitive interviewing.(30) The majority of patients had cancer and a low
level of education. This might be reflected in the preferred choices and giving importance to certain
attributes or levels than otherwise. Consequently, some of the difficulties might not be recognised as
nuances in the meaning and applicability of the packages might get unnoticed when a simpler approach
to making choices is used. However, these will be the predominant characteristics of our sample in the
main study and it is therefore appropriate to follow the suggested changes and to expect some of these
difficulties in the future. Additionally, the participation of low-educated patients and caregivers ensures
that the DCE is comprehensible across a wide range of people.

Conclusion
Administering a DCE through a face-to-face survey is acceptable and feasible with palliative care patients
and their family caregivers, and the cognitive interview is a helpful tool to capture difficulties in
participating. However, due to the nature of advanced disease not all patients are able to participate. All
the difficulties found are manageable and will be given more attention in the main study phase. The
results of this pilot study will inform the main study which is expected to help HPC services to best suit
the needs of patients and family caregivers in the future.

Disclosures and acknowledgements
The authors declare no conflicts of interest. We are grateful to the patients and family caregivers who
participated in the pilot study and the health professionals from the HPC who helped recruit participants.
This work was supported by the Calouste Gulbenkian Foundation as part of the DINAMO Project, which aims to enhance advanced training and research to optimise home palliative care in Portugal (Principal Investigator – Barbara Gomes, Scientific Director – Irene J. Higginson, other members – Pedro L. Ferreira, Helder Aguiar, Ana F. Lacerda, Vera P. Sarmento, Duarte Soares, Rita Canario, Maja de Brito, Catarina Ribeiro, Diogo M. Branco). We would also like to thank and recognise the Institute of Public Health of University of Porto for all of the support while hosting BG and MdB.

References


Tables and figures

Table 1. HPC attributes and levels used in the DCE

<table>
<thead>
<tr>
<th>HPC attributes</th>
<th>Attribute levels</th>
</tr>
</thead>
<tbody>
<tr>
<td>Team’s availability</td>
<td>weekdays 9-17</td>
</tr>
<tr>
<td></td>
<td>weekdays &amp; weekends 9-17</td>
</tr>
<tr>
<td></td>
<td>weekdays &amp; weekends 24/7</td>
</tr>
<tr>
<td>Support for family caregivers</td>
<td>standard, no extras</td>
</tr>
<tr>
<td></td>
<td>standard + short-term respite</td>
</tr>
<tr>
<td></td>
<td>standard + brief psycho-educational intervention</td>
</tr>
<tr>
<td></td>
<td>standard + both of the extras above</td>
</tr>
<tr>
<td>Homecare support</td>
<td>consultancy</td>
</tr>
<tr>
<td></td>
<td>consultancy + practical home help</td>
</tr>
<tr>
<td></td>
<td>consultancy + practical home help + advanced technical support</td>
</tr>
<tr>
<td>Information and planning</td>
<td>standard, no extras</td>
</tr>
<tr>
<td></td>
<td>standard + advanced planning of care</td>
</tr>
<tr>
<td></td>
<td>standard + case conference with general practitioner</td>
</tr>
<tr>
<td></td>
<td>standard + both of the extras above</td>
</tr>
<tr>
<td>Waiting time</td>
<td>3 days</td>
</tr>
<tr>
<td></td>
<td>6 days</td>
</tr>
<tr>
<td></td>
<td>9 days</td>
</tr>
</tbody>
</table>
Table 2. Sample characteristics
<table>
<thead>
<tr>
<th></th>
<th>Patients (n=10)</th>
<th>Family caregivers (n=11)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>Female</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median; min.-max.</td>
<td>75.5; 51-91</td>
<td>58; 48-81</td>
</tr>
<tr>
<td><strong>Primary diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>7</td>
<td>-</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td><strong>PPS</strong> (^1)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median; min.-max.</td>
<td>45; 10-80</td>
<td>-</td>
</tr>
<tr>
<td><strong>POS</strong> (^2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median; min.-max.</td>
<td>17; 10-25</td>
<td>-</td>
</tr>
<tr>
<td><strong>Health state on the day</strong> (^2)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median; min.-max.</td>
<td>30; 10-70</td>
<td>70; 0-100</td>
</tr>
<tr>
<td><strong>Relationship to the patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>-</td>
<td>6</td>
</tr>
<tr>
<td>Daughter</td>
<td>-</td>
<td>3</td>
</tr>
<tr>
<td>Parent</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>-</td>
<td>1</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Divorced</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------</td>
<td>---</td>
</tr>
<tr>
<td><strong>Level of education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Basic education-1st cycle</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Basic education-3rd cycle</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>High school</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Bachelor</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Master’s degree or higher</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Missing</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

| **Working situation**    |       |   |
| Working                  | 0     | 1 |
| Sick leave               | 0     | 1 |
| Retired                  | 7     | 5 |
| Unable to work due to disability | 2 | 0 |
| Unemployed               | 0     | 3 |
| Other situation          | 0     | 1 |
| Missing                  | 1     | 0 |

Note: ¹ Palliative Performance Scale (PPS) measured by interviewer; ² self-reported Palliative care Outcome Scale; ³ self-reported on EQ-5D Thermometer; ⁴ equivalent to today’s 4th grade; ⁵ equivalent to today’s 9th grade.
Table 3. Stages and problems in information processing with proposed solutions

<table>
<thead>
<tr>
<th>Stage of Information processing</th>
<th>Aspects identified</th>
<th>Proposed solution</th>
</tr>
</thead>
<tbody>
<tr>
<td>COMPREHENSION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Misinterpretation or errors</td>
<td>Two attributes mixed up because the order of the attributes is changed in each choice set.</td>
<td>More attention to the description of the structure of the card.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>More attention with the explanation of the attribute Waiting time: Waiting time refers to the time between the referral and the first contact with the HPC team (phone call or visits), i.e. until the start of the HPC.</td>
</tr>
<tr>
<td></td>
<td>Misinterpretation of the Waiting time attribute.*</td>
<td></td>
</tr>
<tr>
<td>Request for clarification</td>
<td>FCG looking for confirmation of their understanding of the Support for family caregivers/Waiting time* attribute.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Unclear to what does the conference with the GP refers to (Only the first meeting or later coordination of care as well.)</td>
<td>Offering explanation, description and concrete examples as much as needed. Promoting to use the key card.</td>
</tr>
<tr>
<td></td>
<td>Thinking on the current experience, FCG did not understand how the role of the family GP could be implemented.</td>
<td></td>
</tr>
<tr>
<td>Errors or difficulties in linking key terms to the concepts they aim to represent</td>
<td>To what does the Information and planning attribute refers to.</td>
<td>Promote the use of the key card as a memory aid when needed.</td>
</tr>
<tr>
<td></td>
<td>Difficulties following the packages without the interviewer summarising the choice set.</td>
<td>Interviewer summarising the cards as needed, but in a neutral way in order to avoid influencing the decision making.</td>
</tr>
<tr>
<td>RETRIEVAL OF INFORMATION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forgetting or struggling to</td>
<td>Difficulty remembering what entails</td>
<td>Offering explanation, description and concrete examples as much as</td>
</tr>
<tr>
<td></td>
<td></td>
<td>needed.</td>
</tr>
</tbody>
</table>

* Authors' own terminology.
<table>
<thead>
<tr>
<th>Recall errors</th>
<th>Did not know how to respond to why they chose the service package.</th>
<th>Extra probing.</th>
</tr>
</thead>
</table>

**Judgement**

<table>
<thead>
<tr>
<th>Lack of confidence in the accuracy, completeness, relevance of the information retrieved</th>
<th>Did not know to respond to what was the difficult part of the DCE.</th>
<th>Explain there is no right or wrong answers.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did not know what service package to choose and looks for confirmation in the interviewer.</td>
<td></td>
<td>Explain our intention is to get to know the opinion of each individual participant.</td>
</tr>
<tr>
<td>Indecisive for state the preference for one of the two packages due to similarities or both packages having something that was valued.*</td>
<td></td>
<td>Explain there is no right or wrong answers.</td>
</tr>
<tr>
<td>Difficulty maintaining and considering all the information together when making the decision.</td>
<td></td>
<td>Explain our intention is to get to know the opinion of each individual participant.</td>
</tr>
<tr>
<td>Difficulty making decision towards one of the service packages because:</td>
<td>Summarizing the service package and pointing out the differences.</td>
<td></td>
</tr>
<tr>
<td>- There were some levels of the attributes the FCG felt she did not need.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- FCG did not understand how the role of the family GP could be implemented.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Discrepancy between a general principle and personal experience.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Simplification of the service package and pointing out obvious illogical choices to prevent</th>
<th>Choosing the service package that has less</th>
<th>Highlighting and pointing out obvious illogical choices to prevent</th>
</tr>
</thead>
</table>

- *FGC = Family Caregiver
- DCE = Decisional Conflict Evaluation
exercise graphical symbols. unidimensional approach to DCE.

RESPONSE

<table>
<thead>
<tr>
<th>Errors or difficulties</th>
<th>Difficulty with non-plausible combination of the attribute levels Technical advanced support and Accessibility 24/7.</th>
<th>Discussed with a health professional how this specific example is managed in reality.</th>
</tr>
</thead>
<tbody>
<tr>
<td>mapping the judgement onto a response category or scale</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Problems editing the final response for consistency, acceptability</td>
<td>Looking for confirmation if her rationale for the choice of the service package is acceptable.</td>
<td>Explain there is no right or wrong answers.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Explain our intention is to get to know the opinion of each individual participant.</td>
</tr>
</tbody>
</table>

OTHER DIFFICULTIES

<table>
<thead>
<tr>
<th>FCG commented the MD explained that blood transfusion (used as example for Advanced technical support) legally could not be provided at home in Portugal.*</th>
<th>Discussed with a health professional how this specific example is managed in reality. “Give blood transfusions” was replaced with “monitors and controls complex symptoms like pain and breathlessness” and added “frequent treatment of wounds and pressure sores”.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service package does not correspond exactly to the family’s situation.</td>
<td>Supportive communication in case of clinically relevant distress activating “Serious event protocol.”</td>
</tr>
<tr>
<td>Emotional reaction towards Advanced care planning attribute. (Reminded of the imminent death as one of the future scenarios she is not ready for).</td>
<td>Cards in larger print.</td>
</tr>
<tr>
<td>Difficulty seeing the symbols or reading from the card.*</td>
<td>Supportive communication and encouragement.</td>
</tr>
<tr>
<td></td>
<td>Highlighting these are hypothetical examples.</td>
</tr>
</tbody>
</table>
Comments on the number of the choice sets.*

Application of reality when making choices.*

Note: * The difficulty occurred more than once.
Figure 1. Example of choice card

<table>
<thead>
<tr>
<th></th>
<th>Package A</th>
<th>Package B</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Availibility</strong></td>
<td>Monday to Friday</td>
<td>Monday to Sunday</td>
</tr>
<tr>
<td><strong>Support at home</strong></td>
<td>Consultancy</td>
<td>Consultancy + Practical help</td>
</tr>
<tr>
<td><strong>Support for family caregivers</strong></td>
<td>Standard support for family caregivers</td>
<td>Standard support for family caregivers + Respite</td>
</tr>
<tr>
<td><strong>Information and planning</strong></td>
<td>Standard Information and planning + Conference</td>
<td>Standard Information and planning</td>
</tr>
<tr>
<td><strong>Waiting time</strong></td>
<td>3 days</td>
<td>6 days</td>
</tr>
</tbody>
</table>

Which option would you choose?  
(Please tick one box only)  

- Package A  
- Package B
Figure 2. Key card

<table>
<thead>
<tr>
<th>Availability</th>
<th>Monday to Friday</th>
<th>Monday to Sunday</th>
<th>Monday to Sunday</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time when the patient and family may contact the team to ask for help or advice.</td>
<td>Consultancy</td>
<td>Practical help</td>
<td>Advanced technical support</td>
</tr>
<tr>
<td>Support at home</td>
<td>Advises the patient and the family recommends changes to the health professionals previously involved and directly responsible for the care (e.g. general practitioner, oncologist, primary care nurses)</td>
<td>The team helps with patients' care (e.g. organizing medication, helping with hygiene and lifting from bed), changes the medication and has direct responsibility over care</td>
<td>The team provides advanced technical support at home (e.g. monitors and controls complex symptoms like pain and breathlessness at home and prepares medication for injections, catheters and other devices so that the patient is properly medicated for the control of pain and other symptoms – e.g. with syringe driver if needed, frequent treatment of wounds and pressure sores).</td>
</tr>
<tr>
<td>Support for family caregivers</td>
<td>Standard support for family caregivers</td>
<td>Respite</td>
<td>Sessions to support family caregivers</td>
</tr>
<tr>
<td>Support offered to family caregivers</td>
<td>The team assesses family needs and helps in coping with the illness</td>
<td>A member of the team may stay in the home for some hours to give respite to the family caregiver</td>
<td>The family caregiver participates in sessions that include emotional support, self-care support and sessions for learning techniques of symptom management (e.g., pain control).</td>
</tr>
<tr>
<td>Information and Planning</td>
<td>Standard information and planning</td>
<td>Conference</td>
<td>Advanced care planning</td>
</tr>
<tr>
<td>Information and care planning that the team offers to patients and family members</td>
<td>The team provides all information required by patients and family caregivers and helps with care planning for the immediate problems</td>
<td>The team organizes and attends a meeting with patient and/or family members and with the general practitioner to organize and coordinate care</td>
<td>The team anticipates future scenarios which are explained to patients and/or family members in order to develop a joint action plan for problems that may arise in the short, medium and long run.</td>
</tr>
<tr>
<td>Waiting time</td>
<td>3 days</td>
<td>6 days</td>
<td>9 days</td>
</tr>
<tr>
<td>Refers to the time between the patient and family are referred to home palliative care and the first contact with the team (first call or visit), until commencement of care.</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>