Using discrete choice experiments to elicit palliative care preferences in lower middle-income countries: An exploratory study in Bhutan

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Abstract

Background: Design and delivery of specific palliative care in many lower middle-income countries such as Bhutan remains limited. Designing care programmes to respond to the needs of patients and family networks is essential, but evidence on these preferences is limited.

Aim: We have conducted a discrete choice experiment on Bhutanese patients and family members to explore preferences for palliative care.

Design: The discrete choice experiment consisted of 15 choice tasks in which each respondent considered two competing palliative care services. Data were collected through the recruitment of respondents in conjunction with the clinician support teams, with data collected from both patients and their family members. All responses were pooled across the groups and analysed using the conditional logit regression model.

Setting/participants: Fifty-seven respondents (20 patients and 37 family members) out of 98 (50 patients and 48 family members) identified (58.2%) were recruited through the three large referral hospitals in Bhutan. Patients had to be diagnosed with an advanced illness or at the end-of-life phase, but be able to understand and be willing to complete the survey. Similarly, family members had to be willing and able to complete the survey, and to be defined as the primary caregiver by the patient.

Results: Transparent information provision, cost, family training and use of traditional healing practices were keen drivers of choice, with location of care and place of death relatively less important.

Conclusion: Our results will guide future service design decisions in Bhutan and demonstrate the need for localised preference studies to enable culturally appropriate care including the provision of traditional healing practices.

Plain language summary

Eliciting the preferences for palliative care among patients and families in Bhutan using discrete choice experiment

Background: The provision of effective palliative care remains limited in many low- and middle-income countries including Bhutan. Designing care programmes as preferred by the patients and family is essential, but evidence on these preferences is limited, especially in developing countries. Aim: To explore the preferences of patients with advanced illness and their families for palliative care in Bhutan. Methods: The study used a questionnaire integrating a discrete choice experiment

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which included 15 sets of hypothetical scenarios. Each respondent considered two competing palliative care services described by six attributes – location of palliative care, place of death, cost/expenses involved, palliative care needs, information and communication needs and support for the families. Data were collected from patients living with advanced/terminal illness and their family members. The study sites included the three referral hospitals in Bhutan. Results: Fifty-seven respondents (20 patients and 37 family members) completed the survey. All responses were pooled across the groups and analysed using the conditional logit regression model. Transparent information provision, cost, family training and use of traditional healing practices were valued more highly than the location of care and place of death. Conclusions: The results will guide policy makers in Bhutan as efforts are being made to develop appropriate palliative care service in the country.

Keywords

palliative care, Bhutan, low- and middle-income countries, discrete choice experiments, willingness to pay

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Introduction

Palliative care is a holistic approach to care aimed at improving the quality of life of patients diagnosed with an advanced illness, those at end-of-life and their families.¹ Palliative care provides relief from serious health-related suffering caused by physical pain and other symptoms including psychological, social, emotional and/or spiritual distress due to a life-limiting illness.² The need for palliative care is ever-increasing globally due to the ageing population and concomitant upsurge in chronic illnesses. Palliative care is needed most in low- and middle-income countries (LMICs) where almost 80% of global palliative care needs occur.3 However, despite the World Health Organization (WHO) identifying it as a fundamental human right,⁴ palliative care, which is a cost-effective, humane and a realistic approach, is not available or is minimally developed in most LMICs.^{3,5}

In Bhutan, palliative care is not available in most parts of the country apart from a limited home palliative care service initiated in 2018 at the national referral hospital in the capital city, Thimphu.⁶ Patients with life-limiting illnesses and those at end-of-life are mostly cared for and managed within usual medical care where the unique and often complex needs of the terminally ill patients and their families are often not adequately met.^{7,8}

The needs for palliative care, especially in LMICs, are often very complex.³ Besides pain management and other symptom relief, other needs such as reproductive health support, health literacy and financial support are essential to improve the quality of life among palliative care patients and families.⁹ Another essential factor to consider in palliative care is information and communication about the disease, its treatment outcomes and prognosis which can help the patient and the family in proper planning of the former's remaining days.^{10–13} The WHO emphasised that to maximise its impact, especially in resource-constrained countries, palliative care must be integrated into the national public health program.^{14–16}

In recent years, Bhutan has begun to recognise the importance of palliative care.^{7,8,17} While there was no known palliative care activity until 2017 in Bhutan,³ with the establishment of a home palliative care service in 2018 at the national referral hospital, isolated palliative care is today available. Efforts are being made in developing palliative care knowledge and skills among healthcare professionals across the country,^{18,19} which is one of the essential WHO public health strategies in developing palliative care.¹³

Evidence shows that palliative care can be provided in various settings including hospitals and primary health centres as in-patient and out-patient palliative care, at nursing homes and aged care facilities, in the communities and in the patient's home.²⁰ A home palliative care service is often preferred by patients and families, as it allows increased chances of remaining at home towards the end-of-life and dying at home,^{21,22} however, this is not always an ideal option because symptom control is reported to be better in the hospitals and home deaths are more frequently preferred by the patients than their family caregivers.^{23,24}

Bhutan has unique cultural, spiritual and religious beliefs and values, particularly around chronic illnesses, death and dying.²⁵ For example, religious rituals, traditional medicine and other local healing practices are often considered essential at end-of-life and after death. Other factors like the rugged terrain and lack of transport infrastructure make transportation of very ill patients difficult, particularly for those residing in the rural communities.²⁶ These, coupled with limited bed capacity in the hospitals, suggest home palliative care service could be a better option for patients and families especially when considering the potential for strong family and community support during

illnesses and bereavement. Moreover, despite healthcare being completely funded by the government,^{27,28} Bhutanese patients and families affected by life-limiting illnesses have reported financial issues due to non-medical out-of-pocket expenses as being one of the main problems faced besides pain and other symptom relief.^{7,8} As per the Bhutan Living Standard Survey 2022, households in the urban areas recorded an average annual income of almost Nu 600,000 (USD 6931.97), whereas the rural households recorded a mean income of a little over Nu 275,000 (USD 3177.15).²⁹

Further, recent evidence showed that despite Bhutanese patients wanting to know their disease prognosis,⁷ some of their family members did not want to reveal the diagnosis and prognosis to their dying loved ones.⁸ Past studies have suggested more research is needed to clarify informational needs and other important needs like reproductive health needs among terminally ill Bhutanese patients.⁷ Several studies indicate that support for family members caring for their seriously ill and dying loved ones is vital.^{21,30–36} Bhutanese family members caring for their loved ones with terminal illness have reported high support needs.⁸

As efforts are being made to develop and integrate a contextually appropriate palliative care service into the Bhutanese healthcare system, it is vital that the government and policymakers understand what is important for the service users (patients with advanced illness, those who are dying and their families), especially in terms of location of palliative care service, place of death and what to include in palliative care services.

Discrete choice experiments are increasingly utilised to measure community attitudes towards different aspects of a service, partly because they allow disentangling and comparison of the importance of different aspects of that service. The discrete choice experiment is a quantitative method used in healthcare to determine the service attributes that are preferred and valued by the service users.³⁷ When concerned with condition-specific groups, a discrete choice experiment gives patients and families the opportunity to report their preferences by making a series of choices between alternatives of hypothetical but realistic descriptions of the services.^{36,38} While there is limited discrete choice experiment evidence in LMICs, studies from developed countries such as Australia have reported patients' preferences for location of care, place of death and use of life-sustaining measures during the latter stage of their terminal illness.³⁸ Their participants prioritised factors like cost of care, pain management, patient comfort and support for caregivers more than the location of care and place of death.³⁸ For example, an Australian study by Hall et al. found that family members of patients receiving home palliative care preferred daily home visits by a nurse, 24/7 availability of phone consultations, frequent home visits (i.e. at least once a week) by a doctor, personal care assistant and respite care.³⁹ In Portugal, a discrete choice experiment on home palliative care was developed where attributes like palliative care team's availability, support for family caregivers, homecare support, information and planning, and waiting time were explored.³⁶ Participants in the Portugal study preferred more clarifications on certain aspects such as waiting time, and support for family caregivers and information and planning.³⁶ Other studies from Singapore showed that families and older adults in the community preferred services that facilitated home deaths for patients with advanced cancer.^{40,41}

This current study aimed to investigate the preferences for palliative care, utilising the discrete choice experiment approach, mainly around location of care, place of death, cost involved and range of care needs among Bhutanese patients affected by life-limiting illnesses and their families. The objective of this study is to inform suitable policies for integrating appropriate palliative care into the Bhutanese health system.

Methods

Development of discrete choice experiments

A discrete choice experiment was developed to elicit the palliative care service attributes most preferred or valued by patients diagnosed with advanced illness and their families. The attributes and levels were developed using published discrete choice experiment on palliative care conducted in Australia, Singapore, United States and Portugal (discrete choice experiments are not yet available from LMICs as far as we are aware) and other reviews of discrete choice experiments.^{22,36,38,39,41–43} Based on the available evidence and the contextual and practical realities in Bhutan, six attributes were defined: (1) location of palliative care needs, (5) information, communication and planning and (6) support for family members. These attributes and associated levels are presented in Table 1.

Survey and experiment design

To generate choice sets that efficiently estimated effects, we used Ngene software (ChoiceMetrics Pty Ltd). We required the estimation of 13 coefficients in our modelling (allowing for a reference category in each Table 1 attribute, and note that cost is treated as a continuous variable to allow estimation of willingness to pay, described below) and therefore specified that the design would have 15 choice pairs. To allow estimation of the regression model, it is a condition that there are a greater number of choice sets than there are parameters. So, we needed a design with at least 14 choice sets. To maximise the data from each respondent, we asked each to complete all 15. Table 2 presents a sample of a choice set. We defined our choice sets as pairs without an opt-out, as the receipt of care is close to universal among those in an end-of-life setting,

Attributes	Levels		
Location of palliative care service	 Mostly home Mostly hospital Either home or hospital (depending on the symptom severity) 		
Place of death	 At home In the hospital Either home or hospital (as appropriate at that moment) 		
Cost involved	 Nu 20,000 (USD 239)* Nu 70,000 (USD 837) Nu 120,000 (USD 1435) Nu 170,000 (USD 2033) 		
Palliative care needs	 Standard** Standard + traditional healing practices^a Standard + traditional medicine^b Standard + reproductive health needs 		
Information and communication needs	 Complete information about the disease, treatment and prognosis + end-of-life wishes (other than place of death) Complete information about the disease, treatment and prognosis Not all the details (e.g. prognosis) 		
Support for family members.	 Standard*** Standard + respite support Standard + training and education Standard + 24/7 consultation 		

Table 1. Attributes and levels for the discrete choice experiments.

*I US Dollar=83.62 Bhutan Ngultrum as of July 2024.

**Basic support includes pain and other symptom (physical, psychological, emotional and spiritual) relief.

^aHealing practices that are completely provided by lay people in the village.

^bA formal traditional healthcare service provided by trained Drungtshos (traditional physicians).

***Basic support (weekly visit by palliative care trained professional) that enabled care for their sick relative and support that related directly to their own well-being.

Table 2. A sample of a choice set.

Characteristics	Scenario A	Scenario B
Location of palliative care service	Mostly home	Either home or hospital (depending on the symptom severity)
Place of death	Either home or hospital (as appropriate at that moment)	At home
Cost/expenses involved	Nu 170,000 (USD 2099.00)*	Nu 20,000 (USD 247.00)
Palliative care needs	Standard**	Standard + traditional healing practices
Information and communication needs	Complete information about the disease, treatment and prognosis + end-of-life wishes (other than place of death)	Not all the details (e.g. prognosis)
Support for the family	Standard*** + respite support	Standard $+$ training and education

*I US Dollar=83.62 Bhutan Ngultrum as at July 2024.

**Basic support includes pain and other symptom (physical, psychological, emotional and spiritual) relief.

***Basic support (weekly visit by palliative care trained professional) that enabled care for their sick relative and support that related directly to their own well-being.

and standard care could be defined using our chosen dimensions and levels. Other than cost (for which we assumed a small negative coefficient reflecting that higher cost is unattractive if everything else is unchanged), we used non-informative priors reflecting that we did not have good information about community preferences on these dimensions. The design was designed to maximise D-efficiency. Lancsar and Louviere⁴⁴ previously stated that 20 observations per version are required to estimate

reliable models; following this rule of thumb, and given we have a single version (as all respondents answer the same discrete choice experiment tasks), our results should be robust to a reasonably small sample size.

Study setting, population and sampling

The study was conducted in the three referral hospitals in Bhutan – the national referral hospital in Thimphu; the

central regional referral hospital in Gelephu; and the eastern regional referral hospital in Mongar. Patients diagnosed with advanced illnesses such as cancer; heart, lung, liver and renal failure; motor neurone disease; AIDS, multi-drug-resistant tuberculosis, dementia and those at end-of-life irrespective of the diagnosis in need of pain and other symptom relief; as well as family members, preferably the primary caregiver identified by the patient, were identified for the study. A purposeful sampling strategy was used to identify the participants. Participants were recruited if they were 18 years of age or above, and were able to and willing to participate.

Data collection

Data were collected from April to June 2024. The study participants (patients and their families) were identified with the help of the treating team of doctors and nurses. The patient and their family member were then approached to invite them to participate in the research. If interested and where inclusion criteria were met, the participant information form was read and translated to them which helped them decide whether to participate or not. For those who decided to participate, a structured discrete choice experiment survey (Supplemental Appendix 1) was used. Completing the survey was quite challenging given that the majority of the participants being illiterate and the discrete choice experiment approach, involving a number of choice sets, were often time-consuming, coupled with most of the participants (especially patients) with inadequately managed pain or having other symptoms (physical, psychological, emotional or spiritual) distress. Except for a handful of participants who completed the survey on their own with minimal assistance, most of the participants required the researcher to translate the survey verbally to the local dialects (which do not have a written form) and complete it on their behalf. The lead author of the study collected the data and is fluent in several local dialects of Bhutan.

Data analysis

The data were analysed using the widely used conditional logit model. Exploration of heterogeneity is frequently valuable in discrete choice experiments but was not possible here given significant challenges around recruitment as highlighted above, and hence the limited sample size. The conditional logit has been described in detail elsewhere⁴⁵ and is a standard tool for modelling mean preferences using discrete choice experiment-type data.

To maximise potential policy impact, we then estimated willingness to pay for movements between levels of each dimension. These compare the coefficient of cost with the other coefficients by dividing the latter by the former. These can in principle be used to support policy-making, through the comparison of costs of service with the implied community willingness to pay. To estimate willingness to pay, we used the standard delta method, which allows reporting of a 95% confidence interval around the mean estimate.⁴⁶

Results

Demographic characteristics

Out of 98 participants (50 patients and 48 family members) identified, 57 (20 patients and 37 family members; 58%) completed the survey. Among the non-participants, 25 have refused participation, 13 patients were either too ill to participate or had hearing or speech impairment and 3 of the patients were not allowed to participate by their family members who feared that the former will come to know about their poor prognosis. Seventeen out of 20 patients knew about their diagnosis, and all family members were aware about it. While 12 patients had advanced cancer, 5 were diagnosed with other non-malignant conditions. Three patients who did not know their diagnosis wished to know. The participants' age ranged from 18 to 85 years (mean 54.75 and SD 16.66031). The sociodemographic details of the study participants are provided in Table 3.

As expected, the patient cohort tends to be older than the family member cohort, with a median age 13 years greater. Both patient and family member cohorts were reasonably balanced in terms of gender. Reflecting Bhutan's religious characteristics, the majority of respondents were Buddhist. The family member cohort was more likely to have completed some formal schooling, potentially reflecting the increasing uptake of education in the country over time. The family member was most likely to be the child of the patient (43.2%) but a range of other relationships both spousal and otherwise were observed.

Conditional logit results

The conditional logit results are presented in Table 4. The willingness to pay estimates are expressed in terms of 1000s of Bhutanese Ngultrums. To facilitate interpretation, the willingness to pay estimates are also expressed in USD, using the exchange rate as of July 2024 (1 USD=83.62 Ngultrums).

The data suggest some strong trends in responses. As expected, respondents were price-sensitive and preferred paying less for palliative services, all other things being equal. Receipt of information about the disease, treatment and prognosis was seen as very important, as shown by a large negative coefficient on not receiving this information. Support for family was considered important, particularly support including training and education. Relative to standard palliative care, the mean respondent valued

Characteristic	Level	Patient cohort (<i>n</i> =20)	Family member cohort (<i>n</i> =37)
Age	Median (IQR)	53 (46–70)	40 (32–52)
Gender	Female	60%	48.7%
Any children	Yes	75%	Not collected
Religion	Buddhism	75%	73.0%
C C	Hinduism	25%	24.3%
	Christianity	0%	2.7%
Education	No schooling	60%	29.7%
	Any schooling*	40%	70.3%
Annual household income	0-50,000	45%	35.1%
	50,000-200,000	45%	27.0%
	Over 200,000	10%	37.8%
Relationship to patient	Child	N/A	43.2%
	Spouse	N/A	27.0%
	Parent	N/A	2.7%
	Other	N/A	27.0%

Table 3. Sociodemographic characteristics of the study participants.

*Non-formal education, Buddhist studies and primary education to Master's degree.

Table 4. Conditional logit results and willingness to pay estimates.

Dimension	Level	Coefficient (SE)	WTP relative to base (000s; 95% CI)	USD WTP estimate
Cost	Continuous (expressed in 10,000s)	-0.027 (0.007)**	N/A	
Location of palliative	Mostly home	Base level		
care	Mostly hospital	0.198 (0.111)	73 (-15,161)	873
	Either home and hospital	0.357 (0.110)**	131 (24,239)	1567
Place of death	At home	Base level		
	In the hospital	0.117 (0.110)	43 (-36,123)	514
	Either home and hospital	0.291 (0.119)*	107 (11,204)	1280
Palliative care needs	Standard	Base level		
	Standard + traditional healing practices	0.572 (0.132)**	210 (71,350)	2511
	Standard + traditional medicine	0.201 (0.141)	74 (-31,179)	885
	Standard + reproductive health needs	0.087 (0.140)	32 (-71,134)	383
Information needs	Complete information about the disease, treatment and prognosis + end-of-life wishes	Base level		
	Complete information about the disease, treatment and prognosis	-0.205 (0.112)	-76 (-164,13)	-909
	Not all the details (e.g. prognosis)	-1.026 (0.122)**	-377 (-575, -180)	-4508
Support for family	Standard	Base level	, , , , , , , , , , , , , , , , , , ,	
	Standard + respite support	0.291 (0.134)*	107 (-4,218)	1280
	Standard + training and education	0.606 (0.166)**	223 (72,374)	2667
	Standard + 24/7 consultation Model R^2	0.380 (0.140)** 0.1523	140 (16,264)	1674

Statistical significance is noted at the 1% level (**) and at the 5% level (*). WTP, willingness to pay.

having additional traditional healing practices. The coefficients on the levels regarding where palliative care was delivered and where death occurs were relatively smaller, but the option to have the choice to have them occur in either the home or the hospital setting was statistically significant at the 5% level relative to the base (mostly at home, or at home). The willingness to pay estimates demonstrate the same pattern (as expected as they are a transformation of the coefficients) but suggest the difference between the best and worst possible combination of levels was US\$12,533.

In terms of responding to the choice sets, only 5 patients could 'fully understand' the choice sets and the rest reported 'partial understanding', whereas, 19 family members understood the choices fully and 18 could partially understand. While 11 patients and 16 family members reported that it was 'difficult' to answer the questions, 7 patients and 14 family members stated it was 'fairly easy'.

Discussion

The results reflect an important first step in identifying the aspects of palliative care that are of greatest importance for the recipients of this care and their families. The evidence suggest that complete information, family training and the provision of traditional healing practices are valued more highly than either the location of service delivery or place of death. These findings partly align with those collected in other settings. Similar to the Australian study by Kenny et al.,³⁸ the location of death was not as important as other factors such as support for family members. This was in contrast to the Singaporean study by Finkelstein et al.,⁴⁰ and by Malhotra et al.,⁴¹ both of whom emphasised the importance of place of death.

Past studies have revealed that Bhutanese patients wanted to be informed of their advanced illness⁷ but not all family members wanted their loved ones to know about the terminal disease.⁸ This current study reiterates that both patients and families actually valued complete information about the disease including the treatment plans, the likely outcomes and even discussing their end-of-life wishes. While effective communication is vital in palliative care,⁴⁷ sharing information in a culturally sensitive and empathic approach as preferred by patients and families is equally crucial.⁴⁸

This study also valued training for family caregivers which is consistent with the past study that reported support needs to enable family members in managing symptoms and providing personal care.⁸ Family members often play an integral role in providing personal care, managing symptoms and delivering psycho-social and emotional support to their very ill and dying loved ones while requiring care and support for their own well-being.^{49,50} Hence, including appropriate training opportunities for the family caregivers into the national palliative care guideline, which is currently being developed, is essential.

In Bhutan, like in many other parts of the world,⁵¹ traditional healing practices play a vital role in chronic illness, death and dying,²⁵ and our study has shown that participants highly valued access to this. While the Ministry of Health has developed guidelines on safe delivery of traditional healing practices,⁵² these healers may benefit from palliative care training to ensure that they facilitate adequate symptom management such as pain medications which do not necessarily form part of the healing practices.

The study reported here has both strengths and limitations that should be acknowledged. As the first discrete choice experiment study to our knowledge in Bhutan, it represents an important step in integrating patient and family preferences into questions around appropriate service design both in palliative care and more generally. It demonstrates that Bhutanese preferences for palliation are similar in some regards to those shown in other jurisdictions, but that we cannot simply generalise findings between settings given the differences in culture, geography and the socioeconomic realities. National-level data on the demographic characteristics of patients and their caregivers were also unavailable and thus we were unable to draw a comparison with our sample. We acknowledge that the sample size was modest; recruitment of Bhutanese patients proved very challenging. To mitigate this issue, we ensured that our sample reached the threshold suggested by Lancsar and Louviere.⁴⁴ The recent review by Xia et al.⁵³ reports response rates for palliative care discrete choice experiments, demonstrating considerable non-response. While we followed best practice in maximising response⁵⁴ (through, e.g. working with clinicians to improve uptake, initiate personal contact with potential respondents and provide support for respondents struggling to understand the task), our response rates may mean that our sample was healthier and better educated than the palliative care population more generally. However, we did observe important patterns in preferences despite this limitation, and believe that our work represents a benchmark from which future Bhutan-based studies can build. Due to the available sample, we could not separately report preferences for patients and caregivers; thus, our findings should be considered as a combination of the preferences of these two key stakeholders' groups. Disentangling the two potentially divergent views is an important next step reflecting the work of Malhotra et al.,⁴¹ who demonstrated differences between the two.

Conclusion

This study found that Bhutanese patients and their families affected by advanced illness valued complete information about the disease, treatment, prognosis and end-of-life wishes; utilising traditional healing practices and training for family members, more than the location of palliative care service delivery or place of death. These findings are crucial to integrate as efforts are made to develop appropriate palliative care service in Bhutan.

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Ethical considerations

This study was approved by the Human Research Ethics Committee at the University of Western Australia (2023/ ET000750) and the Institutional Review Board at the Khesar Gyalpo University of Medical Sciences of Bhutan (IRB/ Approval/PN/2023-010/1085).

Author contributions

TaraDeviLaabar:Conceptualisation;Investigation;Methodology;Writing – original draft.

Richard Norman: Conceptualisation; Formal analysis; Methodology; Writing – review & editing.

Christobel Saunders: Conceptualisation; Writing – review & editing.

Mahbub Ul Alam: Conceptualisation; Writing – review & editing.

Ian W. Li: Conceptualisation; Formal analysis; Methodology; Project administration; Supervision; Writing – review & editing.

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Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy and ethical reasons.

Supplemental material

Supplemental material for this article is available online.

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