

Palliative Care Needs among Patients with Advanced Illnesses in Bhutan

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Abstract

Background Palliative care improves the quality of lives of patients and families affected by life-limiting illnesses through the prevention and relief of suffering. While palliative care is well established in developed countries, it is inadequate or non-existent in most developing countries. Palliative care is an emerging concept in Bhutan, a tiny Himalayan Kingdom. A small community palliative care service is available in the national referral hospital with three dedicated inpatient palliative care beds. This study explored the needs for palliative care among patients diagnosed with advanced illnesses and is a component of a larger project aimed to inform a suitable palliative care model for the country.

Methods This is a cross-sectional descriptive study. A survey, using a structured questionnaire including the EORTC QLQ-C30, was carried out among patients with advanced illness in hospitals, primary care units and communities across the country. Purposeful and snowball sampling strategies were used to recruit study participants.

Results Seventy (76%), out of 93 eligible patients, agreed to participate in the survey. Participants reported low to moderate scores on physical, role, emotional, cognitive and social functioning, a moderate score for the global health/ quality of life scale and moderately high (worse) scores in symptoms including fatigue, pain, insomnia, loss of appetite and the financial impact from the disease.

Conclusions The symptom burden experienced by patients affected by terminal and advanced illnesses demonstrates the need for palliative care in Bhutan. These findings will help inform the development of a public health-focused palliative care model, modified to the Bhutanese context, as recommended by the World Health Organization.

Background

Advanced cancer and other life-limiting illnesses can cause overwhelming suffering in patients and families demanding not only medical expertise but also support for the psychological, social, emotional, and spiritual distress throughout the disease trajectory [1]. Palliative care (PC), identified as a fundamental human right [2–4], is an approach to care that improves the quality of life of patients and families through the prevention and relief of suffering [5]. Provided across health care settings, PC is patient- and family-focussed, based on ethical principles, shared decision making, advanced care planning and excellent symptom management [6]. As a multidisciplinary approach, PC can be initiated at the diagnosis of a life-threatening disease along with the therapeutic management, continued throughout the disease trajectory until end-of-life and extended to grief and bereavement support of family members [7].

In response to continuous efforts by the World Health Organization (WHO) and other international organizations to ensure universal access [8, 9], PC services are mostly well established in developed countries [1, 10]. However, out of 56 million annual global deaths, almost 40 million happen in developing countries [11], and more than 33 million of those could benefit from PC [12]. In 2014, it was estimated

that 78% of adults and 98% of children requiring PC were in low and middle-income-countries (LMIC) [1]. It is predicted that by 2060, 48 million people will die annually while experiencing serious health-related suffering and 83% of these deaths will occur in LMICs [13]. In 2014, the World Health Assembly declared that PC is an ethical responsibility of health systems and an ethical duty of all health care providers [14]. Tragically, PC still remains very minimal or non-existent in most developing countries [1, 10, 15–17]. The WHO, having identified several barriers in the provision of PC in developing countries, recognised PC as a public health priority and recommended four key strategies; (1) appropriate policies, (2) adequate availability of medications (including opioids), (3) education of health care workers and the public, and (4) implementation of PC services at all levels of health care [18, 19].

Bhutan, a tiny Himalayan Kingdom, a size similar to that of Switzerland, with a population of 771,608 [20], is landlocked between two giant nations of the world, China and India. Popularly known to the world for its concept of Gross National Happiness, Bhutan has made steady progress in modernization and poverty reduction since the early 1960s. Its annual per capita income stands at US\$ 3438.16 [20], and the United Nations has recommended its eligibility to graduate to a middle income country by 2021 [21].

Healthcare in Bhutan is provided through a three-tiered system where the Basic Health Unit (BHU) functions at the primary level, district hospitals at the secondary level and the regional and national referral hospitals at the tertiary level. The integration of traditional medicine with the national health system is unique to Bhutan [22]. Having advanced both economically and socially, the disease patterns have altered significantly over the years. While vaccine-preventable diseases like polio are almost eradicated, infectious diseases such as HIV, dengue fever and Multi-Drug Resistant Tuberculosis (MDR-TB) are still on the rise [23]. Life expectancy has doubled from 35 in the 1960s to 70 in 2015 [24] and the incidence of non-communicable diseases (NCD) like heart, lung, liver and kidney diseases and cancer are increasing [25]. Cancer is often diagnosed at an advanced stage in Bhutan [26].

Despite the growing number of people dying with conditions that are likely to benefit from PC, its development remains at a nascent stage in Bhutan. In 2018, a home-based PC group, consisting of a few nurses and doctors who received PC training in India, was initiated at the Jigme Dorji Wangchuck National Referral Hospital (JDWNRH) primarily for pain management for cancer patients. In addition, three beds were allocated for PC in the oncology ward in JDWNRH [26]. However, the needs for PC among patients with advanced illnesses have not been studied. The objective of this paper, a component of a larger study to inform the development of a PC model for Bhutan, is to explore PC needs of patients with advanced illness.

Methods

Study design and setting

This study is a cross-sectional descriptive study using structured patient interviews. Data collection was scheduled for May to July 2019 in an attempt to avoid the usual monsoon season in Bhutan, which

routinely disrupts travelling through the mountainous areas. Study sites included the JDWNRH, two regional referral hospitals, district hospitals and BHUs, both Grade I and Grade II, spread across Bhutan (Fig. 1). BHU Grade I is a 10-bed community hospital equipped with basic diagnostic facilities managed by one or two general doctors along with a few nurses and allied health workers. BHU Grade II is a primary health care centre managed by health assistants.

Study population and sampling

Patients with advanced illness (e.g. cancer, heart, lung, kidney, liver failure, motor neuron disease, Parkinson's disease, Huntington's disease, Alzheimer's disease/dementia, and HIV/ AIDS) and those at the end-of-life were included, recruited with the help of doctors, nurses and allied health care workers. Purposeful sampling, guided by diagnosis, end-of-life status, and willingness to participate, was used to recruit patients in the hospital. In the communities, using a snowball sampling strategy, patients nominated by clinicians were approached at their homes. Participants were excluded if they were < 18 years, diagnosed with acute illness, unconscious, semiconscious or delirious who could not give consent and those who were unwilling to participate. The final study size was determined pragmatically, in consideration of the eligible/willing participants and the duration of field work.

Survey instrument

Data were collected using structured interviews to complete a questionnaire which included questions about socio-demographic characteristics, the clinical information of the patients and the European Organisation for Research and Treatment of Cancer (EORTC) quality of life questionnaire (EORTC QLQ-C30). The latter is an integrated, 30-item questionnaire, to assess the health related quality of life (QOL) of cancer patients participating in both clinical trials as well as non-trial studies for which reliability and validity have already been established [27].

The EORTC QLQ-C30, used to determine the physical, psychological, social functioning and overall quality of life of patients, includes five functional scales (physical, role, emotional, cognitive, and social functions), three symptom scales (fatigue, nausea and vomiting, and pain), and a two-item global health and quality-of-life scale. The remaining six single items assess additional symptoms including dyspnoea, appetite loss, sleep disturbance, constipation, and diarrhoea, as well as the perceived financial impact of the disease and treatment. For the functional scales and global health status/QOL, the scores range from 0 to 100, with a higher score representing a higher level of functioning and QOL. The symptom scale scores also range from 0 to 100, however, higher scores represents a greater degree of symptoms or problems.

Although the EORTC QLQ-30 was specifically developed for cancer patients [27, 28], past studies [29] have used it to compare the QOL between cancer and non-cancer patients. Given the complexities of low literacy levels and prevalence of non-written dialects, translating the EORTC QLQ-C30 to *Dzongkha*, the national language, was not feasible. Thus, the EORTC QLQ-C30, English version, was considered to be the most appropriate tool for the study. The required consent to use this tool was obtained from the EORTC. A

pilot test conducted with four patients in JDWNRH, the two regional referral hospitals and Trashigang district hospital found that the survey did not require changes as there were no issues regarding clarity and sensitivity of the questions.

Data collection

Field notes were maintained to record any difficulties during data collection to allow TDL reflective consideration or potential bias during interpretation. To ensure that all potential participants were supported to be involved, generous time was set aside so that each patient was comfortable. Patients who could read and write English completed the survey questionnaire by themselves, if they wished. For the majority who could not read and write, TDL, who is fluent in all the main dialects used in Bhutan, was available to translate all information and the questionnaire at the bedside and completed the questionnaire in English on the participants' behalf.

Data analyses

Statistical analyses were conducted using the Statistical Analysis System (SAS) software, version 9.4 [30]. Firstly, descriptive statistics were calculated; means and standard deviation (SD) for interval data, and frequency and percentage for categorical data. There was no missing data. An independent sample T-test was conducted to compare the EORTC QLQ-30 scores between cancer and non-cancer patients. Statistical significance level was set at alpha 0.05. The graphical illustrations were generated using Microsoft Excel, version 16.0.

Ethical Consideration

Ethical approval was provided by the Human Research Ethics Committee at the University of Western Australia and the Research Ethics Board of Health in Bhutan with Reference numbers, RA/4/20/4990 and REBH/Approval/2018/097, respectively. While the overall administrative clearance for the study was provided by the Policy and Planning Division in the Ministry of Health in Bhutan, permission to access the patients was obtained from the administration of the individual study site. Informed consent was taken from every participant in the form of signature or thumb print.

Results

Field notes

Data collection was hampered by several unforeseen difficulties including a severe cyclone [31] which made travelling from one study site to another impossible, and a tragic accident [32] involving a public bus hit by a landslide, resulted in a government caution against public travel. Recruitment was slower than expected because a large number of potential participants were too ill, in pain or in distress to be approached. Most of the patients were illiterate, however, even many of those who could read and write preferred the researcher to read and explain the participant information form and felt most comfortable to

fill the questionnaire along with the researcher. Only nine patients filled the questionnaire independently. None of the patients became distressed requiring assistance while completing the survey.

Participants

Out of 93 eligible patients identified, 70 (76%) agreed to participate. Ten (14%) patients were recruited from the community and the remainder (60, 86%) from hospitals. Among the 23 patients who did not participate, 9 (39%) were too ill or in too much pain and distress and 8 (35%) were not able to provide consent due to being unconscious, semi-conscious, deaf and dumb, or delirious. Four (17%) patients were not allowed to participate by their family members who feared that their loved ones would be aware of the serious prognosis of the illness. The remaining 2 (9%) who declined to participate did not provide a specific reason. Eighty seven percent of the patients had to be guided through the questionnaire.

Sociodemographic characteristics

Participating patients' ages ranged from 18–85 years (mean 46.1, SD 15.5). The majority were married (53, 76%) and had at least 1 child (57, 81%). Among those who had more than 1 child, the eldest child's age ranged from 6–69 years, (mean 25.6, SD 13.2) and the youngest child's age from 1–47 years, (mean 16.8, SD 10.3). The sociodemographic characteristics are presented in Table 1.

Table 1
Sociodemographic characteristics of patients

Patients (n = 70)					
	<i>n</i>	%		<i>n</i>	%
Gender			Education level		
Female	39	55.7	Never been to school	29	41.4
Male	31	44.3	Higher secondary	10	14.3
Marital status			Primary	9	12.9
Married	53	75.7	Bachelors & above	8	11.4
Never married	9	12.9	Middle Secondary	6	8.6
Widowed	4	5.7	Monastic/religious	5	7.1
Divorced	3	4.3	Non-formal education	3	4.3
Separated	1	1.4	Occupation		
Have Children			Housewife	24	34.3
Yes	57	81.4	Private/Corporate	15	21.4
No	13	18.6	Civil servant	8	11.4
How many children (n = 57)			Self-employed	4	5.7
1–3	39	68.4	Farmer	3	4.3
4–6	16	28.1	Others☒	16	22.9
7–9	2	3.5			
Spoken language					
<i>Sharchopkha</i>	28	40.0			
<i>Dzongkha</i>	24	34.3			
<i>Lhotsham</i>	12	17.1			
Others☒	6	8.6			

☒ *Bumthapkha, Khengkha, Kurtoepkha*; ☒ Monk, nun, student, ex-army, ex-civil servant, not employed, security guard, NGO employee

Clinical information of the patients

Sixty two (89%) patients knew their diagnosis and the remaining eight (11%) wished to know. A large minority of the patients (n = 29, 42%) were diagnosed with cancer and the rest had a range of non-

malignant conditions (Fig. 2). The majority of the patients, (n = 46, 66%) reported that they were admitted to the hospital for 1 to 3 times, 16% for 4 to 6 times, and 10% for more than 7 times since diagnosis. For 41 (59%) patients, the longest admission to hospital lasted more than 2 weeks.

Descriptive Statistics for Patients using EORTC-QLQ-30

The functional scales demonstrated low to moderate levels of functioning, with scores ranging from 32.1 for Role to 57.6 for the Cognitive Scale. The symptom scales including the single item symptoms ranged from low (good) with diarrhoea (20.0) through to moderate problems (fatigue 61.6) and a severe (worse) problems related to the financial impact of the illness (74.3). The mean score for the global health/QOL scale was 47.4. There were no differences in EORTC symptom or functioning subscales between cancer and non-cancer patients ($p = < 0.05$) except for constipation ($p < 0.001$). The results of the EORTC subscales are shown in Table 2.

Table 2
The EORTC QLQ-C30 mean scores and comparison between cancer and non-cancer patients

	Item [⊠]	Cancer patients		Non-cancer patients		Combined patients		p-Value (< 0.05)
		Mean Score	(SD)	Mean Score	(SD)	Mean Score	(SD)	
Functioning scales [⊡]								
Physical	15–19	39.1	(31.4)	43.6	(34.6)	41.7	(33.1)	0.573
Role	20,21	31.6	(39.9)	32.5	(39.4)	32.1	(39.4)	0.925
Emotional	35–38	39.9	(38.0)	39.2	(37.6)	39.5	(37.5)	0.938
Cognitive	34,39	58.6	(27.7)	56.9	(27.4)	57.6	(27.3)	0.799
Social	40,41	43.7	(38.7)	33.7	(36.6)	37.9	(37.5)	0.283
Global health/ QOL scale [⊢]	43,44	48.6	(21.4)	46.5	(26.2)	47.4	(24.1)	0.724
Symptom scales and/or items [⊣]								
Fatigue	24,26,32	59.4	(34.8)	63.1	(29.8)	61.6	(31.7)	0.639
Nausea and vomiting	28,29	19.5	(30.6)	26.8	(33.5)	23.8	(32.3)	0.349
Pain	23,33	55.2	(35.7)	39.8	(37.2)	46.2	(37.1)	0.087
Dyspnoea	22	25.3	(34.1)	34.1	(37.6)	30.5	(36.2)	0.309
Insomnia	25	43.7	(39.9)	36.6	(37.1)	39.5	(38.2)	0.454
Appetite loss	27	41.4	(38.5)	43.9	(35.3)	42.9	(36.4)	0.781
Constipation	30	50.6	(34.1)	17.1	(27.0)	31.0	(34.2)	< 0.001
Diarrhoea	31	20.7	(28.7)	19.5	(29.8)	20.0	(29.2)	0.868
Financial impact	42	81.6	(36.3)	69.1	(40.4)	74.3	(39.0)	0.180

⊠Numbers as per the item numbers in the questionnaire; ⊡Functional scale scores range from 0 to 100, with a higher score representing a higher level of functioning or QOL; ⊢Symptom scale scores range from 0 to 100, with higher score representing a greater degree of symptom severity.

Discussion

A better understanding of the factors influencing the QOL among patients with advanced illness can create awareness and facilitate policy development, particularly in resource constrained countries[33].

Herrera and colleagues [34] remind us that PC provision should not be determined by the patient's geographical location, his/ her disease condition, or ability to pay, but on needs alone. Other studies [35, 36] further support the contention that needs assessed deliberately among patients provide useful information to plan programmes and interventions that meet the explicit requirements of a local population. The findings of this study are fundamental in developing PC services in Bhutan.

Forty two percent of the patients in the study had advanced cancer. Cancer in Bhutan has increased from 923 cases in 2013 to 1,824 in 2017. Cancer is identified as a major threat to public health in the developing countries [37]. The remaining 58% were diagnosed with non-malignant diseases including CKD, MDR-TB, HIV, ALD, COPD, SLE, spinal cord injury and a massive chronic gangrenous wound. In 2017, along with 144 cancer deaths, the health facilities recorded 212 deaths related to heart disease, 166 to ALD and 39 to CKD [25]. Substantial numbers of chronic patients also die at home without a cause of death being reported.

Fitch [38] identified that, when diagnosed with cancer, both the patient and family experience a wide range of needs throughout the illness trajectory, ranging from physical needs to emotional, psychological, social, financial and spiritual needs. The needs of patients with non-malignant conditions are also increasingly identified [39–41]. This research found that patients diagnosed with advanced illnesses in Bhutan have poor levels of functioning and varied levels of symptom severity indicating high support needs, consistent with advanced illnesses in other LMICs [33, 42–45]. Both cancer and non-cancer patients in Bhutan reported substantial symptom burdens. There was, however, no statistically significant differences in symptom severity or level of functioning between cancer and non-cancer patients except for constipation (p value < 0.05). This is in contrast to the findings of Thome and colleagues [29], who found that elderly cancer patients in Sweden had poorer scores, more complaints and subsequently poorer quality of life compared to non-cancer patients.

There are no published studies of normative EORTC QLQ-C30 data among Asian PC populations. The existing normative data is most available for general populations and the mean scores for the Global Health/QOL across Australia (68.5, SD 21.5), Columbia, (77.1, SD 18.5), the European countries (66.1, SD 21.7) and Korea (67.7, SD 68.8) provide a reasonable picture of quality of life scores for those without advanced illness [46–49]. One study from Ethiopia [33], another developing country, that focused on cancer patients mostly with later stage disease, reported a better mean global health/QOL score than patients with advanced illnesses in Bhutan (Ethiopia 54.6, SD 26.2 compared with Bhutan 47.4, SD 24.1) despite the mean score for pain in cancer patients in the two countries being similar (Ethiopia 55, SD 36.2, Bhutan 55.2, SD 35.7). Symptoms like fatigue and financial difficulties related to the illness are worse among Bhutanese cancer patients (59.4, SD 34.8 and 81.6, SD 36.3, respectively) compared to Ethiopian cancer patients (52.6, SD 36.1, and 67.1, SD 41.2, respectively) and much more than the general population in the aforementioned countries [33, 46–49].

In this study, both cancer and non-cancer patients experienced moderate pain (mean 46.2, SD 37.1). Pain is one of the most common and the most feared symptoms experienced by patients with advanced

illnesses [6], and can significantly influence the psychological and emotional domains which affects the overall QOL of both patients and families [50, 51]. Morphine, an inexpensive, safe and easy-to-use opioid is the most effective treatment for moderate to severe chronic pain [52]. In Bhutan, oral morphine is available at all levels of health care except BHU Grade II. Parenteral morphine is available only at the JDWNRH and the regional referral hospitals [53]. However, its use may be erratic given that PC is an emerging concept where physicians may lack experience in PC and the use of opioids for patients who are dying and/or for extended periods. In areas where PC is not well developed, several barriers to prescribing morphine have been reported including availability of the drugs, limited knowledge and opiophobia among physicians, along with the influence of patients and families [54, 55]. The high demonstrated need for improved pain control highlight this as a priority area for development in new PC services in the Bhutan.

Social problems were far reaching for participants, in addition to their medical condition. Most were married and many had young children - some of them had their eldest child just as old as 6 years and youngest merely 1 year, indicating increased psychological and social needs. Parenthood is one of the major concerns when diagnosed with an advanced illness [56], however, the needs specific to dying patients and their dependent children are not well met even in the developed countries with comprehensive PC [57–59].

Forty one percent of the Bhutanese patients in this study did not go to school and 13% had just primary education— indicating that 54% of the patients had significant problems with literacy. In the Ethiopian study [33] previously discussed, 53% of patients were also illiterate. DeWalt and colleagues in their systematic review on literacy and health outcomes concluded that “*low literacy is associated with a range of adverse health outcomes*” [60] (p. 1238). In another comprehensive review, Shahid and colleagues [61] identified misinformation and misunderstandings related to PC and hospice services among the public. Hostad and colleagues [62] have thus emphasized public education as an integral component of PC which provides information, knowledge and skills enabling patients, particularly the marginalized and vulnerable groups, to adapt effectively when faced with a life-limiting diagnosis. Given the low levels of literacy in Bhutan and a lack of knowledge about PC, even amongst health professionals, education and raising awareness about PC is important for the public in Bhutan.

Sixty one percent of the patients in this study did not have a reliable job or income, which was reflected in the high financial impact of their disease and treatment, and was flagged as one of the most significant problems faced by both cancer and non-cancer patients. Although health care in Bhutan, including referral abroad, is funded by the government [63], patients still need to make out-of-pocket payments for services such as admission to private cabins instead of the general ward which is usually noisy and privacy often compromised; for some medicines that are not included in the essential drug list; and for the services availed from the private diagnostic facilities both within and outside the country [22]. Patients incur expenditure on the repeated travel to and from the referral centres required for the treatment and management of their advanced illness. This is consistent with a study in Pakistan where, due to lack of home PC services, rural patients travelled long distances to access care at hospitals in

urban areas [64]. Another study in India states “*where patients are primary earners, visits to the hospital mean further reductions in income*” [65] (p. 228). The scenario is the same in Bhutan. Moreover, Bhutanese often spend huge amounts of money on rituals, prayers, offerings and other traditional healing practices when confronted with life-limiting illness because patients and family members strongly believe that diseases are caused by bad, vengeful spirits causing imbalances in the vital elements – bile, phlegm and wind channels, within the body [66, 67].

When diagnosed with life-limiting illness, patients may experience ‘total pain’ [68] involving physical, psychosocial, emotional and spiritual domains. This appears no different in the Bhutanese context. Ben-Arye and colleagues [69] have identified that patients, especially in the developing countries, are able to access traditional medicine, based on cultural and spiritual foundations, along with modern medicine which offers parallel benefits from both natural and scientific treatment. In Bhutan, having traditional medicine integrated into the national health system is opportune for developing PC as it provides health care choices for patients with life-limiting illness [67]. Several studies [61, 70, 71] have identified the role of traditional healers as complimentary to allopathic treatment in cancer management and end-of-life care. Well informed and engaged local traditional healers in Bhutan can play a significant role in advancing PC amongst their patient community.

The findings of this study are consistent with previous research in both developed and developing countries [28, 42–45, 72, 73] which has shown that both cancer and non-cancer patients have varied needs across the illness trajectory that affected their overall QOL—ranging from physical symptom control to psychological, emotional, cognitive and spiritual support, as well as the need for food and financial assistance. Studies have, however, found that cancer patients in the developed countries had higher unmet needs related to psychological and spiritual domains compared to patients in developing countries, whose main needs were pain medication, food and financial support [74]. In developing countries, patients also had information needs about diagnosis, treatment options and side effects along with the need for psychological and spiritual support [35].

Palliative care aims to address the broad range of symptoms and needs of patients with life-limiting diseases described in our study. Murtagh and colleagues [75] emphasize that, when assessing PC needs for a country or a region, it is vital to understand the benefit of such programmes to the local population. The WHO recommends that a PC service should, at a minimum, identify both cancer and non-cancer patients who could benefit from PC; assess, reassess and address their physical, psychological, social, emotional and spiritual distress and determine culturally appropriate goals of care [6]. In rural Africa, PC integrated into disease-modifying therapies and into the routine HIV services have reduced physical pain and improved psychosocial and spiritual wellbeing including socioeconomic assistance for most patients [76, 77]. Furthermore, Bakitas and colleagues in their study of oncologists’ perspectives of concurrent PC among advanced cancer patients found that PC improved quality of life of patients and families, facilitated better quality of care with less aggressive end-of-life care, and reduced emotional distress [78]. These findings are relevant and applicable to the Bhutanese context.

Patients with advanced illnesses in this study were admitted to the hospital many times since diagnosis, and the majority (59%) spent at least 2 weeks in hospital during each admission. Several studies [10, 18, 79, 80] have found that effective PC services can avoid repeated, often unnecessary, visits to emergency departments at the end-of-life. Palliative care services have also reduced long-term hospital admissions and the referral of patients abroad, thus reducing escalating health care costs. Almost 40% of the health care expenses are known to occur in the last 3 months of life and account for almost 70% of end-of-life expenditures [81]. The government of Bhutan is already experiencing extreme challenges with the ever escalating cost of health care [22]. Integrating public health approach of PC into the existing health care system can help reduce this huge medical expense.

While the principles of PC remain universal, the WHO and other international organizations reiterate that PC models should be contextual based [1, 8, 9]. Modified to its social, cultural, spiritual and economic context, even resource constrained countries like Bhutan can provide effective PC services as demonstrated by Kerala in India, Arusha in Tanzania, Brasov in Romania, Vietnam and Argentina [1, 82, 83].

Strengths and limitations

There are several strengths and limitations to this study. Bhutan has varying cultural and belief systems in response to chronic illness, death and dying and post-death rituals. A strength of this study was the inclusion of participants from all regions across the country. Although a sample size of 70 participants is small, the challenges faced to hear those 70 voices were great, and the study would be difficult to repeat for someone not fluent in the local dialects. A limitation was the use of only the EORTC-QLQ-30 which resulted in a reduced understanding of other needs such as information, spiritual and sexual needs of the patients. Due to complex practicalities including low literacy, issues with translation and the potential for encountering cultural taboos, we foresaw difficulties in using multiple tools and chose to use just one to maximise participation. This was also the first research conducted with this population in Bhutan. Future studies could consider a bigger sample and include other tools to explore additional needs in such patients.

Conclusion

The symptom burden experienced by people affected by terminal and advanced illnesses demonstrates the need for PC in Bhutan. Bhutan is a small developing nation with a small population and has primary health care and traditional healing systems underpinned by compassion and equity. With a very limited home PC service now initiated, this study of patients' needs will help inform the development of a broader public health-focused PC model, modified to the Bhutanese social, cultural and economic context, as recommended by the WHO.

Abbreviations

PC- Palliative Care; JDWNRH- Jigme Dorji Wangchuck National Referral Hospital; EORTC QLQ-C30- European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire; QOL- Quality of Life; WHO- World Health organization; CKD- Chronic Kidney Disease; MDR-TB- Multi Drug Resistant Tuberculosis; HIV- Human Immunodeficiency Virus; ALD- Alcoholic Liver Disease; COPD- Chronic Obstructive Pulmonary Disease; SLE- Systemic Lupus Erythematosus.

Declarations

Ethical approval and consent to participate: Ethical approval was provided by the Human Research Ethics Committee at the University of Western Australia and the Research Ethics Board of Health in Bhutan with Reference numbers, RA/4/20/4990 and REBH/Approval/2018/097, respectively. Informed consent was taken from every participant in the form of signature or thumb print.

Consent to publish: Not applicable.

Availability of data and materials: 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.

Competing interests: The authors declare no competing interests.

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Authors' contributions: TDL collected the data, data analysis and prepared the manuscript. CJ conceived the idea. CS, CJ and KA reviewed and edited the manuscript. All authors read and approved the final manuscript.

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Figures

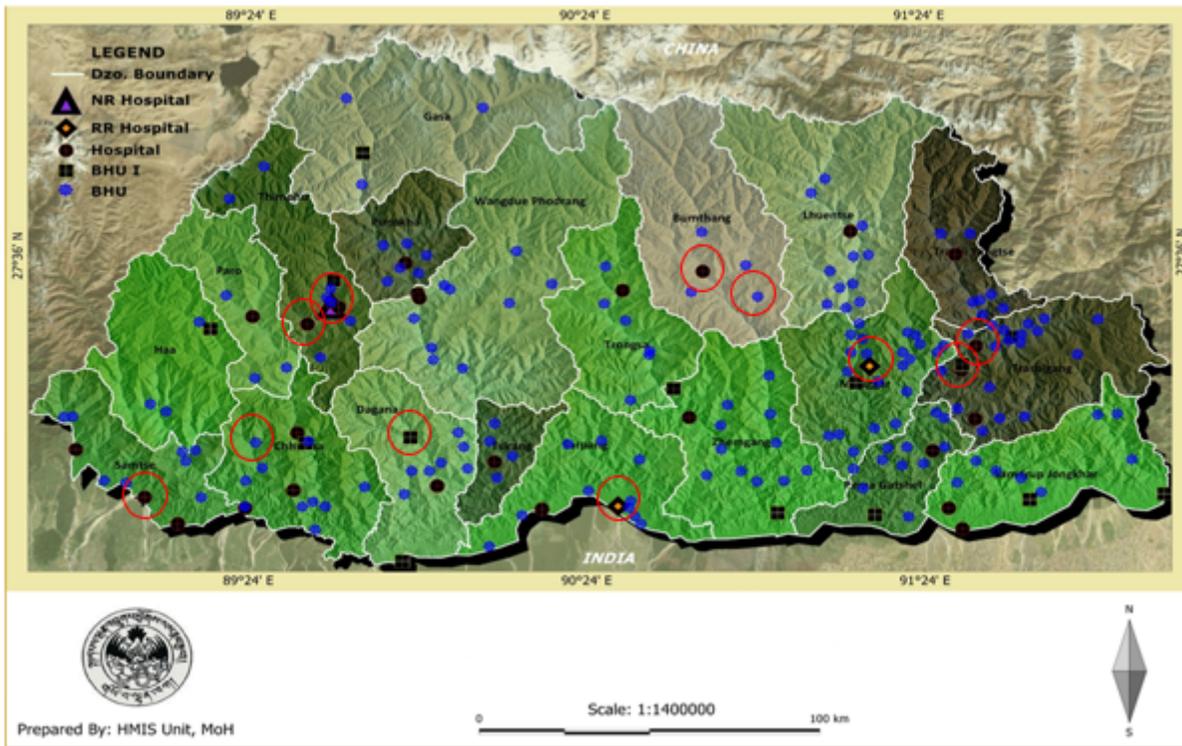


Figure 1

Map of Bhutan showing the study sites marked with red circles (Permission to use the Map is provided by the Policy & Planning Division, Ministry of Health, Bhutan) Note: The designations employed and the presentation of the material on this map do not imply the expression of any opinion whatsoever on the part of Research Square concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. This map has been provided by the authors.

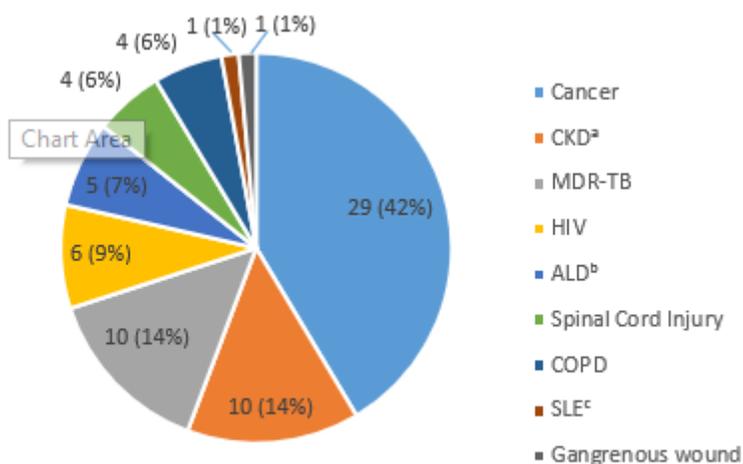


Figure 2

Diagnosis of the patient participants (n=70) ^aChronic Kidney Disease; ^bAlcoholic Liver Disease; ^cSystemic Lupus Erythematosus

Supplementary Files

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