

Original Article

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Disparities in end-of-life outcomes among advanced cancer patients in Sri Lanka: Results from the APPROACH study

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Abstract

Objective. A Universal Health Coverage goal is to provide access to affordable palliative care to reduce disparities in end-of-life (EOL) outcomes. To assess progress toward this goal in Sri Lanka, our primary aim was to systematically assess differences in patients' physical, psychological, social and spiritual outcomes, and their perceived quality of care by their socioeconomic status (SES).

Methods. As part of the multi-country APPROACH (Asian Patient Perspectives Regarding Oncology Awareness, Care and Health) study, we surveyed 199 patients with a stage IV solid malignant tumor and aged >21 years from the largest government cancer hospital in Sri Lanka. We assessed their physical (physical and functional well-being, symptom burden), psychological (anxiety, depression, emotional well-being), social (social well-being), and spiritual outcomes and perceived quality of care (physician communication, nursing care, and coordination/responsiveness).

Results. Low SES patients reported significantly lower physical and functional well-being, emotional well-being, spiritual well-being including meaning/peace and faith; and significantly higher symptom burden, anxiety and depressive symptoms compared with patients from high SES ($p < 0.05$ for all outcomes).

Significance of results. Results have implications regarding reducing barriers in access to appropriate palliative care and EOL care services to stage IV cancer patients from low SES in Sri Lanka.

Background

For patients with a terminal cancer, palliative care is a basic human right. Recent Lancet Commission reports and World Health Assembly resolutions called for palliative care as an essential component of Universal Health Coverage (Knaut et al., 2018). Central to universal health coverage is also a focus on equity, in that all patients with advanced cancer, irrespective of their socioeconomic status (SES), are able to access palliative care services at the end of life (EOL). Nonetheless many patients with advanced cancer in low- and middle-income countries, especially those from low SES, experience poor outcomes at the EOL and perceive their care to be of poor quality (Mandelblatt et al., 1999; Vart et al., 2015; Halpern and Brawley, 2016; Allen et al., 2017; Yabroff et al., 2019).

In this paper, we examine data from Sri Lanka, a middle-income country in Asia where palliative care services have not yet been formally established. According to the 2015 national cancer registry, the overall age-standardized cancer incidence rate in Sri Lanka is 122.0/100,000. Nearly 40–60% of patients present to the healthcare system in the advanced stages (stage III or IV). Oro-pharyngeal, lung, colorectal, and oesophageal cancers are the most common cancers among males, whereas breast, thyroid, colorectal, and cervical are the most common among females (National Cancer Control Programme, 2015).

The 2015 Economic Intelligence Unit Quality of Death Index Report covering 80 countries, ranked Sri Lanka as 65th, indicating a poor quality of EOL care (The Economist Intelligence Unit, 2015). However, more recently Sri Lanka has identified the development of palliative care as a priority within National Health Policy (2016–2025). The National Strategic Framework for Palliative Care Development was drafted in 2018 highlighting palliative care as a right of every person with a life-threatening illness such as cancer (Ministry of Health, 2016).

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The annual cost of managing a stage III or IV cancer patient is SLR 303 620 (US\$2,027) (Amarasinghe et al., 2019). Despite public facilities providing several services free of cost, outcomes at the EOL among patients from low SES households attending these facilities are likely to be worse. Patients from low SES households may still incur considerable out-of-pocket costs to pay for transportation to hospitals, and medications, treatments and services not available within public hospitals (Kumara and Samaratunge, 2016). A comprehensive understanding of SES differences in EOL outcomes can inform efforts to improve access to cancer care services in Sri Lanka.

The primary aim of this paper is, thus, to assess the SES differences in EOL outcomes including patients' physical, psychological, social and spiritual outcomes, and their perceived quality of care including patient–physician communication, healthcare coordination, and nursing care. A secondary aim is to examine differences in EOL outcomes by patients' other demographic characteristics including ethnicity, gender, marital status, and age. Literature from various settings suggests that patients from minority ethnic groups experience worse EOL outcomes (Harris, 2001; Zimmermann et al., 2011; Fiscella and Sanders, 2016; Vandan et al., 2019). In the South Asian setting, women are often excluded from making decisions, have limited access to and control over resources compared to men (Fikree and Pasha, 2004), and therefore are likely to experience worse EOL outcomes (Borooah, 2016). Being married can be a source of social and emotional support (Kim and McKenry, 2002) thereby improving EOL outcomes (Wachterman and Sommers, 2006; Reisinger et al., 2018). Studies also show that younger patients are more likely to perceive quality of care to be worse compared with older patients due to their greater expectations regarding care (DeVoe et al., 2009), even though older patients may have less access to health care due to their economic dependence on others and worsened mobility (Wagner and Wagner, 2003). We, therefore, hypothesize that patients from minority ethnic groups, females, and those who are unmarried will experience worse EOL outcomes. We also hypothesize that older patients will have worse EOL outcomes but will perceive their quality of care to be better than younger patients.

Methods

We used data from the APPROACH (Asian Patient Perspectives Regarding Oncology Awareness, Care and Health) study. APPROACH is a multi-country cross-sectional survey of patients with an advanced cancer in eight Asian countries including Sri Lanka, China, India, Vietnam, Myanmar, Bangladesh, Philippines, and Indonesia. In each country, one or more major public hospital/s were selected for recruitment of patients. Each site recruited approximately 200 eligible patients. The overall goal of the APPROACH study was to identify key areas for improvement in EOL care and to develop capacity for conducting palliative care research within each site. The current paper uses data from the Sri Lanka APPROACH site.

We recruited patients from National Cancer Institute of Sri Lanka, Maharagama. Eligible patients included those aged >21 years, with solid malignant tumors in advanced stage (stage IV), aware of their diagnosis of cancer, currently receiving inpatient and/or outpatient care in the institution, and who had undergone at least one cycle of anticancer therapy. Awareness of cancer diagnosis was assessed by asking patients at the beginning of the survey if they had ever been diagnosed with cancer (among three

other health conditions). Survey was terminated for patients who reported not being diagnosed with cancer. The study coordinator assessed the patients' ability to communicate in either of the three languages in use in the country (Sinhalese, Tamil, and English) and confirmed the eligibility of the patients to participate in the study. The study instrument was pilot tested with ten consenting patients.

Study investigators first developed the questions in English. Subsequently, professional translators translated these into Sinhalese and Tamil and then back translated them into English. The original and back-translated English versions were compared and reconciliations were made where necessary. Further revisions were made to these questions based on feedback from the physicians and cognitive interviews with ten eligible patients in the study site. We used licensed translated versions for validated scales.

Written informed consent was obtained from the voluntary participants. This study was approved by Ethics Review Committee, Faculty of Medicine, University of Colombo (Protocol No: EC-17-157) and by Institutional Review Boards at the National University of Singapore (NUS-IRB Approved Protocol No.: NUS-2883, NUS-IRB Reference Code: B-15-319).

Outcomes

We assessed the following EOL outcomes:

Physical outcomes: We assessed physical and functional well-being using respective subscales from the Functional Assessment of Cancer Therapy-General (FACT-G) (Smith, 2014). The Physical Well-Being and Functional Well-Being have seven items each, and total scores ranging from 0 to 28.

We assessed symptom burden through a checklist of ten symptoms (pain, breathlessness, constipation, weight loss, vomiting, swelling, dry mouth and throat, lack of energy, nausea, and any other) found in the Functional Assessment of Chronic Illness Therapy-Palliative scale (Lyons et al., 2009). We asked respondents to rate the severity of each symptom over the last 7 days on a scale of 0 (not at all) to 4 (very much). We calculated symptom burden by averaging the severity of symptoms reported.

Psychological outcomes: We measured emotional well-being using the FACT-G emotional well-being subscale. This is a 6-item scale with a total score ranging from 0 to 24. We also assessed anxiety and depression using respective subscales from the Hospital Anxiety and Depression Scale (Snaith, 2003). Each subscale has seven questions resulting in a total score ranging from 0 to 42.

Social outcome: Social well-being was measured through the FACT-G social well-being subscale. The subscale has seven items with a total score ranging from 0 to 28.

Spiritual outcome: Spiritual well-being was assessed using the Functional Assessment of Chronic Illness Therapy-Spiritual which consists of two domains: meaning/peace and faith. Items in the first domain emphasize meaning and peace through eight items with a total score ranging from 0 to 32. Items in the second domain focus on a sense of strength and comfort from one's faith through four items with a total score ranging from 0 to 16. The resulting total spiritual well-being score ranged from 0 to 48.

Perceived quality of care: Patient-reported quality of care was assessed using 14 questions assessing interpersonal aspects of cancer care used in previous research (Ayanian et al., 2004; Catalano et al., 2013; Ning et al., 2020). The items were grouped into three domains: physician communication, nursing care, and care

coordination and responsiveness. Each domain was scored on a 100-point scale, with 0 representing worst possible care and 100 representing optimal care.

Independent variables

SES (Main independent variable): We assessed SES using an item that asked patients to classify the economic status of their household as being poor, lower middle class, upper middle class, or wealthy. The latter two categories were combined to represent “high SES,” whereas the former two categories represented “low SES” and “middle SES,” respectively. We also assessed patients’ years of education.

Demographic and clinical factors (Other Independent variables): We recorded patients’ age, gender, marital status, ethnicity (Sinhalese, non-Sinhalese), type of cancer (breast, gastrointestinal, genitourinary, respiratory, others), and setting of survey (inpatient, outpatient).

Statistical analysis

The scores for EOL outcomes and its domains were assessed in terms of means, standard errors (SE), percentages, and proportions. We report the internal consistency reliability of all scales used in our sample using Cronbach’s alpha. Using separate linear regression models, we assessed the association between each outcome — physical (physical and functional well-being, symptom burden), psychological (emotional well-being, anxiety, and depression), social (social well-being), spiritual (overall spiritual well-being, meaning/peace, faith) and perceived quality of care (physician communication, nursing care, and coordination and responsiveness of care) and the independent variables listed above. All analyses were conducted using STATA 15.

Results

Socio-demographic variables

One hundred and ninety-nine ($n = 199$) patients were interviewed between 30 March 2018 and 21 June 2018. Table 1 presents the demographic information of the respondents. The mean age of the patients was 56 years and mean years of education was 10 years. Most were females (66%), married (75%), Sinhalese (86%), and middle SES (57%). The most common cancer types were gastrointestinal (26%), genitourinary (26%), and breast (24%). Most patients (92%) were recruited from inpatient clinics (Table 1).

Table 2 shows the distribution of outcome measures in the sample and their Cronbach’s alpha. Cronbach’s alpha for all outcomes except care coordination and responsiveness of care was above 0.70, indicating good internal consistency reliability.

Table 3 shows that, consistent with our hypothesis, low SES patients reported significantly lower physical and functional well-being, emotional well-being, spiritual well-being including meaning/peace and faith; and significantly higher symptom burden, anxiety, and depressive symptoms compared with patients from high SES ($p < 0.05$ for all outcomes). Perceived quality of care was not associated with SES.

Non-Sinhalese (minority) ethnic groups reported significantly poorer physician communication, nursing care, and coordination of care and social well-being compared with the Sinhalese ethnic group. However, the non-Sinhalese ethnic groups reported

Table 1. Socio-demographic and disease-related characteristics of patient sample

Characteristics	Mean/ Number of patients	%
Age: mean (SD), range	56 (12.6), 22–83	
Years of education: mean (SD), range	10 (4.3), 0–23	
Gender		
Male	67	34
Female	132	66
Marital status		
Married	150	75
Unmarried	49	25
Ethnicity		
Sinhalese	172	86
Others	27	14
Socioeconomic status, mean (SD), range		
Low	55	28
Middle	114	57
High	30	15
Patient type		
Outpatient	15	8
Inpatient	184	92
Type of cancer		
Breast	47	24
Gastrointestinal	51	26
Genitourinary	52	26
Respiratory	31	16
Others	18	9

significantly higher overall spiritual well-being and meaning/peace ($p < 0.05$ for all outcomes).

Results also showed that female patients reported higher faith. Being unmarried was significantly associated with higher depressive symptoms, lower social well-being, lower overall spiritual well-being and lower meaning/peace and faith scores. Older patients reported lower anxiety and those with higher education reported better spiritual well-being but perceived quality of nursing care to be low ($p < 0.05$ for all outcomes).

Discussion

Our study is the first to shed light on SES and other demographic differences in EOL outcomes for patients with advanced cancer in Sri Lanka. Most notably, our results show that patients from lower SES report worse EOL outcomes.

SES differences in patients’ physical, functional, social, emotional, and spiritual outcomes can be attributed to several reasons. In the Sri Lankan context, the majority (90%) of the population living below the national poverty line reside in rural areas. Because cancer centers in urban areas are better equipped and more popular than in rural areas, many patients from rural

Table 2. Distribution of end-of-life outcomes in the sample ($N = 199$)

	Mean (SD)	Cronbach's alpha
<i>Physical outcomes</i>		
Physical well-being subscale (0–28)	13.3 (7.1)	0.81
Functional well-being subscale (0–28)	14.2 (5.3)	0.77
Symptom burden (0–40)	13.9 (7.1)	
<i>Psychological outcomes</i>		
Emotional well-being (0–24)	16.6 (5.3)	0.76
Anxiety subscale (0–21)	7.5 (4.6)	0.76
Depression subscale (0–21)	9.0 (5.0)	0.84
<i>Social outcomes</i>		
Social well-being (0–28)	20.5 (5.5)	0.76
<i>Spiritual outcomes</i>		
Overall (0–48)	31.2 (9.4)	0.87
Meaning/Peace subscale (0–32)	18.0 (7.4)	0.86
Faith subscale (0–16)	13.2 (3.3)	0.87
<i>Perceived Quality of Care</i>		
	Mean (SD)	
Physician Communication	77.4 (27.9)	0.71
Nursing Care	84.7 (33.8)	0.85
Care Coordination and Responsiveness	73.2 (20.9)	0.54

areas choose to travel to urban areas to access cancer treatments. Although clinical services and medicines are available free of cost within the Sri Lankan public health system, the costs incurred in traveling and loss of daily wages are likely to disproportionately affect patients from low SES. The public hospitals also periodically experience shortages in essential symptom relief drugs; when this happens, low SES patients may have trouble managing their symptoms adequately while those who can afford are able to buy medications from private pharmacies. These factors, coupled with the pre-existing higher psychological distress due to financial difficulties and poor health literacy reported among the Sri Lankan rural population (Knipe et al., 2019), may have contributed to worse EOL outcomes among patients from low SES.

Although several studies have been conducted regarding the presence of SES differences in health status and health care utilization globally (Braveman and Tarimo, 2002), the evidence regarding SES inequalities within the context of EOL outcomes remains fragmentary. Previous studies have reported that low SES cancer patients are more likely to experience higher mortality (Ward et al., 2004; Louwman et al., 2010; Chang et al., 2012; Parise and Caggiano, 2013; Manser and Bauerfeind, 2014; Tomic et al., 2018), depression (Fagundes et al., 2014) and other comorbidities (Louwman et al., 2010; Tomic et al., 2018), and greater symptom burden (Ilowitz et al., 2018) compared with higher SES patients. Low SES cancer patients are also less likely to receive palliative care (Beccaro et al., 2007; Lewis et al., 2011), and to die at home (Beccaro et al., 2007). The current study adds to the literature by examining SES inequalities systematically for multiple domains at the EOL.

Our results showed that patients with more years of education perceived their quality of nursing care to be worse. It is possible that even when quality of care provided to all patients is the same, those with higher levels of education perceive their quality of care to be worse due to greater expectations regarding care (Johansson et al., 2002). Future research should examine and correct for such systematic variation in reporting behavior in order to get a better estimate of differences in quality of care among patients with different levels of education.

We found that patients from minority ethnic groups perceived their quality of care to be worse. Sri Lanka, including the Colombo district, has a predominantly Sinhalese-speaking population. It is possible that Tamil-speaking minorities may be experiencing difficulties communicating with their physicians. At NCIM (the setting for this study), the number of patients per consultant is nearly 1,200 per year. This may compromise the quality of communication during consultation for patients requiring a translator. Studies from other countries have also indicated that when patients do not speak the same language as their physicians, they are less likely to understand physician's explanations, participate in medical discussions and more likely to perceive health care quality to be worse (Schinkel et al., 2016; Steinberg et al., 2016; De Moissac and Bowen, 2018).

Furthermore, data from Sri Lanka also suggests that minority ethnic groups are more likely to live in rural areas and belong to low SES. Thus, they are likely to face many deprivations and experience distress prevalent in rural communities and among those from low SES, which may also adversely affect their EOL outcomes (Department of Census and Statistics, 2001; Minority Rights Group International, 2018). Results indicated that unmarried patients experienced worse EOL outcomes across several dimensions. Having a spouse provides a source of care, comfort, and affection at the EOL (Kim and McKenry, 2002). On the other hand, unmarried patients could lack a caregiver who could assist with medication adherence and activities of daily living, resulting in worse psychological, social, and spiritual well-being.

The study has implications for healthcare providers, policy makers, and researchers. Hospital cancer services should conduct holistic assessment of physical, functional, emotional, social, and spiritual outcomes among patients with an advanced cancer, especially those from low SES households. Patients experiencing worse outcomes can be referred for targeted support from specialist providers. Public hospital services can also provide low SES patients with more support in obtaining appropriate medications and navigating the healthcare system. Healthcare providers can also support patients with low levels of education routine consultations, by educating them about their illness and treatment option, and by monitoring their treatment compliance. Hospitals can also ensure that language needs of patients from minority ethnic groups are addressed through availability of trained interpreters during consultations. Patients who are unmarried or lack a caregiver may also benefit from greater support in managing their medications, functional activities, and distress. Policy efforts to improve EOL care services in Sri Lanka can focus on improving quality of cancer medical care especially within disadvantaged regions of the country including rural areas. Lastly, future research efforts should design and evaluate models of care delivery that intervene to mitigate the effect of SES deprivation on EOL outcomes. The impact of these efforts on EOL outcomes should be evaluated through an equity stance.

The study is not without limitations. First, participants in the study came from one major public hospital in Sri Lanka, situated

Table 3. Association between patient demographics and end-of-life outcomes

Variables	Physical outcomes			Emotional outcomes			Social outcomes	Spiritual outcomes			Perceived Quality of Care		
	Physical well-being	Functional well-being	Symptom burden	Emotional well-being	Anxiety	Depression	Social/ Family well-being	Overall spiritual well-being	Meaning/ Peace	Faith	Perceived Physician Communication	Perceived Nursing Care	Perceived Coordination and Responsiveness of Care
	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)	β (SE)
Age (in years)	0.0 (0.0)	-0.0 (0.0)	0.0 (0.0)	0.1 (0.0)	-0.06** (0.0)	0.0 (0.0)	0.0 (0.0)	0.0 (-0.1)	0.0 (0.0)	0.0 (0.0)	0.2 (0.2)	0.2 (0.2)	0.1 (0.1)
Females	-0.6 (-1.2)	-0.4 (-0.9)	1.5 (1.2)	-0.7 (-0.9)	0.8 (-0.8)	-0.2 (-0.9)	0.1 (0.9)	1.3 (-1.5)	-0.1 (-1.2)	1.4** (-0.6)	1.4 (5.1)	-6.8 (6.1)	-6.1 (3.8)
Education (in years)	-0.2 (-0.1)	0.1 (-0.1)	0.1 (0.1)	0.1 (-0.1)	0.0 (-0.1)	0.0 (-0.1)	0.0 (0.1)	0.3** (-0.2)	0.3** (-0.1)	0.1 (-0.1)	-0.5 (0.5)	-2.3*** (0.6)	0.2 (0.4)
Socioeconomic status													
Middle	-0.2 (1.4)	-1.8* (1.0)	-0.5 (1.4)	-1.0 (1.0)	0.7 (0.9)	0.4 (1.0)	-0.4 (1.1)	-3.2* (1.7)	-2.3* (1.4)	-0.9 (-0.6)	-3.3 (5.9)	4.3 (7.0)	-2.1 (4.4)
Low	-5.9*** (1.7)	-5.7*** (1.2)	4.4*** (1.7)	-4.6*** (1.2)	4.3*** (1.0)	4.6*** (1.2)	-3.6*** (1.3)	-9.9*** (2.1)	-7.7*** (1.6)	-2.1*** (0.8)	2.0 (7.1)	-4.1 (8.4)	-5.6 (5.2)
Non-Sinhalese ethnic group	-1.4 (-1.5)	1.4 (-1.1)	1.1 (1.5)	-0.5 (-1.1)	-0.2 (-0.9)	-0.9 (-1.0)	-3.0*** (1.1)	4.7** (-1.8)	4.0*** (-1.4)	0.7 (-0.7)	-18.0*** (6.1)	-18.7** (7.3)	-10.6** (4.6)
Unmarried marital status	-2.3* (-1.2)	-0.8 (-0.9)	2.6 (17.7)	-0.4 (-0.9)	0.6 (-0.7)	2.3*** (-0.8)	-2.6*** (-0.9)	-4.0*** (-1.4)	-2.8** (-1.1)	-1.1** (-0.6)	-3.4 (4.9)	-2.139 (5.8)	-2.9 (3.6)

Reference categories: Male (for gender); high (for socioeconomic status); Sinhalese (for ethnic group); married (for marital status). Regressions adjusted for site of primary cancer (breast, gastrointestinal, genitourinary, respiratory, others).

* p -value < 0.10.

** p -value < 0.05.

*** p -value < 0.01.

at Maharagama, a suburb of Colombo. These participants may not represent advanced cancer patients in other parts of the country, especially those residing in rural areas. Second, although minorities make up about 25% of the total population, these constituted only about 15% of our study sample. This is likely because minority ethnic groups predominantly reside in the Northern and Eastern provinces of the country and tend to seek treatment from provincial and district general hospitals in these areas. Thus, our study sample may not accurately represent the ethnic distribution in the population. Third, our measure of SES relied on self-reports from patients. While there is a possibility that patients may not have been able to accurately perceive their SES, previous studies have shown the validity of self-reported SES measures (Singh-Manoux et al., 2005; Williams et al., 2017). Despite the limitations, this is the first study of its kind providing insights into EOL care in Sri Lanka incorporating standardized and validated instruments.

Conclusion

Our study results show that there are differences in EOL outcomes among advanced cancer patients who receive care at one of Sri Lanka's largest public hospitals by their SES, education, ethnicity, age, gender, and marital status. Notably, low SES patients reported worse physical, emotional, spiritual, and social EOL outcomes compared with those from high SES patients. To reduce inequalities in patient outcomes at EOL within public hospitals in Sri Lanka, there is a need to enable access to appropriate palliative care and EOL care services, and medications to all advanced cancer patients. Future studies should develop interventions supporting vulnerable patient groups to ensure equal access to EOL services.

Conflict of interest. The authors declare that they have no conflict of interest.

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