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# Palliative care within universal health coverage: the Malawi Patient-and-Carer Cancer Cost Survey

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## ABSTRACT

**Objective** Evidence of the role of palliative care to reduce financial hardship and to support wellbeing in low/middle-income countries (LMIC) is growing, though standardised tools to capture relevant economic data are limited. We describe the development of the Patient-and-Carer Cancer Cost Survey (PaCCCT survey) which can be used to gather data on healthcare use and out-of-pocket expenditure (OOPE) in households affected by cancer in LMIC.

**Methods** To identify relevant content qualitative data were gathered using Photovoice to detail concepts of wellbeing and cost areas of importance in households receiving palliative care in Blantyre, Malawi. Existing approaches and tools used to capture OOPE were mapped through a review of the literature. The WHO tuberculosis patient cost survey was chosen for adaptation. Face and content validity of a zero-draft of the PaCCCT survey were developed through review by healthcare professionals and a national stakeholder group. The final survey was translated into local language (Chichewa) and piloted.

**Results** The PaCCCT survey is a tablet-based, third-party administered survey recording healthcare service utilisation and related direct and indirect costs. Coping strategies (loans and dissaving and so on), funeral costs and wellbeing at household level are included. Completion time is <30 min.

**Conclusion** The PaCCCT survey can be used as part of economic evaluations in populations in need of palliative care in LMIC. Such evidence can support calls for the inclusion of palliative care within Universal Health Coverage which requires end-user protection from financial hardship.

## INTRODUCTION

Out-of-pocket expenditure (OOPE) accounts for 23% of global health expenditure and 45% of health expenditure in low/middle-income countries (LMIC).<sup>1</sup> Even where the majority of health services are delivered free of charge,

it is households that bear the brunt of financing healthcare for chronic and life-limiting illnesses. Through the provision of timely access to pain and symptom relief accompanied by patient-centred communication, palliative care has the potential to reduce recurrent hospital visits and related OOPE particularly when integrated within health systems in LMIC. Evidence suggests that access to palliative care can reduce such catastrophic expenditure, though published data in this area are limited.<sup>2</sup>

Universal Health Coverage (UHC) links quality and effectiveness of health services to end-user protection from financial hardship. It currently forms the key policy goal of the WHO. Palliative care is under consideration as a ‘best buy’ under UHC.<sup>3</sup> Despite this and increasing awareness of the role of palliative care in reducing severe health-related suffering, global estimates suggest that up to 61 million people (including 2.5 million children) live and die without access to an essential package of palliative care, which has been priced at US\$3.<sup>4</sup>

A systematic review of the cost-effectiveness of palliative care in LMIC pointed towards favourable outcomes, while highlighting the paucity of current data (10 studies were identified) and lack of standardised definition of terms, data collection and reporting.<sup>5</sup> A review evaluating approaches for collecting household level costs for palliative care patients also failed to identify literature from LMIC.<sup>6</sup> In order to produce a standardised tool to facilitate prospective collection of household level data on OOPE for people requiring palliative care in LMIC, we describe the development of the Patient-and-Carer Cancer Cost Survey (‘PaCCCT’ survey). This survey is currently being used to undertake a study to explore the

**Table 1** Approaches to gathering household cost data in the setting of cancer and/or palliative care

First author, country, year	Qualitative	Self-designed questionnaire	Self-designed questionnaire: tool details provided	Questionnaire informed by qualitative design	Cost diaries	12 months recall of direct costs	Modelling from national census data	WHO health survey questionnaire
Wang, China, 2015							✓	
Gardiner, UK, 2017					✓			
Ratcliff, India, 2017		✓						
ACTION study group, SE Asia, 2015					✓			
Israels, Malawi, 2008	✓							
Bhojani, India, 2012			✓					
Chuma, Kenya, 2007				✓				
Emanuel, India, 2010		✓						
Hamid, Bangladesh, 2014						✓		
Kavosi, Iran, 2014								✓
Zaidi, Pakistan, 2012			✓					
Chen, China 2018		✓						
Hailu, Ethiopia, 2013			✓					
Bennett, New Zealand 2009		✓						
Arrossi, Argentina, 2007		✓						

impact of palliative care on household poverty in Blantyre, Malawi.

## METHODS

### Setting

Malawi is a low-income country listed 171 out of 189 (2018 data) on the Human Development Index. Life expectancy for its population of 18 million people is 64 years (World Bank, 2017). Ten per cent of adults are living with HIV (UNAIDS 2017). Malawi has the highest age-standardised incidence and mortality for oesophageal and cervical cancer in the world,<sup>7</sup> with cancer prevalence on the rise. There are four tertiary-level public hospitals, two of which provide oncology services. Radiotherapy is only available outside the country. Palliative care services have been developed over the last 20 years.<sup>8</sup>

### Stage 1: Photovoice study

To explore concepts of wellbeing and cost areas of importance for households affected by advanced cancer, we conducted a qualitative study using Photovoice. Thirteen co-researchers (seven patients and six family caregivers, mean age 47 years who were all receiving palliative care for a diagnosis of advanced cancer) utilised digital cameras to document experiences of living with life-limiting illness. Through participatory analysis of photographic images, named themes and subthemes were identified. Data on areas of OOPE relevant to healthcare were extracted from audio recordings.<sup>9</sup>

### Stage 2: literature review

In order to build on existing approaches to gathering data on OOPE in populations requiring palliative care in LMIC, a literature review was undertaken. With librarian support an initial search of two online

databases (MEDLINE/PubMed, CINAHL/EBSCO) was used to identify suitable MESH headings, key words and index terms. Disease-type search terms covered both non-communicable diseases (NCDs) and other chronic diseases, as there are few publications in this area specifically relating to populations receiving palliative care. Searches were limited to journals in English published between 1990 and 2017. One hundred and thirty-seven papers were identified for which abstracts were reviewed. Further to this, papers reporting household costs relating to cancer in LMIC from the reference list from Jan *et al's* landmark review on poverty and NCD,<sup>10</sup> were added. Methodological approaches are summarised (with examples) in table 1. Two other papers not otherwise identified but known to authors (JB) were also reviewed. Thereafter members of the author team (LN and SBS both of whom have extensive experience of economic evaluations in LMIC and JB) held a discussion to decide which tools might be suitable for adaptation to gather household level data on OOPE and wellbeing in a palliative care population in Malawi.

The WHO TB patient cost instrument was identified as suitable for adaptation for cost components of the survey. It was constructed within a similar setting<sup>11</sup>, and has since been reviewed and adapted by multi-country stakeholder groups across LMIC settings to assess OOPE and coping strategies (eg, loans and dissaving) with flexibility to adapt to the local context.<sup>12</sup> Data from its use contributed to formulation of the third goal of the WHO End TB strategy, to eliminate catastrophic costs for patients and households affected by TB.<sup>13</sup>

Stage 3: development, review, translation and piloting of the PaCCCT survey

A zero-draft of the PaCCCT survey was developed by JB (a palliative care specialist with extensive clinical experience in Malawi) and ET (a health economist familiar with the use and analysis of the WHO TB patient cost survey tool in LMIC). Changes included separating details of emergency (unplanned) visits from routine (planned) care, with the assumption that emergency care visits would place additional burdens on OOPE. Co-researcher themes and cost areas of relevance from the Photovoice study informed the inclusion of additional assessment items. Content validity of the PaCCCT survey was assessed at two stakeholder meetings first by six experienced Malawian palliative, oncology and home-based care nurses who met and discussed cost areas of relevance to their patient population. They supported the inclusion of an additional brief section on funeral costs, which was included at a national stakeholder review meeting attended by over 40 people comprising members of the public, policy-makers, economists, academics and senior clinicians. Minor changes to wording and flow were incorporated from this meeting. Forward and back translation into local language was conducted by the transcription team at a locally based international research institution. A tablet-based version of the PaCCCT survey was finalised before piloting with six households (patients and family caregivers) at the proposed study site (Queen Elizabeth Central Hospital, Blantyre, Southern Malawi). Following the pilot, the cost section and wellbeing section of the survey were separated. Since patients may only be required to complete the wellbeing section this reduced their section completion time from 45 min to under 30 min. Family caregivers (identified by the patients and consented separately) were able to complete the remainder of the survey in under an hour.

## RESULTS

*Overview of the PaCCCT survey* (online supplementary appendix 1 PaCCCT survey.pdf (V.1.0)).

### Section on household costs

This comprises details of the patient's history of healthcare utilisation and related costs. Healthcare usage categories reflect those available in the local healthcare setting. In Malawi, this includes traditional healers and local pharmacies as well as hospitals and health centres. Direct (eg, medicine, investigations) and indirect (ie, income lost through time for hospital visits/caring) costs are recorded. Health insurance reimbursement and other mechanisms of paying for care (including 'coping strategies' such as loans, borrowing and selling of assets) are recorded. At baseline, costs are recorded from the onset of symptoms until the time of diagnosis. The follow-up section details costs

since the last survey completion, with costs of planned and unplanned care visits recorded separately.

### Section on wellbeing

This comprises three components. The first is the EQ-5D-3L (validated Chichewa version<sup>14</sup>) (used in a paper based format with permission from Euro-QoL). The second is the Integrated Palliative Care Outcome Score (IPOS, developed by Kings College London available from <http://pos-pal.org>). The third section comprises exploratory questions which were identified as of importance to wellbeing through the baseline qualitative study (namely, the ability to work, perceptions of discrimination and the sufficiency of food) reported using a 5-level scale (using a similar format to the EQ-5D-5L). Verbatim details of the patient and carer's main concerns are also entered within the IPOS.

### Section on funeral costs

One of us (SBS) identified that, though funeral costs are a significant burden on households in LMIC, these costs are rarely reported. Through the review process, stakeholder groups approved the use of a brief set of questions which could be asked to family caregivers following separate consent, a minimum of 2 weeks following death.

## CONCLUSION AND NEXT STEPS IN THE USE OF THE PACCT SURVEY

In this paper, we describe the development of the PaCCCT survey that is being used to gather prospective data on healthcare use, household OOPE and wellbeing among households affected by advanced cancer in Southern Malawi. The PaCCCT survey is currently only suitable for households affected by cancer-related illnesses. Further validation of this instrument should be prioritised. We invite others to adapt this survey for their own settings and for other life-limiting conditions. Such data are critical to inform future economic evaluations and to influence global health policy dialogues on UHC with the aim of improving access to services for the many in need of palliative care.

**Correction notice** This article has been amended since it was first published online. The Open Access licence has been changed to CC-BY. The Acknowledgments and Funding section have been updated.

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**Contributors** MJB guided the process and drafted the manuscript. SBS provided conceptual input to the survey adaptation and ET provided technical support on the zero draft. EM, AM, ET and SBS participated in the national stakeholder meeting to revise the survey, then reviewed the

manuscript. LN edited the manuscript. SBS and LN contributed equally as senior authors on the manuscript.

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## REFERENCES

- Lu C, Chin B, Li G, *et al.* Limitations of methods for measuring out-of-pocket and catastrophic private health expenditures. *Bull World Health Organ* 2009;87:238–44.
- Anderson RE, Grant L. What is the value of palliative care provision in low-resource settings? *BMJ Glob Health* 2017;2.
- Organization WH. Tackling NCDs : best buys and other recommended interventions for the prevention and control of non-communicable diseases, 2017. Available: <https://apps.who.int/iris/bitstream/handle/10665/259232/WHO-NMH-NVI-17-9-eng.pdf?sequence=1&isAllowed=y>
- Knaul FM, Farmer PE, Bhadelia A, *et al.* Closing the divide: the Harvard global equity Initiative–Lancet Commission on global access to pain control and palliative care. *The Lancet* 2015;386:722–4.
- Reid EA, Kovalerchik O, Jubanyik K, *et al.* Is palliative care cost-effective in low-income and middle-income countries? A mixed-methods systematic review. *BMJ Support Palliat Care* 2019;9:120–9.
- Gardiner C, Brereton L, Frey R, *et al.* Approaches to capturing the financial cost of family care-giving within a palliative care context: a systematic review. *Health & Social Care in the Community* 2015.
- Bray F, Ferlay J, Soerjomataram I, *et al.* Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA: A Cancer Journal for Clinicians* 2018;68:394–424.
- Markham K, Huwa C, Bates J. Palliative care in Malawi: the current state of services and education. *European Journal of Palliative Care* 2017;24:134–40.
- Bates MJ, Mphwatiwa T, Ardrey J, *et al.* Household concepts of wellbeing and the contribution of palliative care in the context of advanced cancer: a Photovoice study from Blantyre, Malawi. *PLoS One* 2018;13:e0202490.
- Jan S, Laba T-L, Essue BM, *et al.* Action to address the household economic burden of non-communicable diseases. *The Lancet* 2018;391:2047–58.
- Kemp JR, Mann G, Simwaka BN, *et al.* Can Malawi's poor afford free tuberculosis services? patient and household costs associated with a tuberculosis diagnosis in Lilongwe. *Bulletin of the World Health Organization* 2007;85:580–5.
- Tanimura T, Jaramillo E, Weil D, *et al.* Financial burden for tuberculosis patients in low-and middle-income countries: a systematic review. *European Respiratory Journal* 2014;43:1763–75.
- Organization WH. Who end TB strategy, 2019. Available: [https://www.who.int/tb/post2015\\_strategy/en/](https://www.who.int/tb/post2015_strategy/en/) [Accessed cited 2019 30th August 2019].
- Chokotho L, Mkandawire N, Conway D, *et al.* Validation and reliability of the Chichewa translation of the EQ-5D quality of life questionnaire in adults with orthopaedic injuries in Malawi. *Malawi Med J* 2017;29:84–8.