

# Palliative care within Universal Health Coverage and Financial Protection

Does palliative care have the potential to reduce household poverty in a low-income country? : A mixed methods study in households affected by advanced cancer in Blantyre Malawi

Thesis submitted in accordance with the requirements of the Liverpool School of Tropical Medicine for the degree of Doctor of Philosophy

By Maya Jane Bates

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## Abstract

Title: Does palliative care have the potential to reduce household poverty in a low-income country? : A mixed methods study of households affected by advanced cancer in Blantyre Malawi

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### Background

Palliative care aims to improve holistic quality-of-life and reduce serious health-related suffering in the context of life-limiting illness. Although palliative care is integral to Universal Health Coverage, services are widely unavailable for populations in low and middle income countries. This thesis investigates early data and advocacy proposals suggesting that palliative care can support household poverty reduction. Poverty reduction is understood to comprise enhanced wellbeing and reduction in household costs of healthcare. The research was conducted in Blantyre, Malawi in households affected by advanced cancer.

### Methods

A capabilities approach led to the use of Photovoice - a community-based visual participatory action research method - to describe household understandings of wellbeing, and the role of palliative care in supporting wellbeing. Data contributed to the development of the Patient and Carer Cancer Cost (PaCCcT) survey to gather healthcare utilisation data and associated costs. Households were then recruited in a prospective observational cohort study. Multiple linear regression models for total household costs of healthcare and risk ratios for catastrophic costs six months following diagnosis were tested by receipt of palliative care.

### Results

Thirteen co-researchers (six patients and seven family caregivers) compiled, captioned and analysed photographic images. Wellbeing was understood as being happy, having courage and seeing improvements in the patients' condition. The ability to work and/or be part of the community were valued. Palliative care supported these capabilities through the provision of medicine and counselling.

In total, 150 households (patients and their primary unpaid caregivers) were recruited. The average age of patients was 50 years. At six months patients in 89 (59%) households were alive, and in 55 (37%) had died. 6 (4%) households were lost to follow up. 21% of households received palliative care. 64% of households experienced catastrophic costs six months after diagnosis, 47% (9/19) of households who received palliative care vs 69% households (48/70) who did not (RR: 0.69, 95% CI 0.42, 1.13). Palliative care was associated with reduced dissaving (\$11 vs \$34,  $p=0.005$ ). The mean difference in total household costs of healthcare was 36% ( $p=0.707$ ).

### Conclusions

Patients and family caregivers receiving palliative care for advanced cancer engaged actively and safely as co-researchers, reporting their understandings of wellbeing and the role of palliative care. Palliative care was reported to be of value to stabilise and/or improve function rather than as preparation for dying. Access to palliative care was poor, and larger studies are needed to confirm the reductions in catastrophic costs and dissaving described. Palliative care was found to have potential to support

household poverty reduction in Blantyre, Malawi following a diagnosis of advanced cancer .

## Declaration

I, Maya Jane Bates, declare that the work in this thesis is my own under the supervision of Louis Niessen, Bertie Squire and Adamson Muula. At no previous time was this work submitted for a degree or qualification.

Where information has been derived from other sources, or where co-authors have inputted to published papers, this has been indicated.

Maya Jane Bates

## Ethical approval

Ethical approval for the studies was obtained from the College of Medicine Research Ethics committee (P.07/16/1999, P.05/18/2395) and the Research Ethics Committee of Liverpool School of Tropical Medicine (16-045,18/046).

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## Glossary

CEA	Cost-effectiveness analysis
CI	Confidence interval
DALY	Disability-adjusted life-year
DCP	Disease Control Priorities
EHP	Essential Health Package
EQ5D-3L	EuroQoL five dimensions – three levels
HCC	Hepatocellular carcinoma
HIC	High income countries
HIV	Human immunodeficiency virus
HRQoL	Health-related quality of life
HSSP	Health sector strategic plan
IQR	Inter-quartile range
IPOS	Integrated Palliative Care Outcome Scale
KUHeS	Kamuzu University of Health Sciences
KS	Kaposi's Sarcoma
LMIC	Low and middle income countries
LSTM	Liverpool School of Tropical Medicine
MLW	Malawi-Liverpool-Wellcome Trust Clinical Research Programme
NCCP	National cancer control programmes
NCDs	Non-communicable diseases
OOPE	Out of pocket expenditure
PaCCCT	Patient and Carer Cancer Cost
QALY	Quality-adjusted life-year
QECH	Queen Elizabeth Central Hospital
RR	Risk ratio
SD	Standard deviation
SDG	Sustainable Development Goal
SHS	Serious health-related suffering
SSA	Sub-Saharan Africa
TB	Tuberculosis
UHC	Universal Health Coverage
UNDP	United Nations Development Programme
USD	United States dollar
VAS	Visual analogue scale
WHO	World Health Organisation

## Investigators and Collaborating Institutions

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## Candidate's statement on research contributions

I conceived of, developed, designed and conducted all the research contained within this thesis. I was the first author on all published manuscripts.

Supportive roles comprised less than 5% of the work compiled in this thesis. Names, and institutions of other contributors are listed below, by role, with thesis chapter:

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Miriam Gordon	University of Manchester, UK	Statistics and data analysis	7
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Marc Henrion	MLW, Malawi, LSTM, UK		6,7
Louis Niessen	LSTM, UK	Writing review and editing	All
Bertie Squire	LSTM, UK		All
Nicola Desmond	MLW, Malawi, LSTM, UK		4
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Adamson Muula	KUHeS, Malawi		4,5,6,7
Stephen Gordon	MLW, Malawi, LSTM, UK		6,7

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“It’s not that your life has come to an end just because you have been diagnosed with cancer”

I met my colleague in the hospital corridor one day. I asked about her husband who I knew had been diagnosed with advanced cancer. She told me about his recent death, detailing how the household had sold everything they had during his illness: land, vehicle and house included. Her daughter had dropped out of college due to lack of money to pay her fees. My heart was heavy as I walked away.

Witnessing the challenges posed by life-limiting illnesses during fifteen years of clinical practice of palliative care in Malawi led to my interest in undertaking this research. I am thankful to all the patients and their family members who have shown and taught me so much over the years. The courage and resilience of those living with life-limiting disease in the context of extreme poverty are unbelievable. Their suffering is, at times, unimaginable. If this research might in some way help to prevent or relieve some of their (or others) suffering, then it is a job well done.

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I feel immensely privileged to have had this opportunity to learn, reflect, compile, and collate the material and experiences within these pages.

*For the Lord gives wisdom*  
*from his mouth come knowledge and understanding*  
Holy Bible, Proverbs chapter 2, verse 6

To God be the Glory!



# Chapter 1 Introduction

## 1.1 Chapter overview

Global estimates suggest that approximately 90% of the global need for palliative care for adults and children remains unmet. Around 80% of this need is in low and middle income countries (LMIC). Although palliative care is integral to UHC, research evidence from LMIC is minimal, this against a background of unrelieved serious health related suffering for an estimated 24 million adults and children. Limited published data contributes towards a lack of awareness amongst patients, caregivers, health workers and researchers and means that policy makers are uninformed of the potential benefits of palliative care. Palliative care may mistakenly be perceived within the narrow (and undefined) framework of 'end of life' care, existing as a 'luxury' to deliver optional comfort to the few, rather than as an essential part of the continuum of care as supported by resolutions of the United Nations and the World Health Assembly.

In this chapter, the background context and rationale for the body of work presented in this thesis are outlined. Thesis aims and objectives, justification of methods and thesis overview are provided at the end of the chapter. The aim of this thesis was to investigate early data, proposals by global advocates, and recommendations from the Lancet Commission and the World Bank, suggesting that the provision of palliative care contributes towards household poverty reduction in LMIC. Here, poverty reduction is understood to comprise enhanced wellbeing and reduction in household costs of healthcare. Where such proposals are substantiated, they can be utilized at policy level to support improved access to palliative care within UHC.

## 1.2 Background

### *What is palliative care?*

Interventions aimed at reducing the burden of cancer and other non-communicable diseases (NCDs) can play a key role in global development, to meet Sustainable Development Goals (SDGs) including and beyond health (1, 2). Palliative care is one such intervention although reports suggest that only 12% of those in need of palliative care have access to it (3). According to the World Health Organisation (WHO), palliative care is defined as:

*'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (4).*

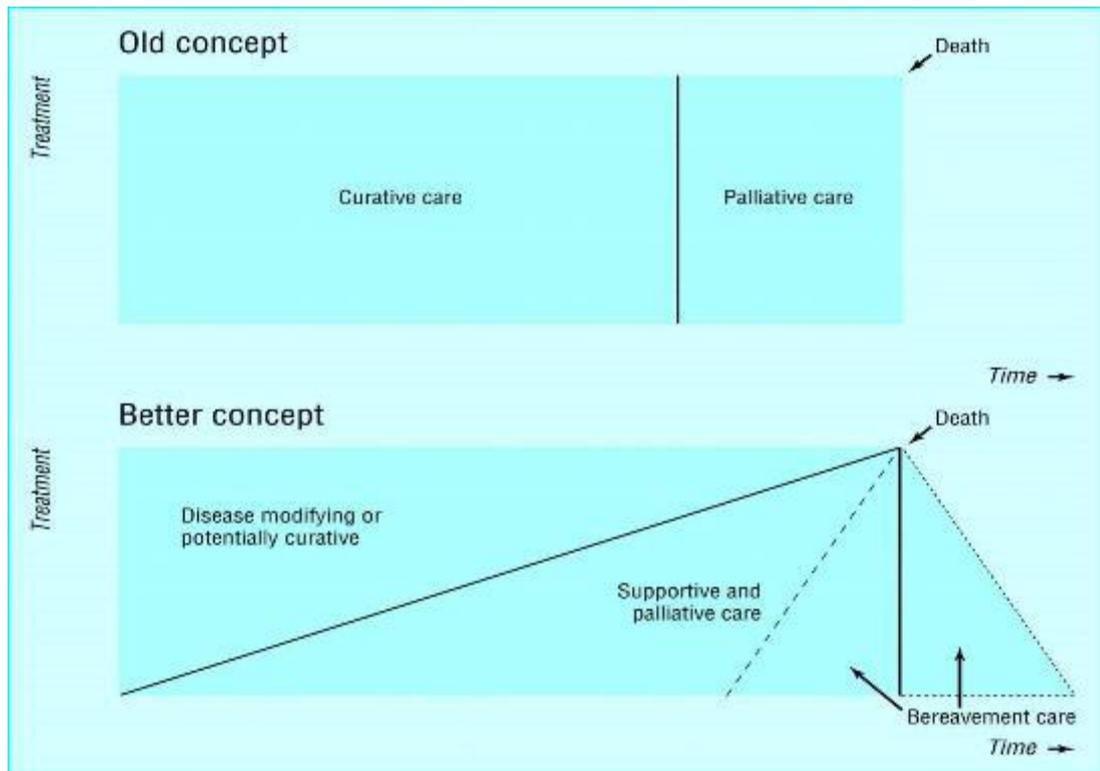
Palliative care was started as a medical discipline in the 1960s, to provide holistic support for patients and families with cancer at the end of life (5). Its value is now recognised across the continuum of care for patients affected by a wide range of both communicable and non-communicable disease, of relevance across all age groups - from children to older persons(6).

Palliative care experts have advocated for an expanded timeframe during which patients and families may benefit from a palliative approach(7). Scott Murray and others, through well publicized work on disease trajectories, have highlighted the need for earlier integrated models of palliative care to be delivered at both primary and specialist level, Figure 1 (8).

*Figure 1 Illness trajectories and palliative care*

from Murray SA, Kendall M, Boyd K, Sheikh A. *BMJ*. 2005; 330:1007-1011

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Traditional models starting at an arbitrary ‘end of life’ or ‘terminal’ stage risk a delay in, or even denial of, access to palliative care expertise. The stigma associated with death and dying may result in patients and families choosing to forego palliative care, and/or health workers delaying referral to these services (9, 10).

*What is the role of palliative care for people with cancer in low and middle income country settings in Africa?*

A cornerstone of palliative care provision is the recognition, assessment, and management of severe pain in the context of life-limiting illnesses. Low doses of immediate release oral morphine have been found to be safe, effective, and available at low cost to the health system in Uganda (11). Barriers to timely and effective access to morphine include health worker ‘opiophobia’ previously described in Malawi (12). In 2002, the World Health Organisation (WHO) outlined a public health strategy for palliative care and integrated the provision of palliative care within National Cancer Control Programmes (NCCPs) (13). Although NCCPs are being increasingly developed across African countries, a recent review reported that pain management and access to morphine (proxy markers for the provision of palliative care) are rarely included (14).

Cancers are the second most common cause of death worldwide and are estimated to be the most common cause of serious health-related suffering in LMIC (15-17). A 70% increase in annual cancer cases and deaths are predicted on the African continent over the next ten years (18), with continued increases in age-standardised death rates from cancer against falling global trends (19). Cancer types in sub-Saharan Africa differ from the global picture: for example, cervical cancer is the commonest cause of death in SSA, contrasting with lung (including trachea and bronchus) cancers which cause most deaths in other regions.

The Lancet Commission for Palliative care and Pain relief proposed that palliative care be conceived of as reducing 'serious health-related suffering' (SHS) supporting the early inclusion of palliative care within the continuum of care for life-limiting and life-threatening illnesses (20). To relieve serious health-related suffering, palliative care comprises pain and symptom relief within the broader holistic assessment and management of psychosocial and spiritual needs of patients and families (20, 21). Providing timely access to palliative care is of particular importance in low- and middle-income countries (LMIC) on the African continent, where cancers are typically diagnosed at an advanced stage (22, 23), treatment modalities such as radiotherapy are often lacking, and health system capacity to deliver continuity of care beyond diagnosis is limited or absent (24).

### 1.3 Building the case for palliative care

In North America, evidence of cost savings at health system level coupled with quality of life gains, and some survival benefits, has resulted in the development of a strong business case for hospital-based palliative care (25). The American Society of Clinical Oncology guidelines now recommend palliative care for all patients from the time of diagnosis of metastatic (advanced) disease (26). Further analysis of these cost savings report that they are driven by reduced length of stay in hospital rather than the result of foregoing costly treatments at the end of life (27). Differences in

health systems and health system financing, including what constitutes 'hospital based' or 'specialist' palliative care limits the generalisability of these findings.

On the wider global stage, health priorities are typically determined by cost-effectiveness – as a measure of efficiency - and by the need to report progress towards agreed global goals that include inequalities and the ability to reach vulnerable populations. Universal Health Coverage requires that “all people have access, without discrimination, to nationally determined sets of the needed promotive, preventive, curative, rehabilitative **and palliative** essential health services, and essential, safe, affordable, effective and quality medicines and vaccines, while **ensuring that the use of these services does not expose the users to financial hardship, with a special emphasis on the poor**, vulnerable and marginalized segments of the population” (emphasis my own) (28). Member countries of the United Nations committed to “accelerate efforts towards the achievement of Universal Health Coverage by 2030 to ensure healthy lives and promote well-being for all throughout the life course”. There is an opportunity for palliative care within Universal Health Coverage (UHC) under Sustainable Development Goal (SDG) 3 which ambitiously calls for ‘health and wellbeing for all at all ages with no-one left behind’(29). Specific indicators relating to the provision of palliative care are however lacking (30).

The World Bank has included palliative care within a ‘high priority package’ of interventions required for ‘Essential Universal Health Coverage’ in Disease Control Priorities 3 (DCP3). Palliative care is proposed as a ‘value-for-money’ rather than ‘cost-effective’ intervention (16). The recommended low cost ‘essential package’ of palliative care proposed is referenced to the Lancet Commission on Palliative care and Pain relief (20). In World Health Assembly Resolution 67.19 global leaders agreed that palliative care should be integrated in the continuum of care for people with NCDs and HIV (37). This landmark resolution included requests to:

- i. 1. develop and strengthen evidence-based guidelines on integration of palliative care into national health systems...that adequately address ethical issues...such as equitable access, person-centred and respectful care.

- ii. 2. encourage research on appropriate models of care in low and middle income countries.

Research in high income settings reports specialist palliative care improving quality of life and delivering cost savings at health system level. Diagnoses of cancer and other NCDs impose significant financial burdens through OoPE at household level in LMIC (31). Palliative care is typically integrated within primary care models in LMIC, providing control of pain and other symptoms, permitting resumption of activities for patients and/or their household caregivers; and timely provision of information: facilitating reduced expenditure on non-beneficial care. Clark et al report opinions of international palliative care experts exploring strategies for future advocacy for global palliative care. Participants from India and countries in Africa highlighted the cost burdens experienced by households affected by advanced disease, considering the need to report the potential for palliative care to deliver cost savings and/or poverty reduction at household level in these settings (30).

A preliminary review of the cost-effectiveness of hospital and home-based palliative care services in LMIC yielded 10 studies reporting favourable outcomes in terms of reduced costs and increased patient satisfaction (32). In a pilot study from Kerala South India, household-level data was gathered from 22 participants (11 patient-carer dyads) on the economic impact of terminal illness (33). The study was conducted within a WHO demonstration site for palliative care at Pallium India (34), to assess the feasibility of delivering carer training (as part of palliative care service delivery) to mitigate some of the impoverishing effects of terminal illness. In a retrospective survey within a palliative care programme in Northern India, households reported a reduction in expenditure on medication, and savings due to reduced visits to the hospital, following enrolment in palliative care. Eight percent of patients and 10% of household carers returned to paid work as a result of palliative care (35). Through training, a small number (5%) of households were also able to access government benefits for the first-time. The protocol of a randomised controlled trial of early palliative care for patients with cancer in Ethiopia has been published (36). This will compare patients who receive a package of oncological care combined with early palliative care, with those who receive standard oncological care alone, reporting on

differences in health system costs and effectiveness through the use of palliative care outcome measures.

#### 1.4 Context and setting

Malawi is a densely populated low-income country listed 174 out of 189 on the Human Development Index (UNDP, 2019 data). Eighty-five percent of the population live in rural areas where only 4% have access to basic amenities such as electricity (37). The World Bank estimates that 51.5% of the population live below the poverty line and 20.1% are in extreme poverty (World Bank, 2016 data). The Essential Health Package (EHP) is provided without cost at the point of care, but OOPE remains a significant burden on rural households accounting for an estimated 12-13% of health expenditure (38, 39). Health care is provided through a network of community and hospital-based services supported by government and faith-based funding across 28 districts. Health expenditure is exceptionally low in Malawi (\$39 per capita), with continuing donor dependence. 62% of financing for health is provided by external partners(39). There are currently no social (state-funded) health insurance or welfare systems in place, and private health insurance is too expensive for most of the population.

The Government of Malawi Health Sector Strategic Plan (HSSPII) 2017-2022 set out an agenda 'towards Universal Health Coverage', aiming to provide access to necessary quality services without financial hardship through the provision of an Essential Health Package (EHP). Priority areas in the HSSP II were determined using evidence of cost-effectiveness based on QALYs and DALYs where these were available (39). Screening for cervical cancer is the only cancer-specific intervention included in HSSP II, with an estimated annual burden of 9000 DALYs per year for Malawi's 9.5 million women. The provision of community-based home-based care has a single minor mention in the document. Although palliative care is not included in the HSSP II, there have been a number of successes in scaling up palliative care training and service provision in Malawi during this period. Coordinated efforts have resulted in improved access to morphine supply (a commonly used proxy for palliative

care development) (40), development of a national palliative care policy and integration of services and training within public sector facilities (41).

The setting for the present research is Queen Elizabeth Central Hospital (QECH) in Blantyre which is one of four publicly funded specialist hospitals in Malawi. It offers services in several areas (surgery, medicine, paediatrics etc.) at secondary and tertiary level and some quaternary referral services for the whole country. The diagnosis of common adult cancers at QECH occurs in both in-patient and out-patient settings. Palliative care services at Tiyanjane Clinic have been provided free of charge for adults at QECH since 2003 (42). Basic palliative care services – staff support and medicines - are provided by government funding, with donor funds providing for additional staff and medicines, training and mentorship, and home visits to sick patients and families. The relative contributions of central (government) and donor funding have not yet been formally costed for this service.

## 1.5 Thesis rationale

This thesis uses a capabilities-orientated approach to explore poverty reduction through palliative care, firstly to describe household wellbeing and the contribution of palliative care following a diagnosis of advanced cancer, and then to investigate whether receipt of palliative care contributes to a reduction in catastrophic cancer-related healthcare costs through reducing costs of non-beneficial care. Issues of relevance to the Sustainable Development Goals and the provision of palliative care within Universal Health Coverage are addressed.

Diagnoses of cancer and other NCDs impose significant financial burdens through direct costs and time lost in paid work at household level in LMIC. International agencies and palliative care advocates propose that the provision of palliative care may support financial protection for households by reduction of pain and serious health-related suffering, though data in this area is currently sparse. Here, poverty reduction is described beyond ‘income’ poverty to include that which households value to be and to do, such that poverty reduction is considered as both enhanced

wellbeing and through financial protection, in this case where households include a patient who has received a diagnosis of advanced cancer.

## 1.6 Thesis aim and objectives

This thesis focuses on households in and around Blantyre, Malawi, comprising patients diagnosed with advanced cancer and their unpaid family caregivers.

The aim of this doctorate is:

To explore the contribution of palliative care to poverty reduction through improvements in household wellbeing and financial protection following a diagnosis of advanced cancer in Blantyre, Malawi

The objectives are:

1. To describe patient and family understandings of wellbeing and the contribution of palliative care to household wellbeing following a diagnosis of advanced cancer (chapters 3,4)
2. To develop a cost survey tool to gather data on healthcare utilisation and related financial costs from households affected by advanced cancer in low- and middle-income settings (chapter 5)
3. To assess the relationship between receipt of palliative care, and catastrophic out of pocket expenditure, dissaving, change in total household income and health-related quality-of-life following a first-time diagnosis of advanced cancer (chapter 6,7)

## 1.7 Thesis structure

This thesis is a publication-based thesis structured into eight chapters. Five manuscripts are included comprising chapters 3-7, four of these have been published (chapters 3-6) and the fifth (chapter 7) has been accepted for publication.

Following the introductory chapter 1, chapter 2 introduces a conceptual framework relevant to the methods employed with reference to the current literature. Chapter 3 reports practical and ethical considerations of the use of Photovoice, a community-based action research participatory method, for populations living with advanced cancer (as an example of life-limiting illness) in low-income settings. Chapter 4 reports the results of the Photovoice study describing household concepts of wellbeing and the role of palliative care. Chapter 5 describes the development of the Patient and Carer Cancer Cost (PaCCcT) survey – a cost tool to assess household healthcare utilisation and associated costs after a diagnosis of cancer, suitable for use in low-income countries. Chapter 6 provides the protocol for the prospective observational cohort study of health-related expenditure and health-related quality of life outcomes for households affected by advanced cancer. Chapter 7 reports the results of the prospective observational cohort study.

Chapter 8 draws together the findings and lessons learnt from this body of research, considering the methodological and empirical contributions to the question of whether palliative care has the potential to reduce household poverty within the current literature. Recommendations for policy and considerations for a framework for future research are proposed.



## Chapter 2 Methods

### 2.1 Chapter overview

In this chapter I introduce concepts of poverty and health of relevance to this thesis with reference to the low-income-country setting of Malawi, in which the research took place. The poverty trap and approaches to estimating costs are introduced. The capability approach is outlined, in which poverty is considered beyond issues of income. Challenges with measuring quality of life in advanced disease are discussed and a conceptual framework proposed.

Further details of methods are provided in chapter 3 (Photovoice), which details issues of patient participation in research in the context of advanced disease, and chapter 5 (gathering data on patient costs) which describes the development of the Patient and Carer Cancer Cost survey.

## 2.2 Economic consequences of ill health and advanced disease in LMIC : what can we learn from the poverty trap?

Although palliative care research has had little engagement with issues of poverty and development (43) there is a wide body of literature to draw on in this field. World Bank economists: Jeffrey Sachs, Adam Wagstaff, Eddy van Doorslaer, and others, have advanced the theory of the poverty trap, Figure 2 (44) which conceptualises the economic consequences of ill health on future generations.

Figure 2 Cycle of Health and Poverty

From Wagstaff et al, 2002 (45)



Households experiencing illness in the context of poverty are subject to relatively greater impact from costs (both direct out-of-pocket expenditure on health and lost work time) which drives them into further poverty perpetuating greater vulnerability (poorer nutrition, worsening of access to basic education and health services) with resulting cycles of deteriorating health and/or survival. In the absence of government welfare payments, health insurance schemes or other easily available safety nets, the poverty trap not only affects individuals but also has a wider impact across households and communities (45).

Many patients face the burden of life-limiting illnesses during what could be their most economically productive years (42) . Patients are responsible for multiple dependents, expressing concern for non-payment of school fees whilst managing their illness. Progressive disease, disability and subsequent death directly impacts property ownership, education, and food security for these dependents (33, 46).

### 2.3 Diminished income : estimating patient costs

Catastrophic costs and impoverishment are used to report financial risk protection outcomes within Universal Health Coverage (47, 48). Total costs of healthcare are calculated against total household income, household consumption or 'non-food' expenditure per year (49, 50). Definitions of 'catastrophic costs' are still a matter of debate (51, 52) varying from 10% to 40% Impoverishment is described through reporting the percentage measure of individuals or households pushed below the poverty line as a result of the costs of ill-health. A systematic review of the global financial burden for patients with non-communicable diseases reported that over 60% of household income was spent as a result of some diseases (53). Such costs typically incorporate both direct OOPE (cost of medicines, tests, transport etc) and indirect costs (due to lost working time as a result of ill health/health seeking). These costs have severe consequences on future socio-economic status and health outcomes (51). Out of pocket expenditure (OOPE) is thought to account for 23% of global health expenditure and 45% of health expenditure in LMIC (54).

Methods to measure the catastrophic cost denominator (total household income, household consumption or 'non-food' expenditure per year ) are debated. Sweeney et al have outlined limitations in the use of self-report when estimating household income, describing proportions of catastrophic costs varying between 0% and 36%, depending on the estimation method (asset linking or minimum wage approach) (55). In extremely poor households those who are sick may forgo treatment rather than experiencing catastrophic costs (38, 56). Impoverishment may be difficult to report as an outcome where the number of households living below the poverty line are already high at baseline.

Patient cost studies additionally report 'coping strategies' including the use of 'dissaving' which refers to the sale of assets (such as bicycles, cattle, or land) and the acquisition of loans to release capital to pay for healthcare. For purposes of reporting, dissaving may be recalled more accurately than retrospective details of healthcare expenditure. Dissaving has been considered as a potential proxy marker of catastrophic costs from analysis of data from Tanzania and India (57).

## 2.4 Understanding poverty reduction beyond cost: the capabilities approach and the measurement of wellbeing

Development specialists and economists in the 1990s realised that poverty should be conceived of as more than 'income poverty'. Robert Chambers wrote in 'Whose Reality Counts: putting the first last first' - *"(development) professionals often construct and use reductionist realities...the realities presented and analysed (through participatory methods at local level) challenge and qualify both the use of proxy indicators for wealth and income and the primacy of income-poverty". "...none of this is to undervalue income as a means to achieving other objectives. But it shows that in local people's reality much more matters besides income, and other criteria – sickness, disability, dependence, being unable to fulfil social obligations, being 'poor in people', and being a miserable sort – again and again come up"*. (58). Chambers emphasised the importance of incorporating broader measures of wellbeing to reflect local understandings of poverty beyond household income status.

Amartya Sen, the Nobel Prize-winning economist, at around the same time of Chambers' writing, was changing the way that global poverty was measured and reported. As a result of Sen's work, and reflecting similar sentiments, international agencies moved away from reporting quality of life through gross domestic product or income per capita, to the Human Development Index (HDI). This is a composite measure of life expectancy, income, and education. Sen's broader philosophical understanding of poverty and wealth, known as 'the Capabilities approach' was outlined in his book 'Commodities and Capabilities'(59). Capabilities were understood as the ability (or 'freedom') to achieve desired outcomes. This approach

recognised the centrality of local perspectives to express desired outcomes aligning closely with the ideas of Chambers. Working with Sen, Nussbaum contrasted the capabilities approach with utility (preference) and resource-based approaches to the measurement of quality of life, summarising capabilities as 'what (s)he can be or do'(60).

Whilst Sen and Nussbaum expounded the capabilities approach within political and developmental discourse, the value of this approach in reporting multidimensional aspects of wellbeing within health economics is increasingly recognised (61, 62). Coast et al used a capability framework to develop quality of life measures based on in-depth interviews with adults in the UK. The resulting ICECAP series of measures includes the ICECAP-A (adults) which described five dimensions of wellbeing: autonomy, attachment, achievement, enjoyment and stability, and ICECAP-SCM (supportive care measure) for older adults at the end of life (63). In Malawi, Greco et al used a capability approach to develop the Women's Capabilities Index for Malawi (64). Analysis of focus group discussions with rural Malawian women described six dimensions of wellbeing: physical strength, inner wellbeing, household wellbeing, community relations, economic security, and happiness. In their discussion, they noted considerable overlap with capability dimensions from other settings in the 'global south', with 'substantial differences' to the ICECAP measures due to differences in resource and cultural context.

## 2.5 Measuring quality of life in palliative care : importance and limitations

Health interventions compete for limited resources. At national level, when comparing alternatives, measures of both the economic costs and the health-related effectiveness of an intervention are considered. Such cost-effectiveness analyses (CEAs) are then used by policy makers and planners to decide on priorities for healthcare e.g. in the design of National Health Services or Essential Health Packages (EHPs) (39, 65). Economic costs can be considered from a health system (provider) or societal (recipient) perspective, although typically are reported from provider perspectives in HIC. Effectiveness of an intervention can be conceived of and measured in a variety of ways, with 'cost per quality-adjusted life-year (QALY)

gained' or 'cost per disability-adjusted life-year (DALY) averted' recognised as standards within the field of health economics (66)

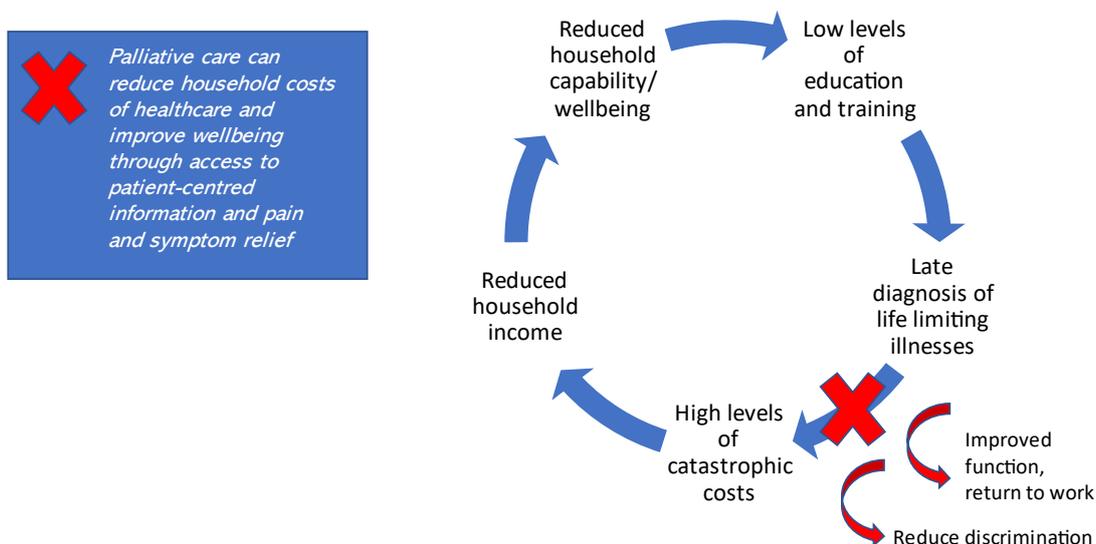
The use of QALYs facilitates the higher-level comparison of interventions across different disease conditions. The 'Q' (quality-of-life benefits) of interventions are generally measured using the EQ5D, SF12, and/or other validated quality-of-life questionnaires. These questionnaires are converted into utility scores on a scale of zero (death) to 1 (full health) and combined with a measure of how much time one spends in that health state (the 'LY'), describing QALYs. Several authors describe 'the QALY problem' in palliative care (67-71) with both the 'Q' and 'LY' aspects of QALYs contested. Researchers question whether the domains included in the EQ5D are applicable for palliative care populations, also proposing 'non-linearity' in the value of time towards the end of life (72).

Round cautions against abandoning the QALY measure in palliative care research (70) as it remains a widely accepted measure of effectiveness, used to determine the allocation of resources for healthcare across disease intervention packages. Alternative approaches proposed to measure effectiveness in palliative care include the PaLY (Palliative care Yardstick) and the SaLY (Suffering Adjusted Life Years) (20, 68) although neither measure have quality of life tools to support their use to date. A percentage measure of home deaths is sometimes used in high-income countries as a proxy for effectiveness in palliative care (73-75). This is yet to be validated in African settings, where its relevance has been questioned (76, 77). The Cochrane review of effectiveness and cost-effectiveness of hospital-based specialist palliative care reviewed 42 studies, reporting inconsistent and/or low quality evidence of cost-effectiveness (75). Only two papers reported in the review were from LMIC (Kenya and Mexico). Cost-effectiveness data for palliative care from any setting, though particularly from LMIC, remains extremely limited (32, 73, 75).

## 2.6 Justification of research methods

Palliative care is a complex intervention for which the Medical Research Council UK (78) and the MOREcare statement on End-of-Life research (67) support a mixed methods approach during early stages of evaluation. This thesis investigates the potential for palliative care to support poverty reduction. In Figure 3 (below), the cycle of health and poverty developed by Wagstaff et al (45) is adapted for settings of life-limiting illness. Here, poverty comprises capability and income perspectives, with a role for palliative care to support poverty reduction proposed.

Figure 3 How does palliative care break the cycle of health and poverty for households affected by life limiting illnesses (adapted from Wagstaff et al 2002)

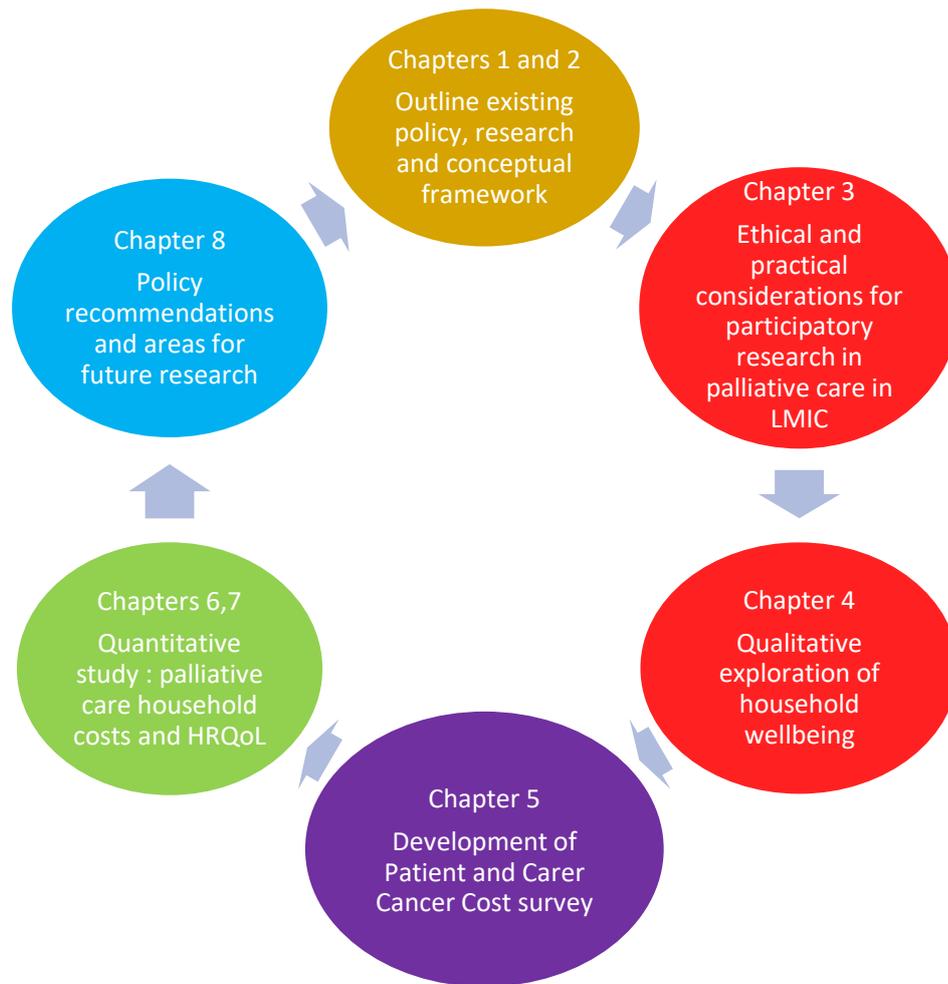


The mixed methods used in this thesis explore the potential for palliative care to support poverty reduction in a low-income country setting (here, Blantyre, Malawi) following a diagnosis of advanced cancer. Firstly, a qualitative approach is used to elucidate household concepts of wellbeing and the contribution of palliative care in the context of advanced cancer. Photovoice is a community-based action research participatory method suitable for a capabilities approach. It enables investigation and description of that which households value 'to be and to do' (capability domains) when affected by a diagnosis of advanced cancer.

The development of the Patient and Carer Cancer Cost (PaCCcT) survey is reported, adapted from the WHO TB patient cost survey. This survey is used to record healthcare utilisation and related household costs in the context of advanced cancer in a quantitative prospective cohort study. Results describe levels of catastrophic expenditure, dissaving, and total household expenditure on health as a proportion of household income. As there are no validated capability measures of wellbeing available for use in this population, wellbeing is instead reported using health-related quality of life (HRQoL) as a proxy, using the Chichewa (local language) validated version of the EuroQoL EQ5D-3L questionnaire. The association between the receipt of palliative care and measures of financial protection (total household expenditure on health as a proportion of self-reported household income and catastrophic costs) is reported, accounting for HRQoL over time.

Figure 4 illustrates this sequential mixed methods approach developed chapter by chapter in this thesis.

*Figure 4 Research cycle by thesis chapter*



*HRQoL: health related quality of life*

## 2.7 Summary and conclusion

Poverty and health are inextricably linked. Household vulnerability to worsening poverty increases following a diagnosis of life limiting illness. In this thesis, qualitative and quantitative methods are conducted sequentially to describe local concepts of wellbeing and the ability of palliative care to reduce poverty through supporting wellbeing then to explore the association between palliative care and financial protection.



## Chapter 3 : Enhanced patient research participation: a Photovoice study in Blantyre Malawi

### 3.1 Chapter overview

In this thesis, in adopting a capabilities approach towards wellbeing, I was particularly drawn to Photovoice as a community based action research method appropriate for traditionally 'hard to reach' communities, incorporating advocacy (engagement with policy makers) as a goal. Within the Photovoice process co-researchers combine photography with critical dialogue to record and reflect on their community's strengths and concerns (). It was first described by Wang and Burris in 1997, who, influenced by Paulo Friere and feminist theory, encouraged a change in the traditional power dynamic of research, enabling the 'researched' to become the 'researcher'.

In this thesis I employed Photovoice, a community based visual participatory action research method in which participants, as co-researchers, described patient and family caregiver understandings of wellbeing and the role of palliative care in household wellbeing the context of advanced cancer. The co-researcher group engaged in critical dialogue around their photographic images, and in thematic analysis. It was important to carefully consider some of the practical and ethical approaches to the conduct of participatory research with patients and families living with life-limiting illness, in this case with advanced cancer. To my knowledge, this was the first-time that Photovoice was used as a research method with a palliative care population in Africa. In this chapter, I documented practical and ethical considerations for the use of Photovoice in a population with advanced progressive disease requiring palliative care.

Chapter 3 was published in BMJ Supportive and Palliative care in February 2018. The publication can be found at the link below and in appendix 1:

<https://spcare.bmj.com/content/8/2/171h>

I led conceptualization and conduct of this work, and was responsible for the original, revised and final manuscript preparation.

## 3.2 Abstract

### Objectives

Patient involvement in palliative care research is a desirable if challenging goal. Photovoice is an action research method in which affected communities gather photographs to document and discuss their communities' strengths and concerns. Engagement with policy makers is a separate stated goal. Photovoice is increasingly used in health-related research but has not been widely described in the palliative care literature. We report on experiences and lessons learnt using Photovoice in Blantyre Malawi to encourage its wider use in research and practice.

### Methods

Thirteen co-researchers (6 patients and 7 household carers, mean age 47 years) receiving community based palliative care, attended nine half day group sessions over a four-month period. Co-researchers produced, selected and analysed photographs. On completion of data collection, they conducted an advocacy event, including a photographic exhibition, to which media representatives and community leaders were invited.

### Results

Procedures to ensure safety of co-researchers, and to obtain consent of individuals identified in the photographs were developed during the planning phase. Co-researchers engaged with the Photovoice process with enthusiasm, although frailty and physical disability (poor sight) limited participation for some older adults. Inclusion of palliative care staff within the research team helped to facilitate open dialogue and clinical review where appropriate.

### Conclusions

In this Photovoice study patients and family members receiving palliative care engaged in an exploration of household wellbeing using photography, participatory analysis and an advocacy event. With appropriate planning Photovoice can be adapted to a range of settings to enhance patient participation.

### 3.3 Introduction

Current evidence suggests that patients and families would appreciate greater involvement in palliative care research (79-81). A patient-centred approach is at the heart of palliative care and research methods should, where possible, reflect this, though concerns about patient vulnerability sometimes prohibit such involvement. Photovoice is a participatory action research method in which co-researchers combine photography with critical dialogue to record and reflect on their community's strengths and concerns (). It was first described by Wang and Burris in 1997 who proposed its use amongst traditionally 'hard to reach' groups, encouraging a change in the traditional power dynamic of research, enabling the 'researched' to become the 'researcher'(82).

**Table 1 Goals of Photovoice**

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- To enable people to record and reflect their communities' strengths and concerns
- To promote critical dialogue and knowledge about important issues through large and small group discussion of photographs
- To reach policy makers

A systematic review of Photovoice studies reported increasing use of the method in health research and included papers from African settings (83). In the palliative care literature Horsfall and Noonan utilised Photovoice alongside other participatory methods to explore the impact of caring for dying patients on the wider community in Australia (84). Caregivers in New Zealand have also used Photovoice to explore their needs (85). Beyond the perspective of caregivers, Photovoice has been used by patients in a variety of challenging clinical settings: chronic pain (86), mental illness (87) and cancer survivors (88), though it has not previously been described in the literature engaging patient participation in the setting of palliative care .

In this paper, we document our experiences and lessons learnt using Photovoice with patients and family caregivers affected by advanced cancer. This study was

conducted at the community based Tiyanjane Clinic in Blantyre, Malawi. Tiyanjane Clinic has provided adult palliative care services through government linked hospital and community based teams in Blantyre, Malawi (South Central Africa) since 2003. A stepwise overview of the process is recorded in order to encourage others to use Photovoice to facilitate patient participation in other settings of research and practice.

### 3.4 Methods

In preparation for the study, two members of the research team attended a Photovoice workshop in London ([www.photovoice.org](http://www.photovoice.org)). This provided a practical and theoretical overview of Photovoice, as well as the opportunity to plan and develop our study design with support from the course facilitator and diverse range of participants.

Two weeks prior to recruitment, all households receiving community based palliative care from Tiyanjane Clinic were approached by their palliative care community nurse with information about the study. Community based volunteers already known to the households acted as fieldworkers, providing a point of contact in case of change in physical status, problems with cameras or any other queries. After obtaining their written consent for participation in the study co-researchers (patients and main household carers) were provided with digital cameras and a basic introduction in their use.

Subsequently, the co-researcher group met twice a week over a period of four weeks. Between meetings they took the cameras home to take photographs on the subject 'the story of my illness'. This broad subject area was chosen to make it as easy as possible to gather images, whilst ensuring that they had some relevance to an ongoing study exploring the wellbeing of households of patients with life-limiting illnesses. Hard copies of digital images were printed and sorted into categories as a group activity. Categories were discussed and named during a process of critical dialogue guided by an external facilitator trained in qualitative research. Towards the end of the meetings co-researchers developed a programme of activities for an advocacy event which was held in a local community hall. Health and community

leaders were invited to the event along with members of the media. In preparation for the advocacy event, co-researchers were invited to individually select photographs for which they wrote a short explanatory caption. These captioned images formed a photographic exhibition at the advocacy event. Secondary analysis of transcripts from audio recordings of group discussions has been undertaken separately.

### 3.5 Results

At the time of the study, sixteen households under the community programme were approached, of which eight agreed to take part (comprising 9 patients and 8 carers). Engagement in research and use of cameras were new activities for all co-researchers in this study. Four older people (patients with brain, thyroid, and oesophageal cancer and one carer) were excluded from the study as they were unable to use the cameras due to their illness (poor sight) or physical frailty. Long term relationships between households and members of the community palliative care programme (included in the research team) helped to facilitate confidence and openness, though reflexivity was required to consider bias that this might introduce. Attendance at group sessions was good and co-researchers engaged enthusiastically during all Photovoice activities including the advocacy event (for which they all turned up early). Co-researchers were provided with transport money, a small amount of mobile phone airtime credit and lunch during the group meetings. One co-researcher (carer) missed some sessions due to the offer of paid work. Another one (patient) was admitted to hospital towards the end of the data collection period and later died. No cameras were damaged, lost or stolen during the research process, and the fieldworker-volunteers were only contacted to request replacement batteries. Co-researchers did not report any problems as a result of having or using cameras in the community. A second process of consent for use of photographic images was included at the end of the data collection period. Separate consent was required for individuals not taking part in the study who could be identified in the images, some withheld their consent which led to the exclusion of these images. Twenty-seven captioned photographs were produced for display at the local advocacy event. These photographs have subsequently been displayed at local and international conferences and workshops.

### 3.6 Discussion

Patient involvement in palliative care research is vital to enhance the patient centred approach intrinsic to the WHO definition of palliative care. Fears of overburdening vulnerable patients have been expressed, though initiatives such as the Palliative and end of life care Priority Setting Partnership have begun to model the potential generated by such involvement (89). Current evidence from high resource settings suggests that patients and family members are keen to play a greater role in research (79-81, 83).

Reviews of Photovoice research report its adaptability across a variety of cultural and contextual settings (90, 91). Design of studies varies considerably in terms of setting, degree of participation, length, scope and number of co-researchers. The length of study and frequency of meetings should be carefully planned with reference to degree of physical frailty and/or anticipated fluctuations in physical status of co-researchers. Studies like ours, taking place within the context of long term services, could be improved by involvement of service users in initial study design. Demands of the process (two meetings each week for four weeks plus an advocacy event) may have influenced those choosing not to participate in our study, though we did not illicit the reasons for non-participation. This would also introduce bias into the population, under-representing the views of those who are more seriously ill. In our study four older people (average age 73, three patients and one carer) were unable to participate due to difficulties using the digital cameras. This problem should be less common in settings where co-researchers are already familiar with the use of cameras.

Although reimbursement for transport costs and mobile phone credit was included in our budget some co-researchers missed sessions due to offers of temporary work. Compensation for lost working time may need to be considered if this study were to be repeated. Inclusion of palliative care nurses and community based volunteers as part of the research team was designed to enhance safety of co-researchers

throughout the process. Consideration of other practical issues - such as use of a community venue close to co-researchers' place of residence - also helped to minimise discomfort and/or drop out during the process. Hospital admission was required for one (patient) co-researcher who deteriorated during the study period. Review and transfer to hospital was overseen by the palliative care community nurse on the research team who also conducted the subsequent bereavement visit (accompanied by the community volunteers in accordance with local cultural practise).

Some of the other challenges of ensuring participation are tackled in a recent review of Photovoice research (91) which also summarises ethical issues of importance when using participatory methods. Safety of coresearchers was considered during development of the protocol and discussed during the group meetings. Trained community home-based care volunteers (acting as fieldworkers during the study) were consulted, allowing the team to draw on their extensive local knowledge. Games were utilised to familiarise participants with the range and power of visual images, and to enable a deeper understanding of the project aims. At the end of the session each household completed a sign out sheet for a numbered digital camera (complete with numbered SD card) for use in their home environment. Where safety of equipment was a major concern, participants had the option of being escorted by the field worker to the home setting for gathering photographs after which the field worker would be responsible to return the camera to the research team. None of the co-researchers used this option during the study. The privacy of all individuals was ensured through the two stage process of consent, firstly to take part in the study, and secondly for captioned images. Before captioned images were printed for public use (e.g. at the community advocacy event), co-researchers were required to obtain consent from any individuals who were identifiable. Selection of photographs was shared : for captioning and public display (e.g. during the advocacy meeting) this was done by co-researchers, for publication this was done by the Principal Investigator, who selected transcribed and translated verbatim quotes and photographs to illustrate the thematic areas identified.

The final goal of Photovoice 'to reach policy makers' was of key interest to us when choosing this method. Access to palliative care and pain relief in low-income settings has been described as an 'abyss' (20) and patient experiences poorly understood (92). Statutory funding is typically prioritised to other areas of health. Co-researchers produced powerful visual representations of their daily household realities. These images have been displayed at a local advocacy event, at the medical school in Blantyre, and at an international palliative care conference. Contacts made at the advocacy event led to an interview on a national television news programme where the lead researcher was invited to talk about palliative care.

### Conclusions

Greater patient involvement in palliative care research should be encouraged. In our experience, with due consideration and careful planning, Photovoice methodology can be used to yield rich and thought-provoking data for research and advocacy. Photovoice can be considered for adaptation and use in a variety of palliative care settings globally.



## Chapter 4: Household concepts of wellbeing and the contribution of palliative care in the context of advanced cancer: a Photovoice study from Blantyre, Malawi

### 4.1 Chapter Overview

Poverty reduction reaches beyond financial outcomes, to the support of what the individual/household values to be or do. In this chapter, I report the results of a Photovoice study in which 13 co-researchers (6 patients and 7 guardians) explored households' understanding of wellbeing and the contribution of palliative care towards poverty reduction - understood here as enhanced wellbeing.

This is the first of two results chapters in this thesis. Thirteen co-researchers (six patients and seven family caregivers) compiled, captioned and analysed photographic images. Wellbeing was understood as being happy, having courage and seeing improvements in the patients' condition. The ability to work and/or be part of the community were valued. Palliative care supported these capabilities through the provision of medicine and counselling.

Chapter 4 was published in PLOS ONE in August 2018. The publication can be found at the link below and in appendix 1.

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0202490>

I led the study conceptualization, project administration (including data collection, data interpretation, formal analysis), and developed the original, revised and final manuscript.

Findings from this study led to a proposal for a Masters project at LTM. I supervised the candidate who successfully completed a dissertation in 2018 entitled "Cancer stigma and its impact on healthcare seeking behaviours in low and middle-income countries: a narrative literature review". The Masters candidate presented findings as an online poster at a meeting of the British Psychology Society in May 2019.

## 4.2 Abstract

### Introduction

Cancer and other life-limiting non-communicable diseases are on the increase in Africa affecting younger populations frequently diagnosed at an advanced stage of disease. The United Nations Sustainable Development Goal 3 aims for 'healthy life and wellbeing for all at all ages', though there is a limited understanding of wellbeing particularly from patients' and families' perspectives in these populations. Palliative care is an approach which aims to improve the quality of life for patients and families affected by life-limiting disease, though access to palliative care has been described as an issue which is 'largely ignored' on the global health agenda. The aim of this Photovoice study was to explore patient and family perspectives of wellbeing and the contribution of palliative care following a diagnosis of advanced cancer in Blantyre, Malawi.

### Methods

Between November 2016 and February 2017, 13 co-researchers (6 patients receiving palliative care for advanced cancer and 7 un-paid family caregivers) gathered photographs to depict aspects of their daily lives. Participatory analysis was conducted, and an advocacy event (including photographic exhibits) held.

### Results

Wellbeing was described as seeing improvements in the patients' function facilitating inclusion in activities of daily living (including income generation) that had not previously been possible due to their illness. Family caregivers, neighbours and community members play a key role as 'courage givers' supported by health workers and religious groups, though discrimination in the form of social exclusion was also reported to be significant with patients expressing that they may be considered 'prematurely dead' in their community. Palliative care improves wellbeing by providing pain and symptom management enabling patients and/or family caregivers to return to household and income generating tasks. Through close interaction with

households and ongoing counselling palliative care services assist to reduce fear and discrimination.

### Conclusions

To achieve Sustainable Development Goal 3 for patients and families affected by life-limiting illnesses in low resource settings, further understanding of the frequency and impact of discrimination is required as well as improved access to palliative care.

### 4.3 Introduction

The number of cancer cases and cancer deaths in sub-Saharan Africa is set to increase by 70-85 % by 2030 (93) forming a major part of the growing challenge of life-limiting non-communicable disease on the continent. Few countries have national cancer plans, and data on cancer type, incidence and outcomes are still severely limited in scope and quality (18, 94). For a variety of reasons over 80% of cancer in the region is diagnosed at an advanced stage requiring a palliative approach from the time of diagnosis (95). Using the principles outlined in the WHO Public Health Strategy for Palliative Care (96) there have been a number of successes in scaling up drug availability, policy, education and service provision across Africa (97-99). Despite this, the Lancet Commission on palliative care and pain relief reported in October 2017 that 'access (to palliative care and pain relief) is a health equity and human rights imperative which has been largely ignored' (20).

Because of global advocacy, the World Health Assembly passed a resolution in 2014 calling for the 'strengthening of palliative care as a component of comprehensive care throughout the life course'. Data from the World Health Organisation estimate that currently only 12% of the 40 million people requiring palliative care globally receive it (100) with services clustered in high income countries of the global north. The World Health Organisation's definition of palliative care focuses on the importance of wellbeing through achieving 'quality of life for patients and families affected by life-limiting illnesses' (101). Though lacking a consensus definition (102), wellbeing is of growing importance in wider global conversations about health following its inclusion in the United Nations Sustainable Development Goal 3 (for health) which aims to 'ensure healthy life and wellbeing for all at all ages' (103).

Qualitative studies exploring quality of life and/or wellbeing of patients and families receiving palliative care are limited. A recent systematic review revealed only one paper (out of a total of twenty four) from the African continent (104). Early work during the development of palliative care services in Africa used standardised questionnaires to assess the needs of patients and caregivers receiving palliative care in five countries in Africa (Zimbabwe, Uganda, Ethiopia, Botswana and

Tanzania) (105). Financial problems and pain were the most commonly expressed needs. More recently data on wellbeing has been measured in palliative care patients in South Africa and Uganda using a quality of life tool (the Missoula Vitas Quality of Life index) which was evaluated as being suitable for the setting (106, 107). Spiritual wellbeing (being at peace and having meaning in life) was found to correlate most highly with quality of life scores.

This study used Photovoice to explore wellbeing for patients and family caregivers and the role of palliative care. Photovoice is a participatory action research method in which photographic material is gathered and used to discuss strengths and concerns of a particular group with the potential to catalyse social change (108). Wang and Burris were the first to describe the approach in the late 1990s (82), detailing its conceptual roots in the work of South American educationalist Paolo Freire and feminist theory. In common with other participatory action research approaches it supports Robert Chambers' notion that 'poor and exploited people can and should be enabled to analyse their own realities' (58). Photovoice is increasingly used both within and beyond health-related research (90, 109). Photovoice was considered appropriate to explore this topic, as an engaging and empowering method for a traditionally 'hard to reach' group incorporating a strong advocacy focus. A small handful of Photovoice studies have been reported from Malawi (21, 110, 111), but to our knowledge, this was the first-time it has been used for palliative care research anywhere in Africa.

Malawi is a densely populated peaceful democratic country listed 170 out of 188 on the Human Development Index. Over 80% of the population live in rural areas as subsistence farmers. Life expectancy is 64 years (112). Cancer prevention and treatment services are slowly improving but access to specialist surgical and oncology services remain extremely limited (113, 114). Many patients are diagnosed once their disease is at an advanced stage requiring a palliative approach (115, 116). Persistent and severe shortage of health workers necessitate greater involvement from family caregivers who are referred to as 'guardians' in the local setting (117).

Palliative care services are provided to a relatively young population facing irreversible progressive illness during what should be their most economically productive years. Nationally coordinated efforts in Malawi have resulted in increased morphine usage (40) (a commonly used proxy for palliative care development), integration of training modules, and service delivery expansion in public sector hospitals (41). Despite these successes, centres of excellence for palliative care in Malawi remain heavily reliant on external donor funding, challenging their sustainability. The Tiyanjane palliative care team has provided palliative care for adults through hospital and community teams based in government facilities in Blantyre district in the Southern Region of Malawi since 2003. Blantyre is the second city of Malawi and is sometimes referred to as its commercial capital. Ndirande is a township area, four kilometres from Blantyre city centre with a population of around 250,000 people. Community-based palliative care services have operated from Ndirande Health Centre since 2005.

To explore concepts of wellbeing and the contribution of palliative care to wellbeing from the perspective of patients and families affected by advanced cancer we undertook a Photovoice study amongst households receiving services at Tiyanjane palliative care clinic in Ndirande.

#### 4.4 Methods

Informed and voluntary written consent was gained from all study participants. All households in which a patient was receiving palliative care from Tiyanjane clinic for a diagnosis of advanced cancer within the catchment of Ndirande health centre were considered eligible. At the start of the study this comprised sixteen households, all of whom were approached in advance of the study by the community palliative care nurse. The nurse provided the patient information sheet (Appendix 2) and discussed any questions about the study with eligible households. Co-researchers (i.e. patients and family caregivers) identified themselves through choosing to attend the first group meeting. The community palliative care nurse followed up non-attenders by phone to check they did not want to take part in the study. The research team comprised six patients and seven household members (self-identified as main un-paid family

caregivers) from eight households, seven field workers (home based care volunteers from the community), two field work coordinators (palliative care nurses), two qualitative researchers (one junior and one senior), one photographer and the research lead (a palliative care physician). All team members were Malawian except for the research lead who is a British family physician (JB) who has been instrumental in establishing palliative care services over the last fourteen years within the community where the study took place.

Reflexivity was required through the data collection and analysis process. The support of palliative care trained health workers was both beneficial and an ethical requirement to ensure the safety of co-researchers and rapid clinical review where indicated (e.g. to relieve severe pain). However, these health workers hold and may inadvertently reinforce certain 'culturally acceptable' assumptions about how people cope with advanced disease and understand wellbeing. As a foreigner and as a doctor providing palliative care the Principal Investigator exerted considerable power in the process with the possibility of introducing bias. Open criticism of (or to) people holding such positions of power is very unusual in Malawi. Co-researchers would be likely to report positively about the hospital and/or palliative care services, since future care may be perceived to be dependent on maintaining good long term relationships. The presence of health workers in the study team would make it difficult for coresearchers to positively report the practice of traditional medicine, which is widely used but negatively valued in the context of government health services. It was important during the analysis phase to maintain a critical awareness of implied (or directly) negative reports of service delivery (e.g. when patients reported pain). The Principal Investigator used regular team meetings and personal blog posts to facilitate reflexivity. A neutral venue (community hall) and third party qualitative researcher (CK) not directly involved in either palliative care (and with no formal health care background) were utilised to minimise bias.

The study was carried out in Ndirande township (four kilometres from Blantyre city centre) where the Tiyanjane community palliative care team is based at the non-fee-paying government health centre. Community sites away from the health centre were used for the group meetings and advocacy event. A two-stage consent process was

used for co-researchers: at the start of the study (for participation) and towards the end of the study (relating to disclosure and sharing of photographic material).

The Consolidated criteria for Reporting Qualitative Research checklist (COREQ) was used for reporting (118) (S3 file).

At the first group meeting co-researchers were informed about the study, then they were invited to ask any outstanding questions before being given the opportunity to consent to participate. They were given digital cameras and received basic training in their use. Over the period of one month (November 2016) they gathered images on the subject: 'the story of my illness'. Practical issues with the cameras were discussed and images selected during one to one sessions immediately before the start of each group session. Field notes were taken by the qualitative researchers (CK, TA) during these sessions. All co-researcher images were transferred to password protected files on the laptop used by the Principal Investigator and backed up securely on a password protected hard drive which was kept in a lockable cabinet. Selected images were printed into hard copies for use in participatory analysis (S4 file). Further details of the conduct of the study have been published separately (119).

Participatory analysis took place during seven (out of a total of nine) group sessions led by the two qualitative researchers: CK (junior qualitative researcher) who had previously conducted a number of focus group discussions (including one linked to a recent photovoice study in rural Malawi) and TA (senior qualitative researcher, MPH) who has many years of qualitative research experience in the health sector. Both were Malawian females, and fluent in Chichewa - the local language of co-researchers. In the first phase (during five group sessions) co-researchers sorted through hard copies of their selected images together, grouping them together into categories with a similar meaning or 'message'. After each grouping exercise these categories were further explored through a process of reflection and critical dialogue using locally adapted prompts based on the SHOWeD prompt described and used by Caroline Wang (108) in earlier Photovoice projects. During the process of dialogue co-researchers agreed on and named these categories. Towards the end of the first

month through reviewing images and reading and re-reading categories aloud as a co-researcher group, categories were brought together into named themes.

As a separate exercise (across two group sessions), co-researchers were invited to individually select photographs for which they composed a short-written piece, conveying what they wanted to tell others through that image ('captioning'). Wherever images were chosen which contained identifiable images of people not directly involved in the study, co-researchers were given consent forms in local language and asked to obtain consent. Where consent was not gained, photographs were excluded from further use. Twenty-seven captioned photographs were displayed in a photographic exhibition at an advocacy event which was staged by the research team at the end of the data collection period. Local health and community leaders and the media were invited to attend, and a speech was delivered by the local district health officer.

Group discussions were audio recorded then transcribed verbatim in local language (Chichewa) and translated into English. A proportion of translated scripts were subjected to quality control by a local third party with expertise in translation and transcription. Secondary deductive analysis was based on the themes and categories identified by the co-researchers, and is reported here, in an attempt to stay as close as possible to a community based participatory research approach. Deductive coding was conducted manually by the Principal Investigator (JB, partially fluent in local language). Analyst triangulation was undertaken by the senior qualitative researcher (TA, fluent in local language) coding all the transcripts and a further selection of transcripts was coded by a third (external) qualitative researcher (JA with experience using Photovoice in rural Malawi). This team met to discuss and reflect on their findings, allowing the opportunity to return to the data to clarify inconsistencies or differences in understanding between the three researchers. Provided that there was appropriate consent, images and quotations illustrative of the co-researchers' themes and categories were identified by the Principal Investigator for inclusion in this report.

Following secondary analysis, a final group meeting was held. Co-researchers reviewed all their selected images and revisited the categories and themes which they had identified. They were then asked whether they wanted to identify any new categories or themes.

## 4.5 Results

A summary of co-researcher demographics is shown in Table 2.

**Table 2 Summary of co-researcher demographics**

Variable	Values	Frequency
Age	<40	6
	>40	7
	Median	44.5
	Range	33-66
Sex	Male	6
	Female	7
Role	Patient	6
	Family caregiver	7
Diagnosis [cancer type in the household]	Cancer (Kaposi's Sarcoma)	5: all HIV +
	Cancer (other)	3 (brain, cervix, thyroid): one HIV +
Religious affiliation	Islam	1
	Christian (various)	10
	Other (Jehovah's Witness)	2

Length of time receiving palliative care	Months (median)	42 (range 9-120)
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Co-researchers generated five themes incorporating ten categories as shown in Table 3. Three themes relate to wellbeing, one to health messaging for cancer and the final theme to the contribution of palliative care.

**Table 3 Co-researcher themes and categories**

	Themes	Categories
1	Things that make us happy	1.1 What is a good day
		1.2 After being sick then being happy
		1.3 Working
2	Courage givers	2.1 Role of guardian
		2.2 prayers
		2.3 the cancer patient receiving medicine from the guardian
3	Discrimination	
4	Cancer as an illness	4.1 Cancer as a disease
		4.2 Patients with illness
5	The help you get from the hospital	5.1 Help from Tiyanjane
		5.2 Transport

Theme 1: Things that make us happy

The ability to work or perform daily chores (such as walking, cooking and cleaning) was considered important for what was 'a good day' (1.1):

“We should be able to walk like that granny when we have woken up better, walking so that the legs should be strong”. PT patient 34 years male (Figure 5)

*Figure 5 What is a good day*



“Here this lady is washing her clothes. She woke up strong this day that she could wash on her own”. MM family caregiver 36 years male. Seeing improvement in the patient brought happiness: 1.2 ‘after being sick then being happy’ (Figure 6).

1.3 ‘working’: “...even though some of us are sick from this disease we are working because of the medicine that we are receiving from Tiyanjane, they give us medicine but seeing that we are able to walk and we are working knowing that our family should be ok because of the medicine that we are given”. GM patient 62 years male (Figure 7)

*Figure 6 After being sick then being happy*

After being sick then being happy



Figure 7 Working

Working



## Theme 2: Courage givers:

Courage was provided from a variety of sources: children, older family caregivers (2.1 'role of the guardian'), neighbours, religious organisations (2.2 'prayers'). Health services worked together with community-based support (2.3 'the cancer patient

receiving medicine from the guardian’) though ‘health worker’ was not identified as a separate category within the theme

“The people who happen to encourage us on some other things for example maybe at home...being free with you by talking to you that you are not supposed to be worried this is not the end but the beginning ...those are the category of people assisting in your everyday life like the everyday food and activities.” PJ 37 year old female patient (Figure 8)

*Figure 8 The role of the guardian*



“I can see some carrying bibles...It’s not that your life has come to an end just because you have been diagnosed with cancer so those people comes and happen to give you courage with the words from the bible”. EK 49 year old female patient

Children were courage givers:

“I took this picture so that she should be eating the food, the children were coming around so that she should be eating”. EM 56 year old female family caregiver (Figure 9)

*Figure 9 Children as courage givers*



and health workers, “when you go there they encourage you and gives you enough courage that ...although I have been diagnosed with cancer it doesn’t mean that I will die today, no I will be alive as long as I follow what the Tiyanjane people are saying”. PJ 37 year old female patient .

### Theme 3: Discrimination

All agreed on this thematic area, although they commented that it was a difficult area to illustrate using photography. Co-researchers also used this theme for the advocacy event. Discrimination was described as being due to cancer patients being thought of as being infectious and/or ‘prematurely dead’.

“My wife left me when I first got sick of cancer, but my child is happy now” PT, 34-years male patient (Figure 10)

*Figure 10 Discrimination*

#### Discrimination



He also reported from his experiences:

“there are some neighbours who insult the cancer patient, for example I was carried on the back, from bus stage to (hospital) and to home. They could insult by spitting and saying that, ‘that one will die and in 3 weeks, there will be a funeral at that house, he should just die’. And some spit when they see me failing to walk, so (I) am asking that these neighbours should not speak these things.”

Another co-researcher added, “There are some people who said that if a person suffers from cancer (they) will automatically die...these rumours are coming from homes”. ET 60-years female family caregiver,

Discrimination could impact the amount of food a patient might be given:

“...if they are discriminating you on some other things...while they have eaten good food but giving you things that ‘just give him a little something to eat’ then the disease continues.” CB 66 years male patient

Theme 4: Cancer as an illness

Co-researchers highlighted the worries, shock and concerns caused to patients and families when they hear the news that they have a diagnosis of cancer (4.2 'patients with illness').

"The guardian is disappointed because the results from the hospital are saying (it) is cancer disease". JM 44 years male patient (Figure 11)

*Figure 11 Cancer as a disease*



Co-researchers expressed their concerns about cancer, including the lack of appropriate messages available in rural communities about the signs and symptoms of disease (4.1 'cancer as a disease'), resulting in delayed presentation to the hospital.

"I feel messages concerning cancer are not widespread...in the villages it is very difficult to reach out because some people have no radios. So if the country or the government can take part by using different ways to disseminate the message of cancer so (we) should know this problem earlier before it gets worse", JM 44 years male patient

Theme 5: The help that you get from the hospital

Palliative care services (Tiyanjane) were reported to provide counselling and medication which assisted patients to return to work (5.1 'help from Tiyanjane').

"I now work properly on my business and all my household chores after receiving medication from Tiyanjane". PJ 37 years female patient (Figure 12)

*Figure 12 Help from Tiyanjane*



Patients and family caregivers were supported to stay together and care for one another by reducing discrimination:

"The children also getting closer to the patient...not being far away because of the counsel from Tiyanjane. Here, without Tiyanjane, our guardians taking care (for us patients) would have been far from us". JM 44 years male patient

This was contrasted with the experience of using traditional healers

"the traditional doctor only knows how to make cuts on the body and to apply his medicine and this makes the wound get worse in the end...we say we have been

bewitched and we end up hating other people. The situation gets worse and you are not free in your family”. PJ 37 years female patient

Co-researchers highlighted delays in diagnosis and receiving care because of transport problems and (palliative care) services only being available at central hospitals rather than at health centres (5.2 ‘transport’).

“In my case I had to travel up and down for more than three weeks in order to be assisted. I did that because my guardian assisted”. JM 43 years male patient (Figure 13)

*Figure 13 Transport*



#### 4.6 Discussion

In this study, we used Photovoice - a participatory action research methodology - to explore household concepts of wellbeing and the contribution of palliative care towards wellbeing within the context of a well-established community based palliative care programme, enabling households to document, reflect on and report their everyday realities. Co-researchers (patients and family caregivers) played a central role in the analysis approach, to merge the rationale for use of Photovoice as a participatory (and thus empowering) tool with its use as a participatory research approach to ensure the presentation and interpretation of subjective viewpoints.

Three themes relating to wellbeing (things that make us happy, courage givers and discrimination), one on health messaging for cancer (cancer as an illness) and final theme relating to the contribution of palliative care (the help we get at the hospital) emerged from the process of participatory analysis.

Palliative care staff (physician, nurses and volunteers) well known to the co-researchers were included in the study team to monitor any changes in health status and to provide a point of contact in case of any difficulties between the dates of the group sessions. None of the co-researchers had used cameras or been involved research before. Long-term relationships between palliative care staff and co-researchers facilitated accountability and acceptability of the process, though is likely to have introduced some bias. For example, reports of care from the hospital were consistently positive, contrasting with reports of use of traditional healers (assumed to be widespread) which were consistently negative. Balancing safety, trust and study acceptability for co-researchers whilst eliminating bias was challenging. By using venues away from the health centre and qualitative researchers for individual and group discussions we tried to reduce this bias where possible.

Although this study relied on convenience sampling for recruitment, cancer type, co-researcher age, sex and educational levels were similar to those from more comprehensive cancer population reports in Malawi (120). Households were selected from a peri-urban setting rather than from rural settings where the majority of Malawi's population lives. Patients with advanced cancer had to be fit enough to use a camera and engage with group activities over a three-month period. The median age of co-researchers was 44 years (range 33-66); three older patients were excluded from the study due to their inability to use the cameras, thus views of older patients may not have been adequately represented.

Co-researchers' first theme 'things that make them happy' was described through the categories 1.1: 'what is a good day?' 1.2: 'after being sick then being happy' and 1.3: 'working'. Greater wellbeing occurs by seeing improvement in the patient and being able to take part in daily activities such as work, cooking, cleaning, farming and

religious meetings. These findings are similar to results from research done amongst healthy subjects in rural Malawi. Greco et al conducted fifteen focus group discussions amongst women's' groups to try to determine 'what is a good life?'. They found that wellbeing was understood beyond basic needs (food, shelter etc.) to include the importance of emotional wellbeing, social functioning and contribution (64). Wellbeing experienced through improved function may be related to the co-researchers' relatively young age (and lack of readiness to accept chronic ill health) and could also be explained by the reduction in self-perceived notions of being a burden, though this was not explicitly stated.

The role ('duty') of family caregivers (known in Malawi as 'guardians') as 'courage givers' was the second theme identified. Greater wellbeing occurs where courage givers are present and/or identified. Receiving a diagnosis of cancer was one of the events co-researchers reported to be associated with anxiety, in common with studies from other settings (121, 122). Anxiety has been linked to worse outcomes for patients with advanced cancer (123). Caregivers were reported to be responsible for practical tasks such as provision of adequate food, medicine (2.3 'the cancer patient receiving medicine from the guardian') and basic cleanliness of the patient, as well as reducing anxieties by providing company, distraction and 'chatting'. Prayers (category 2.2) delivered by religious groups were included in this theme. Prayers gave courage to co-researchers, though criticism was directed to community members who promoted prayers in place of medication, with a 'prayers plus medication' approach favoured.

A third theme of discrimination was discussed at some length by co-researchers and chosen as their theme for the advocacy event, although few photographs were taken to illustrate this. This demonstrates that Photovoice can prompt discussion around negative and/or sensitive issues, even when it may be difficult to use photography. Greater wellbeing occurs through the avoidance of (or protection from) such discrimination. Co-researchers reported fear of infection, being cursed and being considered as 'prematurely dead' as factors which contribute to this phenomenon. It was beyond the scope of this study to explore whether experiences of discrimination were subjective or objective though co-researchers suggested that discrimination

could contribute to delayed presentation of disease, particularly in rural areas where disease understanding was limited. It is also beyond the scope of this study to distinguish between whether the discrimination is due to their cancer or their HIV status, however other published work suggests that internalized stigma in Malawi maybe less than in other countries. HIV was not mentioned by participants during group discussions. Much of the description of stigma related to a sense of whether or not someone was seen [or perceived themselves] as 'useful' in the context of society, this was related to the impact of the illness on their functional state rather than to any specific diagnosis. Additional cultural and linguistic expertise may have been important to gain a deeper understanding what co-researchers were expressing through the use of this term. Discrimination was also reported to be the cause of being abandoned by a spouse and receiving less food. Discrimination through spousal abandonment is consistent with our recently published case series review of women receiving palliative care for cervical cancer at Tiyanjane, which notes relatively high rates of isolation (through divorce and separation as well as widowhood) at household level (124). An understanding of the principle of 'ubuntu' may provide deeper insight into perceptions of discrimination. Ubuntu is an African concept which defines meaning and purpose through the identity of the group rather than the individual (125). This collectivist (rather than individualist) mindset would support observations from practice which note that similarity within 'the group' is more highly valued than diversity in Malawi's socially conservative culture. This could explain, at least in part, how households affected by cancer or other chronic disease may perceive themselves as different and thereby discriminated against by the wider community. There is an urgent need for further studies to explore the perceptions, frequency, experiences and consequences of discrimination amongst patients with cancer in Malawi.

Under theme four 'cancer as an illness' co-researchers expressed their concern about lack of appropriate health messages about cancer. This was felt to particularly affect people in rural areas, where beliefs that the illness is a result of a curse could lead to seeking advice from witch-doctors which resulted in delays in presentation to health services. They identified a role for themselves in carrying cancer messages to their communities, something which they discussed again in the closing stages of the project when the group met to review their identified categories and themes. This

reflects the potential for 'enhanced community engagement in action and advocacy' discussed in Catalani and Minkler's review of Photovoice projects (90) and would be an important area for future work.

Palliative care was reported to contribute to household wellbeing under theme 5 'the help you get from the hospital'. Under category 5.1 'help from Tiyanjane', provision of medication for pain and symptom relief enabled patients and family caregivers to continue with or return to household roles which has been lost due to illness. There were links to theme 1 where seeing improvement in the patient through palliative care was highlighted under category 1.2 'after being sick then being happy'. The positive contribution of palliative care is reported in systematic reviews of the literature from high resource settings (126) though less has been described from low and middle income countries to date. This reflects the relative dearth of published research in palliative care from such settings (127) where locally validated quantitative outcome measures are still under development (128, 129). Co-researchers reported that palliative care services helped to reduce stigma and discrimination through counselling of patients and families and by modelling close contact in clinical settings and through visiting patients at home. Results from our study suggest that ability to return to income generating activities/activities of daily living (for both patient or caregiver) and stigma/discrimination scores should be included in palliative care outcome measures, particularly in settings where younger patients receive palliative care and where other disease modifying approaches (such as chemotherapy and radiotherapy) are unavailable.

#### 4.7 Conclusions

This study reports the first Photovoice study in an African setting amongst households affected by advanced cancer who are receiving palliative care. Wellbeing for households affected by advanced cancer in Blantyre Malawi includes seeing improvement enabling patients or family caregivers to return to household and community activities. Wellbeing was improved by 'courage givers' providing basic necessities (food, medicine and hygiene) as well as reducing anxieties relating to the illness. Discrimination negatively impacts wellbeing and may be implicated in late

presentation of disease. Palliative care contributes to household wellbeing through improving pain and symptom management enabling patients and /or family caregivers to return to household and income generating tasks. Counselling and close interaction with cancer patients provided by palliative care services helps to reduce fears and discrimination. To achieve the United Nations Sustainable Development Goal 3, greater understanding of experiences and impact of discrimination and timely access to community based palliative care services will be needed for households affected by cancer and other life-limiting non-communicable diseases.



## Chapter 5 Building the global support case for palliative care within Universal Health Coverage: the development of the Patient-and-Carer Cancer Cost (PaCCcT) survey in Malawi

### 5.1 Chapter Overview

Gathering primary data from affected populations is both costly and time consuming, and there are a lack of standardised tools to assess the potential for palliative care to support poverty reduction for relevant populations in LMIC. A standardized tool was required both to support this research and to save time and money for future research, facilitating inter and cross country comparisons and wider public policy discourse and reporting in this area.

This chapter describes the process of development of the PaCCcT survey. A literature review of approaches to gathering household cost data on chronic disease in LMIC was conducted. The WHO TB patient cost survey was selected for adaptation. A zero draft PaCCcT survey was developed with reference to cost areas identified within the transcripts of group discussions during the Photovoice study. This draft was reviewed by experienced Malawian palliative care and oncology nurses who endorsed the cultural acceptability of a brief 'funeral cost' section within the PaCCcT survey. Once compiled, the draft one version of the PaCCcT survey was presented for discussion at a national key stakeholder consensus meeting attended by policy makers, academics and senior clinicians. The tool was piloted at the start of the prospective cohort study which is reported in chapters 6 (protocol) and 7 (results). Further work is needed to adapt and simplify this tool to support its more widespread use both in settings of cancer and for other life limiting illnesses.

Chapter 5 was published in BMJ Supportive and Palliative care in September 2019. The publication can be found at the link below and in Appendix 1.

<https://spcare.bmj.com/content/early/2019/10/24/bmjspcare-2019-001945>

I conducted the literature review, planned and led facilitation of stakeholder meetings, and prepared the original, revised and final manuscript.

## 5.2 Abstract

### Objective

Evidence of the role of palliative care to reduce financial hardship and to support wellbeing in low- and 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 health care 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 TB patient cost survey was chosen for adaptation. Face and content validity of a zero-draft of the PaCCCt survey were developed through review by health care 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 health care service utilisation and related direct and indirect costs. Coping strategies (loans and dissaving etc.), funeral costs and wellbeing at household level are included. Completion time is less than 30 minutes.

### 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.

### 5.3 Introduction

Out of pocket expenditure (OOPE) accounts for 23% of global health expenditure and 45% of health expenditure in LMIC (54). Even where the majority of health services are delivered free of charge, it is households that bear the brunt of financing health care 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 currently limited (130).

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 World Health Organization. Palliative care is under consideration as a 'best buy' under UHC (131). Despite this and increasing awareness of the role of palliative care in reducing serious 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 \$3 per capita (132).

A systematic review of the cost-effectiveness of palliative care in LMIC pointed towards favourable outcomes, whilst highlighting the paucity of current data (ten studies were identified) and lack of standardised definition of terms, data collection and reporting (32). A review evaluating approaches for collecting household level costs for palliative care patients also failed to identify literature from LMIC (133). 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 ('PaCCCT') survey. This survey is

currently being used to undertake a study to explore the impact of palliative care on household poverty in Blantyre, Malawi.

## 5.4 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 data, 2017). Ten percent 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 (17) 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 twenty years (41).

### *Development of survey content*

#### 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 (7 patients and 6 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 sub-themes were identified. Data on areas of out of pocket expenditure relevant to healthcare were extracted from audio recordings.

#### 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. 137 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 the Jan et al landmark review on poverty and NCDs,(134) were added. Methodological approaches are summarised (with examples) in Table 4. Two other papers not otherwise identified but known 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 (135) and has since been reviewed and adapted by multi-country stakeholder groups across LMIC settings to assess OOPE and coping strategies (e.g. loans and dissaving) with flexibility to adapt to the local context (53). Data from its use contributed to formulation of the third goal of the End TB strategy to eliminate catastrophic costs for patients and households affected by TB (136).

### 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 firstly 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 including over 40 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 minutes to under 30 minutes. Family caregivers (identified by the patients and consented separately) were able to complete the remainder of the survey in under an hour.

## 5.5 Results

*Overview of the PaCCCt survey (Appendix 4 : PaCCCt survey development :4.1)*

### Section on household costs

This comprises details of the patient's history of health care utilisation and related costs. Health care usage categories reflect those available in the local health care setting. In Malawi this includes traditional healers and local pharmacies as well as hospitals and health centres. Direct (e.g. medicine, investigations) and indirect (i.e. 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 recording the costs of planned and unplanned care visits separately.

### Section on Wellbeing

This comprises three components. The first is the EQ-5D-3L (validated Chichewa version (137)) (used in a paper-based format with permission from Euro-QoL, Appendix 5.1). The second is the Integrated Palliative Care Outcome Score (IPOS,

developed by Kings College London available from <http://pos-pal.org>, Appendix 5.2). 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). 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 two weeks following death.

### 5.6 Conclusion and next steps in the use of the PaCCcT survey

In this paper we describe the development of the Patient and Carer Cancer Cost Survey (PaCCcT survey) that is being used to gather prospective data on health care use, household OOPE and wellbeing amongst 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.

**Table 4 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, <a href="#">2015</a>							✓	
Gardiner, UK, <a href="#">2017</a>				✓				
Ratcliff, India, <a href="#">2017</a>		✓						
ACTION study <a href="#">group</a> , SE Asia, <a href="#">2015</a>					✓			
Israels, Malawi, <a href="#">2008</a>	✓							
Bhojani, India, <a href="#">2012</a>			✓					
Chuma, Kenya, <a href="#">2007</a>				✓				
Emanuel, India, <a href="#">2010</a>		✓						
Hamid, Bangladesh, <a href="#">2014</a>						✓		
Kavosi, Iran, <a href="#">2014</a>								✓
Zaidi, Pakistan, <a href="#">2012</a>			✓					
Chen, China <a href="#">2018</a>		✓						
Hailu, Ethiopia, <a href="#">2013</a>			✓					
Bennett, New Zealand <a href="#">2009</a>		✓						
Arrossi, Argentina, <a href="#">2007</a>		✓						



## Chapter 6: Study protocol for a single-centre observational study of household wellbeing and poverty status following a diagnosis of advanced cancer in Blantyre, Malawi

### 6.1 Chapter overview

Household costs of healthcare and related coping strategies (loans and sale of assets, collectively referred to as dissaving) can impact household vulnerability long after an illness episode and/or following the death of the patient. This is described in the 'poverty trap' in which households enter a downward spiral of impaired health and wellbeing. Palliative care aims to improve quality of life and reduce the serious health-related suffering of patients and families affected by chronic and life limiting illnesses. It is recognised to be integral to the continuum of care for both communicable and non-communicable diseases, relevant before, and beyond, the end of life. Research from high income settings reports that palliative care improves quality of life and delivers cost savings at health system level, with potential to mitigate the effects of the poverty trap.

In LMIC, palliative care may reduce household income poverty firstly through providing assessment and measures to control pain (and other symptoms) to permit resumption of activities, including work, for patients and/or carers. The provision of timely and patient-centred information regarding diagnosis and prognosis supports the reduction of costs on non-beneficial care.

This chapter provides the protocol for the prospective observational cohort study of health-related expenditure and health-related quality of life outcomes for households affected by advanced cancer.

This was published in Wellcome Open Research in March 2020. The publication can be found at the link below and in Appendix 1.

<https://wellcomeopenresearch.org/articles/5-2/v2>

I led study conceptualization, and was responsible for the original, revised and final manuscript preparation.

## 6.2 Abstract

**Background:** Many households in low-and-middle-income countries face the additional burden of crippling out-of-pocket expenditure when faced with a diagnosis of life-limiting illness. Available evidence suggests that receipt of palliative care supports cost-savings for cancer-affected households. This study will explore the relationship between receipt of palliative care, total household out-of-pocket expenditure on health and wellbeing following a first-time diagnosis of advanced cancer at Queen Elizabeth Central Hospital in Blantyre, Malawi.

**Protocol:** Patients and their primary family caregivers will be recruited at the time of cancer diagnosis. Data on healthcare utilisation, related costs, coping strategies and wellbeing will be gathered using new and existing questionnaires (the Patient-and-Carer Cancer Cost Survey, EQ-5D-3L and the Integrated Palliative Care Outcome Score). Surveys will be repeated at one, three and six months after diagnosis. In the event of the patient's death, a brief five-item questionnaire on funeral costs will be administered to caregivers not less than two weeks following the date of death. Descriptive and Poisson regression analyses will assess the relationship between exposure to palliative care and total household expenditure from baseline to six months. A sample size of 138 households has been calculated in order to detect a medium effect (as determined by Cohen's  $f^2=0.15$ ) of receipt of palliative care in a regression model for change in total household out-of-pocket expenditure as a proportion of annual household income.

**Ethics and dissemination:** The study has received ethical approval. Results will be reported using STROBE guidelines and disseminated through scientific meetings, open access publications and a national stakeholder meeting.

**Conclusions:** This study will provide data on expenditure for healthcare by households affected by cancer in Malawi. We also explore whether receipt of palliative care is associated with a reduction in out-of-pocket expenditure at household level.

### 6.3 Introduction

The impact of a diagnosis of cancer on households in low and middle-income countries (LMIC) is dramatic. A study of over 9000 cancer patients in South East Asia reported that 75% of patients had either died or faced financial catastrophe twelve months from diagnosis (138). In African settings, cancer is associated with high mortality, as well as catastrophic financial, psychological and spiritual morbidity (107, 139). Many households experience cancer diagnoses when they would expect to be at their most economically productive (42). For the few patients who are able to access potentially curative cancer therapy, default rates are high (140, 141).

The Lancet Commission on Palliative Care and Pain Relief states that *'access to palliative care and pain relief is a health equity and human rights imperative which has been largely ignored in the goal to achieve Universal Health Coverage (UHC)'*(20). Palliative care is an approach which improves quality of life of patients and families affected by life-limiting illnesses (13). Provision of palliative care should not be limited to those thought to be in 'terminal' or 'end of life' situations; these terms lack clear definition and risk a 'missed opportunity to do better for patients' (142). Cost savings have been associated with a variety of models of delivery of palliative care, though the majority of data are reported from high income settings, and from a health systems rather than patient perspective (32, 143).

Out-of-pocket expenditure (OOPE) accounts for 23% of global health expenditure and 45% of health expenditure in the developing world (54). In Malawi – where the Essential Health Package (EHP) is provided at no cost to users at the point of care – OOPE remains a significant burden on rural households, accounting for an estimated 13-22% of health expenditure (38). Interventions aimed at reducing the burden of non-communicable diseases can play a key role in global development, facilitating progress towards the Sustainable Development Goals including – and beyond – health (47, 134).

In this study we will explore the association between receipt of palliative care and total household expenditure on health (as a proportion of total household income), and wellbeing for those affected by a first-time clinical diagnosis of Kaposi's sarcoma, cervical or oesophageal cancer or hepatocellular carcinoma at Queen Elizabeth Central Hospital in Blantyre, Malawi. We hypothesised that, as a result of pain and symptom management and provision of information about their condition, patients receiving palliative care will maintain or improve their wellbeing whilst requiring fewer repeat visits to health providers. In this way, receipt of palliative care will be associated with a reduction in total household expenditure on health over time, whilst patient (and carer) wellbeing is maintained or improved.

## 6.4 Protocol

### *Details of ethical issues and ethical approval received*

This study has undergone ethical review by, and received approval from, the College of Medicine Research Ethics Committee in Blantyre, Malawi (P.05/18/2395) and the Liverpool School of Tropical Medicine Research Ethics Committee (18/046). All participants (patients and household carers) will be invited to give written informed consent to take part in the study. All electronic and paper-based data will be anonymised.

### *Setting*

Malawi is a low-income country in Central Southern Africa. Health services are provided free at the point of care through a network of community and hospital-based services supported by government and faith-based funding across 28 districts (39). There are four publicly funded tertiary referral ('central') hospitals situated in the cities of Zomba, Lilongwe, Blantyre and Mzuzu. Queen Elizabeth Central Hospital (QECH) in Blantyre is the largest central hospital in the country offering specialist services for gynaecological oncology, oncology, endoscopy and palliative care. Oncology services are at an early stage of development with limited specialist capacity and no radiotherapy available in-country (114). Palliative care services have been established for adults and children for over fifteen years, and are delivered through

in-patient referral, out-patient clinics, and community based care (41, 144). Recruitment for this study will take place from in-patient wards and out-patient clinics (oncology, endoscopy, gynaecological oncology and palliative care) at QECH. Patients with hepatocellular carcinoma will be identified through enhanced case finding via an ongoing study on hepatitis B taking place at the same institution.

#### *Participant identification, recruitment and follow-up*

Patients with a first-time clinical diagnosis of advanced Kaposi's Sarcoma (KS), or cervical or oesophageal cancer will be approached at the site of specialist clinical service (oncology, gynaecological oncology, palliative care) at Queen Elizabeth Central Hospital (QECH). Patients with hepatocellular carcinoma (HCC) will be approached via referral from the study team. Eligibility screening of all patients will be undertaken by the Principal Investigator, following which patients will be provided with a study information sheet and invited to provide written consent. Once a patient has given consent, they will be invited to identify up to four household carers who may be approached to take part in the study. Any (or all) of these carers will be approached as soon as possible after patient recruitment, screened for eligibility, and provided with information before being invited to provide written consent. Eligibility screening, consent and baseline data collection will take place at the hospital, with subsequent data collection taking place either at hospital or at the preferred place of the participants, either home, hospital or local health centre.

In the event of patient death, a household member (either the carer already consented, or an alternative person identified by the previously consented carer) will be invited to consent to complete a brief five-item questionnaire on funeral costs. This data will be gathered no less than two weeks following the death of the patient.

#### *Inclusion: cancer types and diagnostic criteria*

Three cancer types (KS, cervical, oesophageal) have been selected because they have the highest incidence in the local setting (120, 145) and because they are amenable to clinical diagnosis under routine care at specialist clinics at QECH.

Hepatocellular carcinoma is another common malignancy (146), which is currently under surveillance on the medical wards at QECH as part of an ongoing study on hepatitis B in Malawi. Recruitment will rely on clinical diagnosis under the supervision of specialist clinicians, as standard of care for diagnosis in the local setting (Table 5) for criteria used for diagnosis of ‘advanced’ cancer, according to disease type). Histological confirmation is not mandatory, waiting for biopsy result would result in significant delays (147). Cancer staging will be recorded where available.

**Table 5 Diagnostic criteria for advanced cancer**

Cancer type	Diagnostic criteria for advanced disease
Kaposi’s sarcoma:	ALL patients with a first-time diagnosis on clinical examination by specialist doctor AND assessed as AIDS Clinical Trials Group (ACTG) ‘poor risk’ category OR ALL with a first-time diagnosis of KS where staging not done
Cervical cancer:	ALL patients with a first-time diagnosis on clinical examination by specialist doctor AND with disease at International Federation of Gynaecology and Obstetrics (FIGO) stage 2 and above OR ALL with a first-time diagnosis (where staging not done)
Oesophageal cancer:	ALL patients with a first-time diagnosis on endoscopy by specialist doctor AND assessed as being inoperable, OR ALL with a first-time diagnosis (where no management plan/staging stated)

Hepatocellular carcinoma	<p>ALL patients identified with a liver mass followed by confirmatory ultrasound with mass &gt;2cm performed by a specialist doctor</p> <p>AND</p> <p>evidence of local mass effect.</p>
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### *Study tools*

Prior to this study, preliminary work was undertaken to explore household concepts of wellbeing and cost areas of importance to patients following a diagnosis of advanced cancer (21). Following this, we adapted the WHO TB patient cost survey for a cancer population as the Patient-and-Carer Cancer Cost (PaCCcT) survey, details of this process and resulting survey content have been reported elsewhere (148). A locally validated Chichewa language translation of the EQ-5D-3L (paper based) and the Integrated Palliative Care Outcome Scale (IPOS <http://pos-pal.org>, tablet based) will be used to record changes in wellbeing over time. All newly developed content in the surveys have been translated into Chichewa and piloted amongst patients and carers receiving palliative care for advanced cancer(148). Multiple reviews of these questions were conducted with experienced fieldworkers during transition from paper-based to tablet-based format. New questions have also been back translated for quality control by the Malawi-Liverpool-Wellcome Trust Clinical Research Programme (MLW) Translation Unit to ensure consistency of questioning during data collection.

The PaCCcT survey records details of healthcare utilisation from time of onset of symptoms (at the baseline visit conducted at the time of diagnosis) or since the last visit (for follow up visits). Households are asked to provide details of frequency of visits, type of provider, and length of visit (including transportation to and from provider) as details necessary for calculation of all direct and indirect household expenditure on health. Visits to conventional (hospital and health centre) and non-conventional (traditional healers, drugstores) healthcare providers will be recorded. At subsequent follow-up study visits, details of emergency (unplanned) and routine (planned) visits will be recorded separately. Coping strategies (including loans and dissaving) and sources of funding for healthcare utilisation are also recorded. Household income will be captured by self-report and via use of an asset score based

on a locally developed proxy means test for poverty. The Malawi Urban Proxy Means Test for Poverty was originally developed by Payongayong (Payongayong E, Benson T, Ahmed A, et al. (2006) Simple Household Poverty Assessment Models for Malawi: Proxy Means Test from the 1997–98 Malawi Integrated Household Survey). Lilongwe, Malawi: National Statistical Office of the Government of Malawi). The parameters for this test have recently been updated by one of us (PM) using data from the 2016-2017 Integrated Household Survey.

#### *Primary outcome*

Change in total household OOPE on health, as a proportion of annual household income (based on income before the onset of illness) from diagnosis to six months.

#### *Secondary outcomes*

Change in index health status and/or frequencies by level within dimensions within the EQ-5D-3L and/or visual analogue scores from time of diagnosis to six months.

Changes in symptom burden and/or self-reported experience of physical/psychological/spiritual symptom burden using Integrated Palliative Care Outcome Scale.

Study results will be reported using the STROBE guidelines.

Receipt of palliative care will be presented as both categorical (yes [any] / no [none]) variables, or as interval data (based on the number of contacts with palliative care services from baseline to six months).

Poverty status will be derived from two approaches, firstly self-reported household income before the onset of symptoms and secondly from a proxy means test for poverty (derived from Malawi Demographic Health Survey 2006-7) based on household assets. Household poverty status will be presented as tertiles – least poor, poor and non-poor.

Mean (and confidence intervals) and median (and inter-quartile ranges) values will be used to describe the characteristics of the study cohort for continuous variables. Categorical variables will be summarised by frequency tables and bar charts.

The effect of receipt of palliative care on household expenditure will be estimated using a multiple linear regression model, adjusted for expenditure at diagnosis and other potential confounding variables (age, sex, rural/urban dwelling).

Poisson regression will be used to assess the relationship between the number of palliative care visits and change in total household expenditure on health (as a proportion of total household income) from the time of diagnosis to six months.

The unadjusted hazard of death will be estimated using the Kaplan-Meier survival estimator. Survival will be disaggregated by poverty status, sex, number of palliative care visits and cancer type. Cox proportional hazard models will investigate risk factors for death by calculating hazard ratios and 95% confidence intervals. The validity of the proportional hazards assumption for the Cox models will be tested. Log rank tests will be used to test for difference in survival curves between different groups.

#### *Sample size*

The sample size calculation for this study was powered to detect a medium effect (as determined by Cohen's  $f^2=0.15$ ) of a predictor in a multiple linear regression model for change in total household OOPE as a proportion of annual household income. All power analyses are based on alpha = 0.05; power=0.8, using two sided tests.

Comparing single variables (e.g. response variable = change in total household OOPE as a proportion of annual household income, predictor = receipt of palliative care) a sample size of 55 households is required to detect a medium effect. Considering 50% exclusions and 20% dropout a sample size of 138 households is required ( $n= 55 / ((1-0.5)*(1-0.2)) = 138$ ).

Following review of local data from relevant clinics at QECH, an estimated 225 patients are available for recruitment over a six-month period.

#### *Loss to follow-up (LTFU)*

Loss to follow-up may be high in this study population, who have a diagnosis of advanced cancer with a high risk of mortality over the six-month study period. At the time of recruitment participants will be asked to provide details of directions to reach

their household and asked their preferred place for follow-up visits. If they are absent from home on the first home visit, a further two visits will be attempted by the research team before declaring the household lost to follow-up. Phone contact will be tried a maximum of three times before a participant household will be considered lost to follow-up.

Participant households will be given 500MK (\$0.75) mobile airtime at each visit to use in the event of any change of address or patient status during the study. In addition, the study team will call patients and their carers between scheduled visits to check on status and current place of residence. In accordance with local guidelines for compensation of research participants, transport costs for all follow-up visits at the hospital will be reimbursed and participants will be given sugar, tea (at each visit) and local currency equivalent of \$10 per completed visit (at study completion) (149, 150).

#### *Plans for dissemination of outcome and associated data once completed*

Feedback to the local academic and clinical community will be given through participation at local research and clinical meetings. A report of the study will be submitted to the local ethical committee who provided ethical permission and communicated to the broader research community via academic presentations (poster and oral) and publications. A follow-up meeting will be convened with the national policy making forum engaged at the start of the study.

Data will be shared within the research community through an open access repository once peer reviewed publication is complete.

#### *Clinical care*

It is anticipated that due to the underlying diagnosis of advanced cancer, the health status of many patients recruited will deteriorate during the study, and several will die as a result of their cancer illness. The role of the study team is not to provide clinical care; however, participants will be advised to use local health services (health centre, district or central facilities) whenever they are found to be unwell and/or with extreme/unrelieved symptoms at the time of a study visit. Responsibility for their care

(including any treatment, referrals or admission) will remain with locally available health facilities to preserve the integrity of the study.

#### *Distress protocol*

A distress protocol will be developed for study staff to alert the principal investigator (or nominated deputy) in the event of extreme distress in participants (Appendix 5.3).

#### *Recognition and management of risk to study staff*

Following initial training, weekly meetings will be held with study staff to check on their work-related wellbeing. The principal investigator will be available by phone to assist study staff whilst they are in the field should they experience any difficulties in the course of their duties. Training delivered by palliative care team members who are experienced in providing bereavement support in local communities will prepare study staff to handle issues around death and dying and how to administer the funeral cost section of the PaCCCT survey.

#### *Study limitations*

This is a single centre study recruiting patients and their carers from urban and peri-urban settings in Blantyre, Malawi. Patients with four cancer types will be recruited. Study outcomes may have limited generalisability to rural settings and other cancer types. Other common life-limiting illnesses (such as stroke and chronic lung disease) would need separate study due to illness variability in terms of progression, treatment options and outcomes. Generalisability to more well-resourced health settings is also limited, as cancer treatment protocols vary based on availability of resources, e.g. if radiotherapy was available in Malawi, OOPE would potentially increase due to the requirement for multiple hospital visits, though other outcome benefits may also be anticipated.

In common with many studies reporting OOPE (151), much of the data relies on accurate self-reporting of information about healthcare utilisation, household income and costs. Patients and carers may for various reasons under or over report these

data. Use of trained research field staff and regular meetings with the team during data collection will attempt to optimise the quality of data.

The sample size is likely to be underpowered as a result of using Cohen's  $f^2$ . Exposure to palliative care will be based on routine practice and may be insufficient to infer association. It maybe that those choosing not to participate in the study will introduce selection bias in the sample.

#### *Current study status*

Recruitment began in January 2019 and baseline data were collected from 152 households by the end of July 2019. Follow-up is ongoing, due to be completed at the end of January 2020.

## 6.5 Conclusions

Cancer prevalence and mortality are increasing in many LMIC, including those in the African region. There are currently limited data on healthcare utilisation and related OOPE following a diagnosis of cancer in Malawi, where people are typically diagnosed during an economically productive stage of life with disease already at an advanced stage. During a serious illness and following death, the impact of excessive spending on health continues to be experienced by households, disproportionately so by those already adversely affected by poverty.

This study will investigate household wellbeing and poverty status in patients receiving a first-time clinical diagnosis for advanced cancer, to explore whether there is evidence that receipt of palliative care can support a reduction in total household expenditure on health whilst maintaining (or improving) wellbeing in households affected by advanced cancer.



## Chapter 7: Palliative care and catastrophic costs in Malawi following a diagnosis of advanced cancer - a prospective cohort study

### 7.1 Chapter overview

This chapter reports a prospective cohort study which recruited households (patient and unpaid family caregiver) at the time of diagnosis of advanced cancer. Four common cancer diagnoses (KS, oesophageal, cervix and liver) were included. Details of costs (direct, indirect, dissaving) and health related quality of life (HRQoL) of patients and carers were reported using the PaCCCT survey (chapter 5) at baseline and then at one, three and six months after diagnosis (or until death occurred, if this was prior to study completion). Due to the lack of locally validated tools to measure wellbeing in this population, a local language version of the EuroQoL EQ5D-3L was employed. HRQoL for patients and unpaid family caregivers in the household were reported by receipt of palliative care and over time. Descriptive reporting of costs on cancer -related healthcare utilisation was accompanied by calculation of risk ratios of catastrophic expenditure and dissaving by receipt (or not) of palliative care. Multiple linear regression models were used to explore the relationship between receipt (or not) of palliative care and total household costs of healthcare as a proportion of household income.

Chapter 7 reports the results of the prospective observational cohort study and has been accepted for publication. I led the study conceptualization, project administration (including data collection, data interpretation, formal analysis), original and revised draft preparation. Supplementary tables and further information are included in Appendix 6. Other support was provided as follows: Miriam Gordon – regression analysis, Marc Henrion - sample size calculations and checking data tables, Ewan Tomeny -review of STATA do files. Stephen B Gordon - funding acquisition. Claire Morris, Eve Namisango, Leo Masamba, Helena Davies and Gerald Manthalu – manuscript review. Peter MacPherson advised on methods, provided the Proxy Means Test for Poverty questions, and developed graphic presentation of HRQoL results in appendix 6.5. Louis W Niessen and S Bertel Squire provided senior advice on conceptualization, and review and editing of original and revised drafts.

## 7.2 Abstract

### Background

Inclusive Universal Health Coverage requires access to quality health care without financial barriers. Receipt of palliative care after advanced cancer diagnosis may reduce household poverty, but evidence from low- and middle-income settings is sparse. The objective of this study was to investigate total household costs on cancer related healthcare following a diagnosis of advanced cancer, with and without the receipt of palliative care.

### Methods

Households comprising patients and their unpaid family caregiver were recruited into a cohort study at Queen Elizabeth Central Hospital in Malawi, between January and July 2019. Costs of cancer-related healthcare utilisation (including palliative care) and health-related quality-of-life were recorded over six months. Regression analysis explored associations between receipt of palliative care and total household costs on health care as a proportion of household income. Catastrophic costs, defined as >20% of total household income, dissaving and the association with palliative care were computed.

### Findings

In all, 150 households were recruited. At 6 months, data from 89/150 households were available, comprising 89 patients (median age 50 years, 79% female) and 64 caregivers (median age 40 years, 73% female). Patients in 55/150 households had died and 6/150 were lost to follow-up. 19/89 (21%) households received palliative care. Catastrophic costs were experienced by 47% (9/19) of households who received palliative care vs 69% households (48/70) who did not (RR: 0.69, 95% CI 0.42, 1.14,  $p=0.109$ ). Palliative care was associated with substantially reduced dissaving (median US2019\$11 (IQR \$0-30) vs USD\$34 (IQR \$14-75)  $p=0.005$ ). Mean difference in total household costs on cancer-related health care with receipt of palliative care was -36% (95% CI -94%, 594%,  $p=0.707$ ).

### Interpretation

Vulnerable households are subject to catastrophic health-related costs following a diagnosis of advanced cancer. Palliative care may result in reduced dissaving in these households. Further consideration of the economic benefits of palliative care is justified.

### 7.3 Introduction

Globally, 18 million new cases of cancer were recorded in 2018 and 9.5 million people with cancer died (17). By 2030, a 70% increase in annual cancer cases and deaths are predicted in Africa (18). Cancer diagnosis has profound consequences for households in low- and middle-income countries. A recent study of over 9,000 cancer patients in Southeast Asia reported that 75% of patients had either died or faced financial catastrophe 12 months from diagnosis (152). Studies from some comparative settings in Uganda and South Africa report high mortality, catastrophic social and financial consequences, as well as accompanying psychological (anxiety) and spiritual (transcendent) morbidity (106). For the few who access potentially curative therapy, loss to follow-up rates reported in Malawi are high (140).

Palliative care is part of the continuum of care needed to tackle the heavy burden of serious health-related suffering experienced by patients with chronic non-communicable diseases (NCDs), although it is widely unavailable and has not yet been the subject of extensive research in low-income settings in countries in Africa (20, 92). Positive health and economic benefits of palliative care have been reported in systematic reviews, although there are inherent challenges in estimating cost-effectiveness in populations with life-limiting illness (32, 75). Much of the current literature is from high-income settings and describes the impact of palliative care on cost savings at health system level. Current approaches have largely failed to capture relevant data from low and middle-income countries, where cost savings at household level are critically important for patients and families, and to inform policymakers (30, 153).

A study in South Africa reported that palliative care reduced repeat admissions to hospital (154). Patients and families affected by advanced cancer in Malawi valued palliative care for pain and symptom control, facilitating re-integration into society, enabling patients to return to household livelihood activities and/or paid work benefitting wellbeing (21). Timely and compassionate advice for families may reduce or stop the urge for 'doctor shopping' for a cure (155). Hitherto, there are no data from countries in Africa reporting household level costs of health care in settings of

advanced cancer, and the potential for palliative care to prevent or reduce financial catastrophe.

Using a societal perspective, the objective of this study was to investigate whether, among households in Malawi following a diagnosis of advanced cancer, total household costs on healthcare are associated with receipt of palliative care.

## 7.4 Methods

### *Study Design*

We undertook a prospective observational study among households in which a patient had received a new diagnosis of advanced cancer at Queen Elizabeth Central Hospital, Blantyre, Malawi between January and July 2019 . Given the relatively limited survival times anticipated for patients affected by advanced cancer, data were gathered on health care costs related to cancer illness as well as health related quality of life (HRQoL) between diagnosis and six months following diagnosis.

### *Study site and population*

Queen Elizabeth Central Hospital is one of four tertiary referral teaching hospitals in Malawi. Palliative care services at the hospital fulfil criteria for African Palliative Care Association Level 3 i.e. specialist services, including availability of morphine at site and in the home, and degree-level training represented in the team (156). At the time of the study, adult palliative care services comprised two clinicians (one doctor and one clinical officer), four nurses, a part time chaplain / driver and a cleaner. New patients are assessed using a form to identify physical, psychological, social and spiritual needs and concerns of patients and caregivers. Out-patient and home visiting services take place. Referrals to palliative care are made at the discretion of attending clinicians from wards and out-patient clinics. Common reasons for referral include pain and symptom relief, counselling of patients and families on disease understanding, and social needs including nutritional support. Palliative care services

are delivered concurrently with other specialist services; palliative care can be started (or stopped) at any stage of the patient's illness journey as appropriate to their needs.

Basic costs of health services at the hospital, including oncology and palliative care are met by government funding through the Ministry of Health. Following registration at minimal cost, services are provided free of charge to the patient. Supplementary donor funding for palliative care supports some salaries of health workers, medications, nutritional support, and transportation for home visits.

#### *Participant eligibility, recruitment and follow-up*

Participant households (patient-carer dyads) were recruited sequentially from specialist clinics at the hospital when a patient was identified with a new diagnosis of advanced cancer (any one of Kaposi's sarcoma, cervical cancer, oesophageal cancer, or hepatocellular carcinoma (Table 5). Patients 18 years of age or older, living less than 50km from the hospital, with stable co-morbidities (temperature  $<37.4^{\circ}\text{C}$ , BP  $\leq 140/90\text{mmHg}$ , World Health Organization performance score  $\leq 2$ ) and an estimated prognosis of at least three months as determined by an experienced palliative care clinician, were invited to take part in the study. Following study enrolment on a voluntary basis, patients were asked to identify an unpaid family caregiver from the same household. Healthcare utilisation and related household costs including sale of assets and loans taken out (dissaving) were recorded. Health-related quality of life (HRQoL) was recorded using the Chichewa version of the EuroQoL EQ-5D-3L tool (137, 157). All costs for health care for cancer-related illness were collated between diagnosis and six months after diagnosis using the Patient and Carer Cancer Cost Survey (148). Repeat visits at one and three months were made at a site of preference chosen by the respondent (home, nearby health centre or hospital). Frequency of visits was designed to reduce recall time to improve the accuracy of self-reported costs(151). If a follow-up appointment was missed, patients were asked in the subsequent interviews about all costs and dissaving since their last attended appointment. We recorded receipt of palliative care as a binary exposure (yes/no) by household self-report and verified by manual checking of clinic records and hospital data management reports.

Households were defined as rural if they were located outside Blantyre urban administrative boundaries. Self-reported poverty levels were assessed based on World Bank definitions (158). In addition, households reported asset ownership and were divided into poverty tertiles derived from scores calculated from a locally developed proxy means test for poverty (Appendix 5.4). Tertiles were used due to the relatively small sample size.

#### *Study sample size and statistical methods*

Comparing single variables (response variable = total household costs on health care from diagnosis to six months as a proportion of household income, predictor = receipt of palliative care) a sample size of 55 households was required to detect a medium effect size at six months (as determined by Cohen's  $f^2=0.15$ ). All power analyses were based on  $\alpha = 0.05$ ; power=0.8, using two sided tests. Accounting for an estimated 50% exclusions and 20% dropout, the cohort needed a sample size of 138 households. The study sample was in part based on feasibility, with an estimated 225 patients available for recruitment over a six-month period.

#### *Statistical methods*

Analysis was completed using StataCorp version 15, R version 4.1.0 (<https://www.R-project.org/>) and Microsoft Excel (Windows 10). STROBE and CHEERS guidelines were used for reporting (159).

Only households reporting data on the primary outcome (total household costs on health care from diagnosis to six months after diagnosis [ $n=89$ ]) were included in the descriptive analysis. Continuous variables were summarised as means (with 95% confidence intervals [95% CI]) and medians (with inter-quartile ranges [IQR]) if data were skewed. Frequency tables and percentages were used for categorical variables. Wilcoxon rank sum test and Spearman correlation were used for comparisons. Fisher's exact test and relative risk calculations were used to explore catastrophic

costs on health care, comparing households receiving palliative care with those which did not.

We formulated multiple linear regression models to investigate associations between palliative care receipt and total household costs on health over the six months following diagnosis, expressed as a proportion of household income. We derived annual household income from monthly household income before the onset of symptoms. Total household costs included all direct medical and non-medical out-of-pocket expenditure, as well as indirect costs through lost productivity time for both patients and carers. Models were constructed based on previous literature, and controlled for socio-economic status, health seeking behaviour, health status of patient at diagnosis and cancer type (Appendix 5.5).

Dissaving was defined as the sale of assets e.g. bicycles or land, or the acquisition of loans. Dissaving is regarded as a coping strategy to access health services in low-income settings (57). It may be more accurately recalled by household members than precise retrospective details of healthcare related out-of-pocket expenditure and has been considered as a potential proxy marker of catastrophic costs(55). Households were deemed to have faced catastrophic costs on health care if their total costs were greater or equal to 20% of their annual income before illness onset (160). Catastrophic costs were described as relative risks by category, comparing those who received palliative care with those who did not.

Median EuroQoL EQ-5D-3L utility scores (Zimbabwe tariff) and visual analogue scale (VAS) scores were recorded at each time point. The two-sample Wilcoxon rank test was used for HRQoL comparisons between those who had received palliative care and those who had not, and Spearman correlation tests were used to investigate the relationship between VAS scores and utility scores. The unadjusted hazard of death was estimated using the Kaplan-Meier survival estimator, with survival disaggregated by poverty status, receipt of palliative care and cancer type (Appendix 6.6). No multiple testing corrections were applied.

## Other ethical and practical considerations

The study protocol has been published(161). After their final study visit, as per local ethical requirements at the time of the study, households received local currency equivalent of USD 2019\$10 compensation per visit. Data were entered anonymously on Open Data Kit software using locked hand-held devices for data collection. These were stored in a locked room when not in use. Data were uploaded at the end of each working day onto a password protected laptop and uploaded onto a secure server at the Malawi Liverpool Wellcome Trust. Data were erased once uploaded to a secondary server. The database was backed up on a locked an encrypted hard drive. Data will be shared within the research community through an open access repository.

## 7.5 Results

Between January and July 2019, 156 households, comprising 280 individuals (156 patients and 124 caregivers), in which a patient had been newly diagnosed with cancer were assessed for eligibility, of whom 150 households comprising 271 individuals (150 patients and 121 caregivers) were recruited (Table 6). At six months 89 (59%) households representing 153 individuals (89 patients and 64 caregivers) were available for analysis, 19 (21%) had received palliative care and 70 (79%) had not. Between diagnosis and six months 55/150 patients (37%) had died, with 22/55 (40%) of these deaths having occurred before first follow-up (Appendix 6.1). Median time from recruitment to death was 53 days. A total of 5/150 households missed one interview (two at one month and three at three months) but returned for the following interview. 6/150 households (4%) were lost to follow-up (Figure 13).

Median annual household income before illness onset was USD\$204 (IQR \$ 84-660), 67% (60/89) were living in extreme poverty ( $\leq$ \$1.90/day World Bank, 2015). 48 (54%) households were rural. The median age of patients was 50 years (IQR 40-57), and for caregivers was 40 years (IQR 32-49). 70 (79%) patients and 47 (73%) caregivers were female. 60 (67%) patients had cervical cancer, 19 (21%) oesophageal cancer, 8 (9%) Kaposi's sarcoma and 2 (2%) hepatocellular carcinoma (Table 6).

Median annual household income before illness onset for those who received palliative care was USD\$537 (IQR \$107-821) and for those who did not receive palliative care was USD\$179 (IQR \$82-537), ( $p=0.135$ ). In the six months after diagnosis, median total household costs on health were USD\$50 (IQR \$11-101) for those who received palliative care and USD\$55 (IQR \$28-91) for those who did not ( $p=0.704$ ) (Table 9). Median direct costs were USD\$6 (IQR \$4-26) for those receiving palliative care and USD\$12 (IQR \$0-21) for those who did not receive palliative care ( $p=0.252$ ). Median indirect costs were USD\$36 (IQR \$5-56) vs USD\$33 (IQR \$13-56), respectively ( $p=0.980$ ).

Expressed as a proportion of household income, total household costs on health for those who received palliative care was 0.086 (IQR 0.037-0.579) compared to 0.278 (IQR 0.085-0.692) for those who did not receive palliative care ( $p=0.126$ ). After adjustment for other relevant variables through multiple linear regression analysis, the mean difference in total household costs on cancer related health care as a proportion of household income was -36% for those who received palliative care compared to those who did not receive palliative care (95% CI -94%, 594%,  $p=0.707$ ) (Table 7). Two sensitivity analyses were done, over a shorter three month period following diagnosis, and using a different method of calculating the indirect costs. At three months, mean difference in total household costs on health care were -54% (95% CI -95% to 351%,  $p=0.533$ ) with receipt of palliative care. Using minimum wage for calculating indirect costs at six months this difference was -46% (95% CI -95% to 490%,  $p=0.608$ ) (Table 7 and Appendix 6.3).

57/89 (64%) households experienced catastrophic costs (Table 8). 9/19 households (47%) who received palliative care experienced catastrophic costs, compared to 48/70 (69%) who did not receive palliative care (RR 0.69, 95% CI 0.42-1.14,  $p=0.109$ ). Catastrophic costs were more commonly experienced by rural than urban households (37/48 vs 20/41,  $p=0.008$ ). Table 8 shows catastrophic costs by household characteristics. Median dissaving at six months was USD\$11 (IQR \$0-30) for those receiving palliative care and USD\$34 (IQR \$14-75) for those who did not ( $p=0.005$ ).

Patient and caregiver health related quality-of-life scores expressed in mean utility scores at diagnosis were 0.668 (95% CI 0.628-0.707) and 0.826 (95% CI 0.799-0.853) respectively, and 6 months after diagnosis were 0.590 (95% CI 0.534-0.646) and 0.831 (95% CI 0.799-0.863) respectively. Mean VAS scores were 39 (95% CI=35-42) and 32 (95% CI=29-35) at diagnosis and 23 (95% CI=20-25) and 18 (95% CI=15-22) at six months for patients and caregivers, respectively (Appendix 6.5). Comparison of utility and VAS scores 6 months after diagnosis showed no difference with receipt of palliative care between either patients (mean utility scores 0.537 [95% CI 0.412-0.662] vs 0.606 [95% CI 0.543-0.670]  $p=0.150$ ; VAS scores 23 [95% CI 18-28] vs 22 [95% CI 20-25]  $p=0.616$ ) or caregivers (mean utility scores 0.842 [95% CI 0.768-0.917] vs 0.828 [95% CI 0.792-0.864]  $p=0.647$ , VAS scores 22 [95% CI 6-38] vs 17 [95% CI 15-19]  $p=0.284$ ). Patient HRQoL utility scores were negatively correlated with VAS scores at 6 months ( $p=0.005$ ) There was no correlation between total costs on healthcare at six months and HRQoL, irrespective of receipt of palliative care.

## 7.6 Discussion

Advanced cancer diagnosis is associated with catastrophic costs on health care and is a source of household poverty in Malawi. Palliative care may reduce household costs on cancer related illness whilst maintaining quality-of-life. Reductions in dissaving were associated with receipt of palliative care in general. This may in part be explained by the higher median income of households receiving palliative care, although this requires further investigation. After controlling for socioeconomic, demographic and disease related variables, we did not find a statistically significant association between receipt of palliative care and household costs on healthcare related to advanced cancer at six months. Yet, the observed median difference in household costs was in the hypothesised direction and a similar pattern was observed in the sensitivity analyses. To our knowledge, this is the first-time data have been gathered and analysed for households affected by advanced cancer in a low-income country setting.

One-in-five households affected by advanced cancer under routine care received palliative care, which contributed to the study having limited power to measure a significant difference. We recalculated a minimum sample size of 500 households would be required to provide at least 80% power to detect a medium difference (Cohen's  $d=0.5$ ) between groups. Absolute amounts of dissaving were small across all households. Patients from 59% of households were alive six months after a diagnosis of advanced cancer highlighting the importance of palliative care provision well before the last stages (hours and/or days) of life to mitigate longer periods of serious health-related suffering.

A key goal of Universal Health Coverage is for individuals and communities to receive the health services they need without suffering financial hardship. This includes the full spectrum of health services, from health promotion to prevention, treatment, rehabilitation, and palliative care (162). Data were deliberately gathered from patient-carer dyads in this study recognising that financial hardship (and any potential cost savings) relating to serious illness are experienced beyond the individual, and, for a household, even beyond the death of the patient. 67% of households analysed in this study were living in extreme poverty before onset of symptoms. This is not surprising, reflecting the fact that 71% of the population of Malawi live in extreme poverty (163). This provides context for the burden of catastrophic costs on healthcare related to cancer, which contributes further to household vulnerability. The World Bank, United Nations and WHO have ambitious targets to reduce extreme poverty, recognising the role catastrophic costs play, stating that 'no one should be left behind'.

There are some limitations to the concept of catastrophic costs, particularly in extremely poor households. Among them, many who are sick may forgo treatment rather than experience catastrophic costs. This is missed in most studies and UHC debates(164). Additional qualitative work could address questions of whether and how receipt of palliative care influences household costs on health. We were unable to do further subgroup analysis because of the small number of households receiving palliative care. Some details of the timing, number, and type of contacts with palliative care services were available from clinic records, but more detailed descriptors of support activities would help to describe receipt of palliative care as a continuous

variable, which would have contributed to a more robust level of quantitative analyses on exposure.

The Global Atlas of Palliative Care states that only 12% of the 57 million adults and children needing palliative care to reduce serious health-related suffering currently receive it (3). Before starting the study, we considered that it was unethical to randomise households to palliative care, opting to use an observational study design conducted within a routine care setting. All recruited households were affected by advanced cancer and fulfilled criteria to receive palliative care at diagnosis. Although services were offered free of charge within a government funded institution, critical gaps in access to care were seen. Wealthier households in urban areas within the 50km operating radius were more likely to access services. Where integrated out-patient services existed supporting referral to palliative care (e.g. the dedicated weekly palliative care Kaposi's sarcoma out-patient clinic), patients were more likely to receive care. Recommendations from the WHO and the Lancet Commissions for integrated models of palliative care early in the cancer care pathway require urgent implementation(165, 166).

We also note the lower receipt of palliative care among those who live in extreme poverty in rural areas. This is where most Malawians live. Integration of services at all levels with effective linkages between hospital and community-based care would reduce the substantial transport costs for households. Studies detailing costs and outcomes associated with established and innovative models of care e.g. mobile outreach, mentorship and support of staff in rural health facilities and mHealth (167) may be appropriate.

It is striking that HRQoL utility scores were not negatively related to levels of total household costs on healthcare. The main purpose of recording HRQoL was to comment on whether any cost savings attributed to palliative care were gained at the expense of quality-of-life i.e. whether households were 'saving' on health-related costs simply by stopping any form of healthcare. The finding that there were no significant differences in HRQoL metrics (utility scores and VAS scores) between

those who received palliative care and those who did not broadly suggests that cost savings were not gained at the expense of HRQoL.

Utility scores were higher than those observed in an earlier study amongst in-patients at the same institution(168). Observed reductions in HRQoL over time were not unexpected, given that patients had advanced (and advancing) cancer. This study was not designed or powered to explore differences in quality-of-life relating to receipt of palliative care. The relevance and sensitivity of the EuroQoL EQ-5D to adequately capture changes in HRQoL in populations with advanced disease is contested(68). Higher utility scores should be reflected by higher VAS scores, our finding of negative correlation between utility scores and VAS scores for patients at 6 months provides some indication of difficulties in using this tool and warrants further exploration. Lack of validation of existing HRQoL measures for populations with palliative care needs in low and middle-income countries presents difficulties, particularly as reporting of QALYs, DALYs and incremental cost-effectiveness ratios determine priorities for national Essential Health Packages (169).

Our study was a first exploration in this type of evaluation of palliative care in this setting. It has strengths and limitations due to its purposely modest, single-centre observational design. Although public health services in Malawi are provided free at the point of care, financed by taxation and donor funding, there are limited facilities for cancer care e.g. no radiotherapy. Health financing environments and stage of development of oncology and palliative care services vary considerably within and by region, affecting generalisability of findings. Self-reported cost data may be subject to recall bias, despite short recall periods. Seasonal variations affect income in Malawi's largely rural, subsistence farming economy and may confound findings. Refusal (6%) and loss to follow up (4%) rates were low and potential selection bias due to loss to follow up was limited. Loss through death of patients was high as expected and these households were largely excluded in the data collection and analyses. Potential systematic errors resulting from study recruitment patterns (clinically stable majority female out-patients) and through referral patterns to palliative care must be noted. Our analyses do not reflect costs or HRQoL experiences of patients who were less stable at diagnosis.

This prospective descriptive study provides critically needed data to explore the impact of receipt of palliative care on household costs on health care following a diagnosis of advanced cancer in a low-income-country setting. Larger studies should be conducted across a variety of settings using the tools and concepts outlined. Sample size requirements would be reduced where access to palliative care is improved. Future work should explore barriers to, and successes in, models of early integration of palliative care for patients with advanced cancer, defining and describing the intervention exposure (palliative care) in more detail. Ways to comprehensively report cost data in households where patients die should be described. Paucity of funding for both hospital and community services and related research will hamper the development of the evidence base. As cancer research advances in low and middle-income countries , there is a critical need for improved operational tools to gather socio-economic outcomes alongside disease related outcomes in recognition of the high levels of catastrophic costs described in this and other studies. Resource-stratified, evidence based global guidelines have been published for palliative care (170) . Previous calls for new and integrated models of care for non-communicable diseases and other chronic conditions under Universal Health Coverage should include access to publicly funded palliative care.

Figure 14 Flow Chart

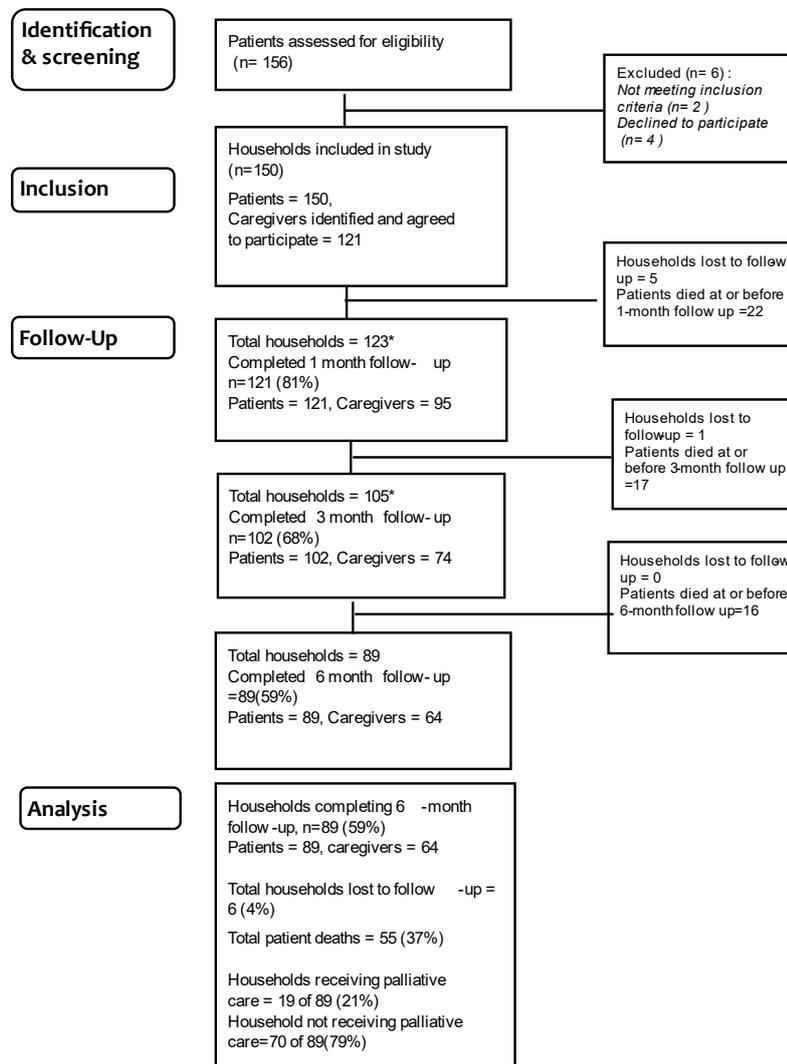


Table 6 Household, patient, and carer demographics at six months following a diagnosis of advanced cancer, by receipt of palliative care

		no palliative care		palliative care	
			%		%
Household	All	70	79	19	21
	Rural	42	60	6	32
	Urban	28	40	13	68
	Most poor	23	33	6	32
	Poor	23	33	5	26
	Least poor	24	34	8	42
	Living in extreme poverty	51	73	9	47
	Household income before illness(inflation-adjusted, USD\$)	180	84-540	540	108-816
Patient	Male	14	20	5	26
	18-40 years	16	23	4	21
	41-60 years	36	51	11	58
	>60 years	18	26	4	21
	Kaposi's sarcoma	3	4	5	26
	Cervical cancer	50	71	10	53
	Oesophageal cancer	16	23	3	16
	Liver cancer	1	1	1	5
	Married	44	63	8	42
	Single/divorced	7	10	7	37
	Widowed	19	27	4	21
	Male	17	27	2	13
	Carer	18-40 years	32	46	6
41-59 years		25	36	8	42
>60 years		7	10	1	5

Table 7 Unadjusted and adjusted % difference in total household costs on health as a proportion of household income following a diagnosis of advanced cancer, by receipt of palliative care

	<b>Unadjusted difference*</b>	<b>95%CI</b>	<b>Adjusted difference *</b>	<b>95% CI*</b>
Household received PC	-62.7%	(-97% , 309%)	-36.1%	(-94.1% , 594%)
Urban	-4.59%	(-86% , 655%)	155%	(-65.1% , 1770%)
Most poor	103%	(-75% , 1550%)	**	
Poor	-22.7%	(-91% , 544%)	**	
Least poor	-35.3%	(-92% , 403%)	**	
Household living in extreme poverty	4180%	(513% , 29800%)	**	
Male patient	-87.6%	(-99% , 31%)	-30.8%	(-98% , 2330%)
Married patient	18.6%	(-84% , 775%)	-16.7%	(-89.7% , 575%)

\*Coefficients have been back transformed from the log-linear regressions and so can be interpreted as the % change in the health share of income with a one unit change in the independent variable

\*\* no data where the explanatory variable was not included in the regression model

Table 8 : Number households experiencing catastrophic health related costs (20% threshold of household income) following a diagnosis of advanced cancer, by receipt of palliative care

	no palliative care (%)	palliative care (%)	Risk ratio	(95% CI)
Household n=89				
All	48/70 (69%)	9/19 (47%)	0.69	0.36-1.04*
Rural	35/42 (83%)	2/6 (33%)	0.40	0.00- 0.88**
Most poor	17/23 (74%)	2/6 (33%)	0.45	0.00-1.05**
Poor	14/23 (61%)	3/5 (60%)	0.99	0.29-1.92**
Least poor	17/24 (71%)	4/8 (50%)	0.71	0.19-1.29**
Extreme poverty	41/51 (80%)	7/9 (78%)	0.97	0.60-1.141**
patient				
Male	8/14 (57%)	1/5 (20%)	0.35	0.06-2.14**
Female	40/56 (71%)	8/14 (57%)	0.80	0.49-1.29**
Kaposi's sarcoma	2/3 (66%)	0/5 (0%)	0.00	n/a
Cervical	38/50 (76%)	7/10 (70%)	0.92	0.51-1.342**
Oesophageal	8/16 (50%)	1/3 (33%)	0.67	0.00-2.13**
Hepatocellular carcinoma	0/1 (0%)	1/1 (100%)	n/a	n/a
other				
Less than median household income before illness	33/37 (89%)	6/7 (86%)	0.96	0.62-1.23**
Greater than median total household costs on health	32/36 (89%)	6/8 (75%)	0.84	0.45-1.17**

\* = confidence interval obtained using a small-sample-adjusted unrestricted maximum likelihood estimator and the Wald normal approximation

\*\* = confidence interval obtained by using the percentile method and bootstrapping (drawing repeated binomial samples for each group with the empirical probability of experiencing catastrophic costs)

Table 9 Household income, health related costs at six months and dissaving by receipt of palliative care (median/IQR, USD2019\$)

	<b>No palliative care</b>		<b>palliative care</b>	
	median (USD\$)	IQR	median (USD\$)	IQR
Household costs of healthcare	55	28-91	50	11-101
Household income before illness	179	82-537	537	107-821
Household costs as proportion of household income	0.278	0.085-0.692	0.086	0.037-0.579
Dissaving at six months	34	14-75	11	0-30

## Chapter 8 Discussion and conclusions

### 8.1 Chapter overview

Palliative care remains minimally documented and typically absent from global health narratives, despite its inclusion in the United Nations definition of UHC. The aim of this thesis was to investigate early data, proposals by global advocates, recommendations of the Lancet Commission on Palliative care and Pain relief and the World Bank, suggesting that the provision of palliative care supports household poverty reduction in LMIC. In this thesis, poverty was framed as comprising 'capability' poverty (chapters 3 and 4) and 'income' poverty (chapters 6 and 7), thus 'poverty reduction' was understood both through enhanced wellbeing and financial protection.

In this chapter I report the methodological and empirical contributions of this thesis towards the question of whether palliative care supports household poverty reduction in LMIC. Lessons learnt are documented with reference to the current literature. A framework is proposed to guide considerations in, and reporting of, future research on palliative care within UHC in the context of LMIC. Policy recommendations are included supporting a context-specific understanding of palliative care service delivery and the potential of palliative care to support poverty reduction in LMIC. This is followed by a concluding summary.

## 8.2 Thesis contribution to the question “Does palliative care have the potential to reduce household poverty in a low income country?”

### 8.2.1 Methods contribution

#### *Summary of methods*

Mixed methods research design was used in this thesis, appropriate for early investigation of a complex intervention. It also enabled reporting of both qualitative (capability) and quantitative (costs) perspectives of poverty reduction. Firstly, Photovoice was used as a participatory method to elucidate patient and family understandings of wellbeing and the contribution of palliative care to household wellbeing. Through review of the literature, data from Photovoice and stakeholder engagement, the Patient and Carer Cancer Cost (PaCCCT) survey was adapted from the WHO TB patient cost survey. This survey was then used within a prospective descriptive cohort study to assess the relationship between receipt of palliative care and catastrophic costs six months after a diagnosis of advanced cancer. Dissaving and HRQoL (using the Chichewa language validated version of EQ5D-3L) were also described over time for patients and their unpaid family caregivers.

#### *The use of Photovoice as a participatory method to describe wellbeing in populations with advanced disease*

Before describing the potential for palliative care ‘to reduce capability poverty’ i.e., to support wellbeing, there was need to gain contextual understandings of wellbeing in this population. Photovoice, a visual participatory qualitative method was employed. Practical and ethical considerations were documented for the conduct of Photovoice with those receiving palliative care for advanced cancer in Blantyre, Malawi (119). Kars highlighted the role played by health workers, ethics committees and family members who may act as gatekeepers for patient participation in palliative care research, fearful of the additional burden on vulnerable patients (171). In this Photovoice project, co-researchers living with, or affected by, life-limiting illnesses were able and willing to generate data (photographic images) on the story of their illness, thereafter, engaging in thematic analysis and an advocacy event to describe their understanding of wellbeing: what they valued to ‘be’ and ‘do’. Receipt of

palliative care was evaluated against enablement towards these self-reported capabilities. Those who were older, particularly frail or limited by disability (tumour-related blindness) were notably unable to fully participate.

Gysels et al reported the findings of a consensus workshop on the ethical challenges of palliative care research, encouraging collaborative approaches to promote best practice (172). Experience with Photovoice demonstrated that patients and their family caregivers in LMIC can and should be involved in the development and conduct of research in the context of life limiting illness. This is in line with Sustainable Development Goal 3 in which 'no-one is left behind', supported through WHO initiatives on patient-centred care (173), and disability activism which requires 'nothing about us without us' (174).

The advocacy component of the Photovoice study included an engaging programme of drama, photographic exhibition and song designed by patients and caregivers. The event was held in a local community hall with other community leaders in attendance, concluded by an address by the District Health Officer. This event and other activities within the study were facilitated through our long-term involvement with co-researchers through the involvement of the community-based palliative care team. Where such long term engagement is not possible, other qualitative methods may be more appropriate. Evans-Agnew and Rosemberg reviewed representation of participant voice in Photovoice publications, focusing on stages of analysis, exhibits and dissemination (91). For the work reported in this thesis co-researchers conducted thematic analysis, prepared captioned images, and designed and lead local dissemination activities (119). However, co-researchers were not engaged with the development of the research question or study objectives, nor were they consulted during the selection of images for inclusion in peer review publication. These elements would enhance the participation of future Photovoice work. (90, 91).

*Measuring costs – the development of the Patient and Carer Cancer Cost (PaCCCT) survey*

Quantitative research investigating the potential for palliative care to support poverty reduction in LMIC is at an early stage of development (130). Approaches differ and there are few published tools, methods or data to guide the conduct of such research (32, 151). This thesis summarizes approaches to the reporting of patient costs in settings of chronic disease in LMIC and the development of the PaCCCT survey. Qualitative data from Photovoice was used sequentially to inform the initial draft adaptation of the WHO TB patient cost survey. Use of this survey as a starting point enabled the rapid generation of a comprehensive and contextually relevant questionnaire suitable for a population affected by advanced cancer.

Early engagement with stakeholder groups including policy makers was important not only for tool validation but also to encourage wider ownership of the process, strengthening future research to policy pathways. Where possible, patients and caregivers should be included in local and national stakeholder meetings.

*Investigating the potential for palliative care to reduce total household costs on cancer related healthcare –*

In chapter 6 the protocol for a prospective cohort study was reported. This details a feasible and ethical approach to assess the relationship between receipt of palliative care and total household costs of cancer related health care following a diagnosis of advanced cancer in a low income country (here, Malawi). Several other methodological approaches were considered. Firstly, the possibility of a randomised controlled trial; however this was difficult to conceive given the early stage of evaluation. Additionally it was decided that randomisation would have been unethical where a (palliative care) service already existed. A cross-over study design would have been hampered by the absence of standard treatment protocols for oncology or palliative care in the local setting.

Study participants had all recently been diagnosed with advanced cancer. The timing of recruitment (at the time of, or in the days after, a diagnosis of advanced cancer) may have been considered too sensitive and a barrier to participation. In practice there were very few refusals (n=6), perhaps due to the principal investigator and study

nurse having extensive prior knowledge of the clinical environment, and from the experience gained by the fieldworkers during Photovoice research. Although an estimated patient prognosis of greater or equal to three months was required for study recruitment, patients were expected to die during the study. To plan for this, particular attention was paid to the training, orientation and support of field workers, including a briefing on how to respond to household bereavements, whether reported via phone or through home visits.

The variable 'household costs of healthcare as a proportion of total household income' was used as a measurable indicator of household poverty, relevant to UHC through the reporting of catastrophic costs. Use of an observational study design introduces limitations of confounding and bias, as a result of which attribution of causality is not possible (175). Cause and effect may be particularly difficult to determine when exploring costs of healthcare in low income settings. Multiple confounding factors influence decisions around accessing care and poverty experiences e.g. unpredictability of the local environment, seasonal patterns of income and pre-existing health inequalities (45). It was also notable that randomisation to receipt of palliative care would have improved access and could have been employed as ethically acceptable.

### 8.2.2 Empirical contributions

#### Summary of results

Photovoice yielded valuable visual data (photographs) from household co-researchers (patients and unpaid family caregivers) and an advocacy event, to inform an understanding of wellbeing and the contribution of palliative care to poverty reduction (21). Wellbeing was reported under three themes: 1. things that make us happy : e.g. ability to work and/or perform daily chores , 2. courage givers : caregivers, children and others reducing anxiety through prayers and health workers through providing medication and 3. (reducing) 'discrimination': being considered 'prematurely dead' resulting in social exclusion. Palliative care services helped to

reduce discrimination through counselling, by modelling close contact in clinical settings and through visiting patients at home.

Relevant cost categories were extracted from a review of audio recorded transcripts of Photovoice critical dialogue. These were referenced within the adaptation of the WHO TB patient cost survey, which, with several additional steps, led to the development of the Patient and Carer Cancer Cost (PaCCCT) survey (148). Following piloting, the PaCCCT survey was employed within a single-centre evaluation of palliative care and household costs of cancer related healthcare. The costs of healthcare following a diagnosis of advanced cancer were described (including healthcare utilization and related costs: direct, indirect and dissaving (161)) and receipt of palliative care. The total household costs of cancer related healthcare were described as a proportion of annual household income. This variable was log transformed (as data were highly skewed) and then analysed within linear regression models to describe the relationship between total household costs of healthcare and receipt of palliative care, controlling for a variety of possible confounding variables. Catastrophic costs were described between diagnosis and six months following diagnosis, being defined as total household costs on cancer related healthcare greater or equal to 20% of annual household income. Risk ratios for catastrophic costs were tested by receipt of palliative care. Data on HRQoL were gathered to report whether cost savings were made at the expense of quality of life, rather than to report effectiveness of palliative care. 64% of households experienced catastrophic costs at six months at the 20% threshold, this was 69% where there was no palliative care, 47% with receipt of palliative care, though this risk ratio was not significant (RR:0.69, p=0.109).

*Use of a capability approach to describe what households value to be and do following a diagnosis of advanced cancer in a low income country setting*

The rich photographic data generated by patients and families as co-researchers within Photovoice provided insights into the context of their lived experience and concepts of household wellbeing. End-user perspectives of the potential for palliative care to reduce poverty i.e. to support wellbeing, were described. Affected households

designed and led an advocacy event around the theme of discrimination which was attended by local community and healthcare leaders.

Using a capabilities approach Greco et al used focus group discussions with healthy rural Malawian women to report domains relevant to their quality of life. These comprised physical strength, inner wellbeing, household wellbeing, community relations, economic security, and happiness (64). Further work with this data has resulted in a Capabilities Index for rural Malawian women (176). In a review of Photovoice, Liebenberg described participatory action research as 'reconnecting science with society for the purpose of social transformation'(177). Qualitative methods are commonly used to explore and identify concepts and values of importance to quality of life. (62, 178). Mitchell's review of applications of the capability approach reported a 'noticeable non-reliance on health status as a sole indicator of capability'(178). Capability domains may be defined by resource and cultural context than by stage and type of illness. Themes reported by Greco resonate with the Photovoice study e.g. 'Things that make us better' with physical strength, economic security and happiness, 'having courage' with household wellbeing and 'discrimination' with inner wellbeing and community relations. These contrast with domains (choice, love and affection, freedom from physical suffering and emotional suffering, dignity, being supported and preparation) which were reported as capability domains from elderly people at the end of life in the UK (179).

#### *The PaCCCT survey to gather household cost data in the context of advanced cancer*

Prior to the PaCCCT survey, there were no standardised tools to gather patient/household level cost data from households with palliative care needs in low-income countries. This survey may save time and money for future researchers and could facilitate inter- and cross-country comparisons and wider public policy discourse and reporting. The WHO TB patient cost survey is an example of this, through the SPARKS collaborative platform which uses data for 'health and social protection research and knowledge sharing' across a global network (<https://sparksnetwork.ki.se/>).

Sweeney et al point out the challenges of balancing the comprehensiveness of a cost survey with time to completion (151). When dealing with sick and vulnerable populations, time taken to complete survey questionnaires is particularly important, as well as consideration of who will provide cost data when the patient becomes too ill to respond to these questions themselves. The PaCCCT survey included details of both routine and unplanned visits, with the assumption that unplanned visits may incur higher costs. In practice, this inclusion did not yield additional data and could be dropped. The length and complexity of the survey required trained staff, adequate time and financial resources for administration and subsequent analysis. These issues limit the wider use of survey in its current form. Gathering data on funeral costs exposed cultural issues relating to who is responsible to pay for funerals within extended family networks. This is likely to have affected the reliability of funeral cost data and requires further consideration in future.

The PaCCCT survey was used to gather data across four types of advanced cancer using clinical information (diagnosis and stage of illness) available within the routine care setting of a tertiary hospital in the low income setting of Blantyre in Malawi. Palliative care is relevant beyond cancer and work is needed to refine and validate a version of the survey for other life-limiting conditions. Details of stage of disease (and related outcomes) are routinely reported in oncological practice, but similar staging systems are not available for other life-limiting illnesses such as stroke or COPD, where patients and families also benefit from palliative care (180, 181). Referral consensus and associated clinical information would be needed to determine when (i.e. at what stage of disease) such patients need palliative care and/or when a cost survey would be administered. The survey also requires adaptation for alternative models of care e.g. community based care, and for settings where additional palliative treatment modalities such as radiotherapy are available.

*Evaluating the potential for palliative care to support household financial protection following a diagnosis of advanced cancer in a low income country–*

Within the limitations of a single centre observational study involving self-reported data, a comprehensive set of data were gathered from this typically neglected and highly vulnerable population in a low-income country setting. Access to palliative care was poor for all households, particularly for those in rural areas. Given the 'access abyss' for palliative care in LMIC described in this and other publications (20), more work is needed to understand and clarify barriers and facilitators in access to, and the integration of, palliative care at community, facility and national level. Access to palliative care maybe affected by health worker perceptions of palliative care which is sometimes perceived as 'giving up' on patients. This affects decisions to seek or refer patients and/or families, who maybe untrained or unwilling to talk about difficult issues such as prognosis and/or death (10, 182, 183).

Using multiple linear regression to control for confounding variables, a non-statistically significant reduction in mean total household costs of cancer related healthcare as a proportion of household income was observed with receipt of palliative care at 6 months. This was also found in sensitivity analyses at 3 months, and at 6 months where minimum wage, rather than self-reported income, was used to report indirect costs. Indirect costs contributed between three and six times the amount of direct costs to total household costs. This is similar to the contribution made by indirect costs in an assessment of catastrophic costs experienced by households affected by TB in Peru (49). Calculations of indirect costs are based on time loss x wage, where wage is either derived from a national minimum wage or from self-reported income before symptom onset. This does not account for the inevitable decline in function, and subsequent reduction in earning potential, which occurs before or following a diagnosis of life limiting illnesses. Other cut off levels have been used to define catastrophic costs of healthcare (including 10% and 40% of non-food household income (134)), these could have been calculated for reflection and comparison. If catastrophic costs (as a binary outcome variable) rather than total household costs of cancer related healthcare (as a continuous outcome) had been the primary outcome, logistic regression would have been utilised. Where patients died during study follow up, some data was unavoidably missing. Handling of missing data in health economic evaluations is a common challenge in palliative care research (184). In this thesis 'missingness' was dealt with by complete case analysis (CCA)

i.e. only households in which the patient had not died before study completion (n=89) were included in the primary analysis. This is likely to have introduced some bias.

The EuroQol Chichewa language validated version of the EQ5D-3L was used due to the absence of any other local language-validated brief instruments to measure quality of life. Work on the EQ5D (for children and adolescents) in Malawi is ongoing (185) (186) and recent work in the UK 'extending the QALY' uses an expanded version of the EQ5D (187). Although this thesis does not set out to describe the utility or limitations of the EQ5D in LMIC, inconsistencies in reported findings (e.g. a lack of correlation between utility and VAS scores) are congruent with reports from palliative care research in high-income settings which have raised concerns about the suitability of the EQ5D for populations with life limiting illnesses (68, 72). The ongoing dearth of contextually relevant tools to measure quality of life for populations affected by life limiting illnesses in LMIC is likely to limit the progress of future work in this area. Data on wellbeing domains described in the Photovoice study will be relevant in future work, both in the development of a capabilities based measure and to critique other new and emerging tools (61) .

### 8.3 Policy recommendations

Poverty reduction strategies are integral to developmental and health agendas in LMIC. Both reduced household costs and improved wellbeing are integral to poverty reduction and are of relevance to households affected by life-limiting illnesses in LMIC.

Patients and family caregivers affected by advanced cancer in Malawi value palliative care to improve function, have courage and reduce discrimination. Framing an understanding of palliative care to relieve 'serious health related suffering' rather than as 'care for the dying' can reduce discrimination for those with life-limiting illness.

National level planning for Universal Health Coverage and Financial Protection should include the provision of and improved access to palliative care at all levels in the health system to support household poverty reduction. Appropriate indicators

(e.g. proportion of patients diagnosed with advanced cancer who access palliative care) should be developed to report progress towards this goal.

Early key stakeholder involvement (including end-users) is mandatory for the development of tools and outcomes for policy relevant research relating to palliative care under UHC.

Measures of wellbeing in populations based in LMIC should reflect the importance of community and/or social inclusion within physical and psychosocial domains.

Standardised cost survey instruments such as the PaCCCT survey should be developed to gather data on financial protection with palliative care and to facilitate comparisons of household costs of healthcare across life limiting illnesses in a variety of settings.

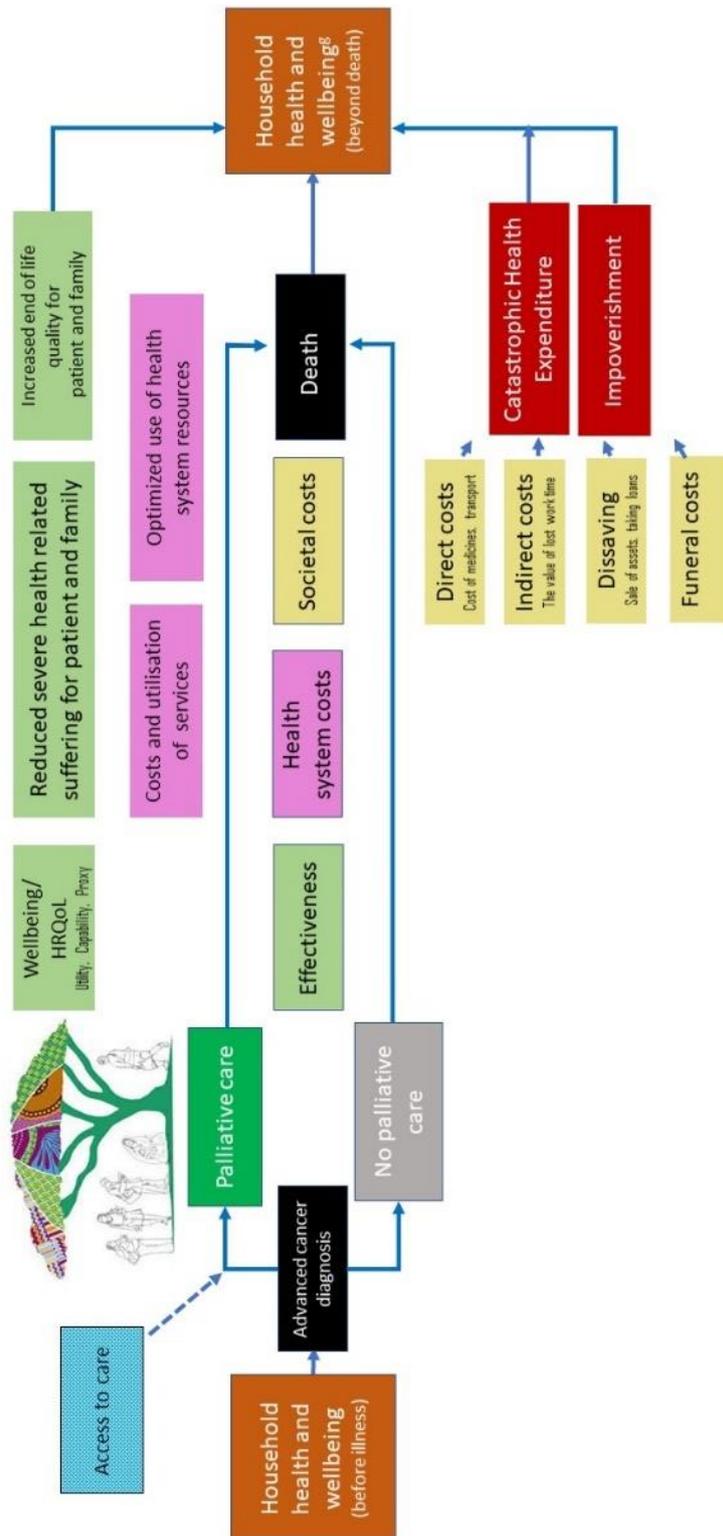
When assessing progress towards the provision of palliative care within Universal Health Coverage, mechanisms to assess the value of interventions beyond individual QALY measures should be considered.

#### 8.4 Palliative care within UHC in LMIC: A framework for future research:

Following reflection on the scope, conduct and contributions of this body of work, a framework summarizing components for future research of palliative care under UHC in LMIC is proposed as an output from this research (Figure 15). The framework aims to guide researchers continuing work in this generally neglected field. The framework includes the important area of health system costs, recognising that these were not considered within the scope of this thesis.

Outcomes in healthcare are often reported at individual level. Here, considering a WHO definition (of palliative care) which encompasses both patients and families, the household scope of financial protection under UHC and the poverty trap, the household is maintained as the outcome unit of interest.

Figure 15 palliative care within UHC in LMIC: a framework for future research



The involvement of affected populations (patients and caregivers) in the development, conduct and reporting of research activities should be reported. Household level outcomes should be clearly defined and reported, where possible both prior to and after a life-limiting illness. These may include but are not limited to:

- Financial protection – catastrophic costs, impoverishment
- Wellbeing/quality of life\* - tools include EQ5D domains, VAS and derived utility scores, measures of serious health related suffering, capability scores, other proxy measures (\*to include details of validation for the population(s) under study)
- Household 'costs' beyond health e.g. adequacy of education and/or food
- Other outcomes including death\*\* (\*\*details of how deaths will be reported and analysed including the handling of missing data)

Descriptions of local funding mechanism(s) for health care (including social/community health insurance, public taxation, donors, etc.) should be detailed, along with the diagnosis/diagnoses of interest and criteria for referral into palliative care. Details of the palliative care service(s) including staffing, site(s), the scope of practice, and measurement and investigation of access to care. Resources and sources of funding and costs of provision of palliative care and comparator service(s), at health system level should be described.

## 8.5 Conclusions

The approaches, methods and results reported in this thesis contribute new tools and evidence supporting the potential of palliative care to reduce poverty at household level following a diagnosis of advanced cancer in the low income country setting of Malawi. Patients and families are affected by life-limiting illness at a younger age whilst still responsible for multiple dependents. With careful planning, participatory research can safely be undertaken with patients and family caregivers from affected households. A cost survey tool to support further research in this neglected field has been developed. Wellbeing comprises seeing improvement in the patient's condition, having courage and minimising discrimination. Palliative care is valued to support these desired capabilities. Catastrophic costs levels were extremely high six months

after a diagnosis of advanced cancer. Receipt of palliative care was found to reduce the risk of catastrophic costs and mean adjusted total household costs on cancer related healthcare but these outcomes did not reach statistical significance. Causal associations were not possible due to the observational study design. Larger multi-centre studies are needed, considering alternative study designs. A framework to guide future policy relevant research on palliative care within UHC has been proposed.

This and future research is critical for policymakers and practitioners who wish to ensure that no one – here, adults diagnosed with advanced cancer in a low-income country - is left behind in the pursuit of inclusive Universal Health Coverage and Financial Protection.

## 8.6 Summary statement

Palliative care is integrated within UHC, endorsed by the United Nations, World Health Assembly, and World Bank (16, 28, 30). Despite this, access to services remains very limited (3). Research evidence on the economic benefits of palliative care, including the financial protection of households in LMIC, is minimal (32, 43). The need to integrate palliative care within the continuum of care is typically absent from broader global health narratives, despite millions of adults and children living with unrelieved serious health-related suffering due to life-limiting illness around the world (20). The lack of published data results in a lack of awareness amongst patients, caregivers, health workers, researchers and policy makers who remain uninformed about, and unable to access, the benefits of palliative care.

In this thesis, I describe a novel application of a qualitative approach (Photovoice) and results from a quantitative study utilising a newly adapted cost survey for use in populations receiving palliative care. Almost two thirds (64%) of households in Blantyre, Malawi had experienced catastrophic out-of-pocket costs on health six months after a diagnosis of cancer. This was reduced to 47% where households were receiving palliative care. Patients and household caregivers reported that palliative care supported household wellbeing through seeing improvements in the condition of the patient, facilitating return to work and/or activities of daily living.

Whilst further studies are required to advance and define economic arguments for palliative care in LMIC, the approaches, methods and results reported in this thesis present new evidence to progress research in this generally neglected area. Such research is critical to inform policymakers, practitioners, and families who wish to ensure that no-one – here, adults diagnosed with advanced cancer in a low-income country - is left behind in the pursuit of inclusive Universal Health Coverage and Financial Protection.

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## Appendix 1 : publications

Chapter 3 reports practical and ethical considerations of the use of Photovoice, a community-based action research participatory method, for populations living with advanced cancer (as an example of life-limiting illness) in low-income settings.

This was published in BMJ Supportive and Palliative care in February 2018

The publication can be found at the link below:

<https://spcare.bmj.com/content/8/2/171h>

Chapter 4 reports the results of the Photovoice study describing household concepts of wellbeing and the role of palliative care.

This was published in PLOS ONE in August 2018

The publication can be found at the link below:

<https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0202490>

Chapter 5 describes the development of the Patient and Carer Cancer Cost (PaCCcT) survey – a cost tool to assess household healthcare utilisation and associated costs after a diagnosis of cancer, suitable for use in low-income countries.

This was published in BMJ Supportive and Palliative care in September 2019

The publication can be found at the link below:

<https://spcare.bmj.com/content/early/2019/10/24/bmjspcare-2019-001945>

Chapter 6 provides the protocol for the prospective observational cohort study of health-related expenditure and health-related quality of life outcomes for households affected by advanced cancer.

This was published in Wellcome Open Research in March 2020

The publication can be found at the link below:

<https://wellcomeopenresearch.org/articles/5-2/v2>

## Appendix 2 : Photovoice

### 2.1 Consent forms: English and Chichewa

**An exploration of household wellbeing and the contribution of palliative care following a diagnosis of advanced cancer: a Photovoice study**



Individual Participant Consent form: English version 1.1 (05/7/2016)

Name \_\_\_\_\_

DoB or Address \_\_\_\_\_

- |  |                                       |
|--|---------------------------------------|
| 1. Have you read or listened to the participant information sheet (v.1.0)?   | <input type="text" value="Yes / No"/> |
| 2. Have you had the opportunity to ask questions?  | <input type="text" value="Yes / No"/> |
| 3. Have your questions been answered, and do you feel that you have had enough information about this study?   | <input type="text" value="Yes / No"/> |
| 4. Do you understand that you are free to withdraw from the study at any time without giving a reason and without any penalties?   | <input type="text" value="Yes / No"/> |
| 5. Do you understand that data collected during the study may be looked at by individuals from Liverpool School of Tropical Medicine and regulatory authorities? Information you provide which is needed for analysis outside Malawi will be anonymised. | <input type="text" value="Yes / No"/> |

If you have answered 'yes' to questions 1-5 please sign the form, or place a thumbprint below, which means that you voluntarily agree to enter the study.

I voluntarily agree to enter this study.

Signature \_\_\_\_\_ Date \_\_\_\_\_

Witness to consent if participant unable to sign their name

(name in capitals) \_\_\_\_\_

Signature \_\_\_\_\_ Date \_\_\_\_\_

Investigator obtaining consent (name in capitals)

Signature \_\_\_\_\_ Date \_\_\_\_\_

Kufufuza Moyo wabwino wapakhomo ndi chisamaliro cha wodwala matenda aakulu komanso a m'gonagona potsatila kupezeka kwa khansa yayikulu: Kafukufuku wa Uthenga m'zithuzi



Chikalata cha Munthu m'modzi wotenga nawo Mbali: Chichewa version 1.1 (05/7/2016)

Dzina \_\_\_\_\_

Tsiku lobadwa/Koyala \_\_\_\_\_

- |  |   |
|--|---|
| 1. Kodi mwawerenga kapena kumvetsera za chikalata chonena za wotenga nawo mbali (v.1.0)?   | <input type="button" value="Inde /Ay"/> |
| 2. Kodi munali ndi mwayi wolunsa mafunso?  | <input type="button" value="Inde /Ay"/> |
| 3. Kodi mafunso anu anayankhidwa, ndipo mukumva kuti muli ndi uthenga wonse wokwanila wokhudza kafukufukuyu?   | <input type="button" value="Inde /Ay"/> |
| 4. Kodi mwamvetsetsa kuti muli ndi ululu wochoka mu kafukufuku panthawi iliyonse osapercka chifukwa ndiponso popanda chilango?   | <input type="button" value="Inde /Ay"/> |
| 5. Kodi mwamvetsetsa kuti zotoleredwa pa kafukufuku zidzawonedwa ndi lwo aku Liverpool School of Tropical Medicine and regulatory authorities? Uthenga mulapercke womwe ungalunike kukawunikidwa kunja kwa Malawi udzazimbayitsidwa. | <input type="button" value="Inde /Ay"/> |

Ngali mwayankha 'cya' ku mafunso 1 mpaka 5 chonde sayinani chikalata, kapena dindani chidindo cha chala m'musi, izi zikutanthawuza kuti modzipercka mwavomera kulowa mu kafukufuku.

Modzipercka ndavomera kulowa mukafukufuku.

Sayini \_\_\_\_\_ Isiku \_\_\_\_\_

Mboni ilolozo ngali wotenga nawo mbali sangathe ku sayina dzina lawo

(dzina muzilembo zazikulu) \_\_\_\_\_

Sayini \_\_\_\_\_ Isiku \_\_\_\_\_

Wofufuza, kutenga chilolozo (dzina muzilembo zazikulu)

Sayini \_\_\_\_\_ Isiku \_\_\_\_\_

## 2.2 Participant information sheet: English and Chichewa

University of Liverpool School of Tropical Medicine Information Sheet



Participant Information Sheet: English version 1.2(21/9/2016)

**An exploration of household wellbeing and the contribution of palliative care following a diagnosis of advanced cancer: a Photovoice study**

### 1. Introduction

Palliative care has expanded in Malawi since it began in 2001, though many patients are still unable to get the help they need once they have a serious disease like cancer. Little is known about the impact on household wellbeing (including costs) of a diagnosis of cancer in Malawi, though research from other low resource settings suggests that the experience is often associated with high costs. We are doing this study to explore experiences of living with/as a patient who has cancer to try to understand more about the challenges that you and your family members face.

### 2. Why have you been chosen?

You are known to be a member of a household in which a patient who has a diagnosis of cancer is living. The patient is under the care of Tiyanjane Palliative care in Blantyre.

### 3. Do I have to take part in the study?

Your agreement to help with this research study is completely optional and if you would prefer not to participate, this will be without penalty or loss of care/benefits to which you would be otherwise entitled. You can choose to leave the study at any time, without providing a reason.

### 4. What will be involved if I agree to take part in this study?

We want to ask you to explore your experience of living with/as a patient who has cancer. This will be done through the use of photographs. The study is composed of seven separate group sessions in Ndirande. As you attend these sessions you will be taught how to use cameras and then asked to take pictures in and around your home environment. This will take place over a period of three weeks. You will be asked to take photographs of aspects of your life which you think best tell the story of your experiences, both before and since having the diagnosis, what things matter most to you, what challenges you face day to day. Later on you will be asked to select photographs and then to discuss them with one of the team. We will record these discussions.

### 5. Will there be any risks involved in the study?

You will be provided with a working camera, SD card and batteries. As part of the training we will discuss with you how to use and handle the camera and how to keep it safe. If you don't feel safe to keep the camera in your household overnight, we will make arrangements for it to be collected and returned the same day.

### 6. Will there be any benefits involved in being in the study?

Return transport cost to the sessions will be provided, and you will receive refreshments during the group session. You will be provided with 20 printed copies of photographs of your choice at the end of the study. You will be able to display your photographs for exhibition to make key stakeholders at national level more aware of your situation.

**7. Who is organizing the study?**

The research is being done by researchers at the College of Medicine linked to the University of Liverpool, Liverpool School of Tropical Medicine.

**8. Who will know what we find out?**

We will use digital voice recording machines to record group sessions and individual interviews and store this information on a computer. This information will be transferred to a computer database but without using your name or address so that you could not be identified from this information. This database will be analysed by researchers at the College of Medicine and Liverpool School of Tropical Medicine. We will share the results of this study with you and your community, at local charity or research meetings and will present the findings at an international conference and in journals.

**9. What happens if you change your mind, move away or become too unwell to continue in the study?**

If you agree to join the study you can change your mind and withdraw your consent at any time. If you move away or become too unwell to continue, we will ask permission from you (or from your household member) if they are happy for us to include the photographs and any interview material with which you were involved.

If you have any questions about this study, please contact our Field work coordinator Mrs Emmie Kalonga on **+265 888893214**.

For any questions regarding participant rights in the scope of this study, please contact the Chairman of the local ethics committee (COMREC). This committee has reviewed and approved all of these studies. The contact details are: COMREC Secretariat, College of Medicine, P/bag 360, Blantyre 3. Tel no: **+265 111 989 766**.

Chikalata chofotokoza za wotenga nawo mbali : Chichewa version 1.2 (21/9/2016)

**Kufufuza Moyo wabwino wapakhomo ndi chisamaliro cha wodwala matenda aakulu komanso a m'gonagona potsatila kupezeka kwa khansa yayikulu: Kafukufuku wa Uthenga m'zithuzi**

**1. Mawu Oyamba**

Chisamaliro cha wodwala matenda akulu komanso a m'gonagona ku Malawi chakula kuchokera pomwe chinayamba mu 2001, ngakhale wodwala ambiri akadali kukanika kupeza thandizo lomwe akufuna pomwe ali ndi nthenda yayikululu ngati khansa. Ndizochepa zomwe zikudziwika za zotsatila za moyo wabwino wa pakhomo (kuphatikizirapo mitengo yake) wa womwe apezeka ndi khansa yayikulu ku Malawi, ngakhale kafukufuku yemwe anachitika malo ena womwenso ali m'gulu losoweka zinthu akuganiza kuti zokumana nazoti zimakhudzana ndi kumwazika kwa chuma. Tikupanga kafukufukuyu kufufuza za zoomwe mumakumana nazo pokhala ndi wodwala khansa kapena ngati wodwala amene ali ndi khansa, kufuna kumvetsetsa zambiri za zovuta zomwe inu ndi apabanja anu mumakumana nazo.

**2. Ndichifukwa chiyani mwasankhidwa?**

Ndinu wodziwika kukhala membala wa banja lomwe lili ndi wodwala yemwe ali ndi khansa yayikulu pansi pachisamaliro cha Tiyanjane Palliative care ku Blantyre.

**3. Kodi ndingatenge mbali mukafukufuku?**

Kuvomera kwanu kuthandiza mu kafukufukuyu ndikwachisankho motheratu, ndipo ngati mungafune kusatenga nawo mbali, izi zikhala zopanda chilango kapena kutaya chisamaliro/phindu lomwe mwa njira iliyonse ndilokuyenerani. Mukhonza kusankha kuchoka pa zokambiranazi nthawi ina iliyonse wosapereka chifukwa.

**4. Chidzachitike ndi chiyani ngati ndalora kutenga nawo mbali mu kafukufukuyu?**

Tikufuna tikufunseni kuti mufufuze pazomwe mwakumana nazo pokhala ndi wodwala/wodwala yemwe ali ndi khansa yayikulu. Izi zichitika pogwiritsa ntchito zithunzi. Kafukufukuyu ali ndi magulu asanu ndi awiri (7) wolekana kakumanidwe kake ku Ndirande. Pamene mukusonkhana mudzaphunzitsidwa momwe mungagwiritsire ntchito makamera ndipo kenako mudzafunsidwa kutola zithunzi mu nyumba ndi malo wozungulira pakhomo panu. Izi zidzatenga nthawi yokwana masabata atatu. Mudzafunsidwa kutola zithunzi za mbali za moyo wanu zomwe mukuganiza kuti zikufotokoza bwino nkhani ya zomwe mumakumana nazo, musanapezeke komanso atakupezani ndi matenda, zinthu zomwe zimakhudzani kwambiri, zovuta zomwe mumakumana nazo tsiku ndi tsiku. Kenako patsogolo mudzafunsidwa kusankha zithunzi ndikukambirana ndi m'ndzi wa a gulu. Tidzajambula mawu pazokambiranazi.

**5. Kodi padzapezeka zovuta mukafukufuku?**

Mudzapatsidwa kamera yomwe ikugwira ntchito, khadi la SD ndi mabatile. Ngati mbali ya maphunziro tidzakambirana nanu momwe mungagwiritsire ntchito kamera ndi kusunga motetezeka. Ngati mukukayika za chitetezo posunga kamera m'nyumba mwanu usiku wonse tidzapanga ndondomeko kuti yidzatengedwe ndi kubwendzedwa tsiku lomwelo.

**6. Kodi padzakhala phindu lopezeka mu kafukufukuyu?**

Ndalama zopitila ndikubwerera ku misonkhano idzaperekedwa, ndipo mudzalandira chakudya ndi chakumwa chozizilitsa kukhosi panthawi yokumana. Mudzapatsidwa zinthuzi zanu makhumi awiri (20) za pa pepala zakukonda kwanu kumapeto a kafukufuku. Mudzatha ku wonetsa zithunzi zanu pachiwonetsero kuti atsogoleri woyanira izi a dziko adziwe za zomwe mukukumana nazo.

**7. Kodi akuchititsa kafukufuku ndi ndani?**

Kafukufuku akupangidwa ndi aza kafukufuku aku College of Medicine molumikizana ndi University of Liverpool, Liverpool School of Tropical Medicine

**8. Kodi adzadziwe ndani zomwe tidzapeze?**

Tidzagwiritsa ntchito kachida kojambulira mawu kujambula misonkhano ya magulu ndi mafunso a payekha payekha ndipo tidzasunga izi mu kompyuta. Zonsezi zidzasunthidwa kupita ku kompyuta yosungilako zinthu popanda kugwiritsa ntchito dzina ndi keyala yanu kuti musadziwike kuchokera mu uthengawu. Mfundo zopezekazi zidzawunikiridwa ndi akafukufuku ku College of Medicine ndi Liverpool School of Tropical Medicine. Tidzagawana nanu zotsatila za kafukufukuyu komanso ndi a gulu lanu, ku malo wokumanirana a zachifundo kapena a zakafukufuku ndiponso tidzafotokoza ndikugawana zotsatilazi ku msonkhano wa mayiko wosiyanasiyana ndi mu mabuku a mwezi ndi mwezi (journal).

**9. Chingachitike ndi chiyani mutasintha maganizo kuchoka kupita kwina kapena kudwala kuti simungapitilize kafukufuku??**

Ngati mwalora kulowa mu kafukufuku mukhonzeka kusintha maganizo ndikusiyana pa nthawi iliyonse. Ngati mutachokapo kapena kudwala kuti simungapitilize kafukufuku, tidzafunsa chilolezo kwa inu (kapena kwa mmodzi wapanyumba panu) ngati inu/kapena wapabanja panu mungakondwe/angakondwe kuika chithunzi chanu ndi zina zakafukufuku yemwe munatenga nawo mbali.

10. Ngati muli ndi mafunso wokhudza kafukufukuyu, chonde lankhulani ndi Field Coordinator Mayi Emmie Kalonga [+265 888803214].

11. Ngati muli ndi mafunso pa zokhudza ma ufulu a wotenga nawo mbali pa kafukufukuyu, chonde lumikizani ndi Mkuu wa bungwe lowona za chikhalidwe cha anthu (COMREC). Bungwe limeneli lawunika ndi kuloleza akafukufuku wonsewa. Keyala ndi manambala wolumikizirana nawo ndi: COMREC Secretariat, College of Medicine, P/bag 360, Blantyre 3. Tel no: [+265 111 989 766].

## Appendix 3 : Photovoice images

### 3.1 Example images



### 3.2 Sample captioned images

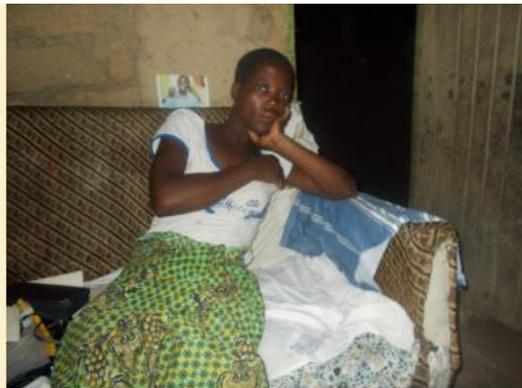




my wife left me when I first got sick with cancer  
but my child is very happy now  
PT, patient, aged 32



It's the guardian's duty to give proper care and  
medication to the patient  
EM, carer, aged 33



the guardian is disappointed because the results  
from the hospital are saying is cancer disease  
JM, patient, aged 43

## Appendix 4 : PaCCcT survey development :

This is available via the following links

[4.1 PaCCcT survey : English and Chichewa](#)

## Appendix 5

### 5.1 EQ5D 3L – English and Chichewa



Health Questionnaire

*English version for the UK  
(validated for Ireland)*

SAMPLE

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

**Mobility**

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities** (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own  
health state  
today**

Best  
imaginable  
health state

100

90

80

70

60

50

40

30

20

10

0

Worst  
imaginable  
health state



**Mafunso a za Umoyo**

**Chinyanja (Chichewa) cha ku Malawi**

*(Nyanja (Chichewa) version for Malawi)*

Chongani mu bokosi limodzi mu gulu lililonse pansipa, chonde sonyezani mfundo zimene zikufotokoza bwino za umoyo wanu lero.

**Mayendedwe**

- Ndilibe vuto lina lililonse poyenda
- Ndimakhala ndi mavuto ena poyenda
- Ndimangobindikira pa kama

**Kudzisamalira ndekha** (*mwachitsanzo kusamba ndi kudziveka ndekha*)

- Ndilibe vuto podzisamalira ndekha
- Ndimakhala ndi mavuto ena posamba kapena podziveka ndekha
- Ndimalephera kusamba kapena kudziveka ndekha

**Zochitika za tsiku ndi tsiku** (*monga kugwira ntchito, kuwerenga, ntchito za pakhomo, za m'banja kapena kuchita zimene zimandisangalatsa*)

- Ndilibe mavuto ali onse pogwira ntchito zanga za nthawi zonse
- Ndimakhala ndi mavuto ena pogwira ntchito zanga za nthawi zonse
- Ndimalephera kugwira ntchito zanga za nthawi zonse

**Ululu/Kuphwanya m'thupi kosowetsa mtendere**

- Ndilibe ululu kapena sindikumva kuphwanya m'thupi
- Ndimakhala ndi ululu kapena kumva kuphwanya m'thupi mwapakatikati
- Ndimakhala ndi ululu kapena kumva kuphwanya m'thupi kwambiri

**Nkhawa/Khumudwa (Osasangalala)**

- Sindikuda nkhawa kapena kukhumudwa
- Ndimakhala oda nkhawa kapena okhumudwa mwapakatikati
- Ndimakhala oda nkhawa kapena okhumudwa kwambiri

Kuti tithandize anthu kunena za umoyo wawo, tajambula mlingo woyesera (chofanana ndi choyesera kuzizira/kutantha kwa m'thupi) womwe umoyo wabwino wayerekezedwa ndi chizindikiro cha 100 ndipo umoyo woipa wayerekezedwa ndi chizindikiro cha 0.

Tikufuna mutisonyeze pa mlingowu mmene umoyo wanu ulili lero kuti uli bwino kapena suli bwino mmene inu mukuganizira. Lembani mzere kuchokera pa bokosi pansipa kupita pa mlingo woyesera umene ukufotokoza za ubwino kapena kuipa kwa mmene umoyo wanu ulili lero.

**Mmene umoyo  
wanu ulili  
lero**

Kuyerekezedwa kuti  
umoyo uli bwino  
kwambiri



Kuyerekezedwa kuti  
umoyo si uli bwino

## IPOS Malawi Staff Administered Version

Patient name : .....

Patient number : .....

Date (dd/mm/yyyy) : .....

**Q1. What have been the patient's main problems or concerns over the past 3 days?**

1.  
.....  
.....

2.  
.....  
.....

3.  
.....  
.....

**Q2. Please tick one box that best describes how the patient has been affected by each of the following symptoms over the past 3 days?**

	Not at all	Slightly	Moderately	Severely	Overwhelmingly	Cannot assess (e.g. unconscious)
--	------------	----------	------------	----------	----------------	----------------------------------

<b>Pain</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Shortness of breath</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Weakness or lack of energy</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Nausea (feeling like you are going to be sick)</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Vomiting (being sick)</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Poor appetite</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Constipation</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Sore or dry mouth</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Drowsiness</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Poor mobility</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Please list any <u>other</u> symptoms and tick <u>one box</u> to show how you feel each of these symptoms has <u>affected</u> the patient <u>over the past 3 days</u>.</b>						

1.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
2.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
3.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

**Over the past 3 days:**

	<i>Not at all</i>	<i>Occasional ly</i>	<i>Sometim es</i>	<i>Most of the time</i>	<i>Always</i>	<i>Cannot assess (e.g. unconsciou s)</i>
<b>Q3. Has s/he been feeling worried about his/her illness or treatment ?</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

<b>Q4. Have any of his/her family or friends been anxious or worried about the patient?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
<b>Q5. Do you think s/he felt depressed?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
	<i>Always</i>	<i>Most of the time</i>	<i>Sometimes</i>	<i>Occasionally</i>	<i>Not at all</i>	<i>Cannot assess (e.g. unconscious)</i>
<b>Q6. Do you think s/he has felt at peace?</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>
<b>Q7. Has the patient been able to share how s/he is feeling with his/her family or friends as</b>	<input type="checkbox"/> 0	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/>

much as s/he wanted?						
Q8. Has the patient had as much information s/he wanted?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
	<i>Problems addressed/ No problems</i>	<i>Problems mostly addressed</i>	<i>Problems partly addressed</i>	<i>Problems hardly addressed</i>	<i>Problems not addressed</i>	<i>Cannot assess (e.g. unconscious)</i>
Q9. Have any practical problems resulting from his/her illness been addressed? (such as financial or personal)	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

# IPOS Malawi Staff Version



www.pos-pal.org

Dzina la wodwala : .....

Nambala ya wodwala : .....

Deti tsiku/mwezi/chaka) : .....

**Q1. Ndi mavuto aji akulu amene wodwala wakhala nawo pa masiku oposerera atatu apitawo?**

1.

.....

.....

2.

.....

.....

3.

.....

.....

**Q2. Chonde chongani bokosi limodzi limene likufotokoza bwino m'mene wodwala wakhudziwira ndi zizindikiro zotsatirazi pamasiku oposera atatu apitawo.**

	Ayi mpan g'ono	Pang' ono kwam biri	Pang' ono	kwambi ri	Mopitiriza muyezo	Sitingat he kuyeza (monga
--	----------------------	------------------------------	--------------	--------------	----------------------	------------------------------------

	pomw e		kwam biri			kukhal a chikom okere)
Ululu	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kuperewera mpweya popuma	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kufooka kapena kusowa mphamvu	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Nseru(kumva kudwala )	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kusanza(kudwala	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kusakhala ndi chilakolako chofuna kudya	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kudzimbidwa	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Zilonda m'kamwa kapena kuuma m'kamwa	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kumva kutopa ngati ugone	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Kulephera kusuntha ziwalo za thupi	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Lembani zizindikiro <u>zina</u> ndipo chongani mu <u>bokosi limodzi</u> kusonyeza m'mene mukuonera pa chizindikiro chilichonse						

chimenea wodwala wakhudzidwa nacho pa <u>masiku opitirira atatu apitawo.</u>						
1.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
2.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
3.	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

**Masiku opitirira atatu apitawo:**

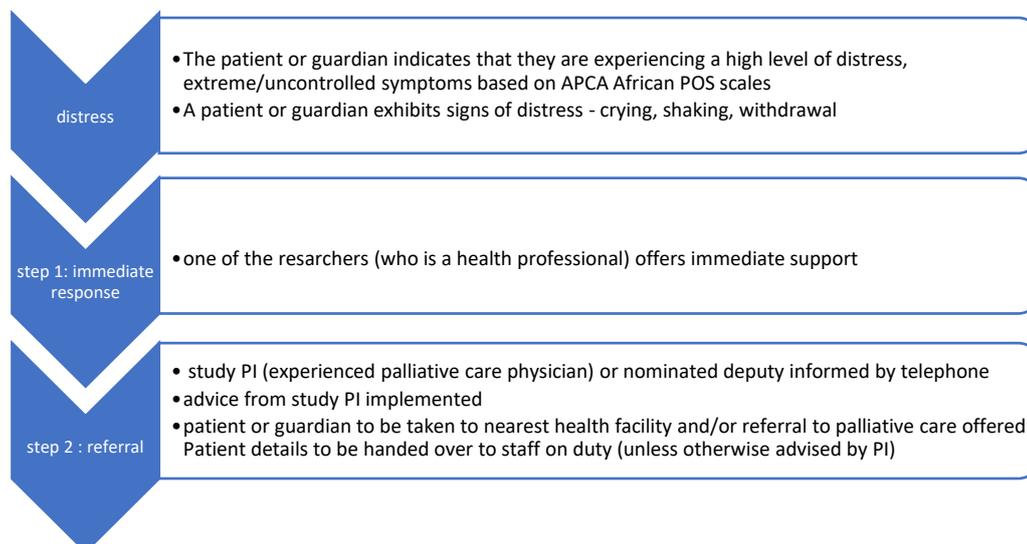
	<i>Ayi mpang'o no pomwe</i>	<i>Panthawi</i>	<i>Nthawi zina</i>	<i>Nthawi zambiri</i>	<i>Nthawi zonse</i>	<i>Sitingathe kuyeza (monga: ali chikomoker e)</i>
<b>Q3. Kodi wodwala wakhala akudandaula zokhudzana ndi kudwala kwawe kapenachifukwa cha thandizo la ku chipatala?</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
<b>Q4. Alipo wina wa m'banja mwawo kapena anzawo amene</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

wakhala ndi nkhawa kapena akudandaula za wodwalayo?						
Q5. Mukuganiza kuti wodwalayu ndi okhumudwa kwambiri?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
	<i>Nthawi zonse</i>	<i>Nthawi zambiri</i>	<i>Nthawi zina</i>	<i>Panthawi</i>	<i>Ayi mpang'o no pomwe</i>	<i>Sitingathe kuyeza (monga: ali chikomoker e)</i>
Q6. Mukuganiza kuti wodwalayu ali ndi mtendere?	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
Q7. Kodi wodwala anatha kugawana ndi banja lake kapena anzake za m'mene akumvera m'mene amafunira	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

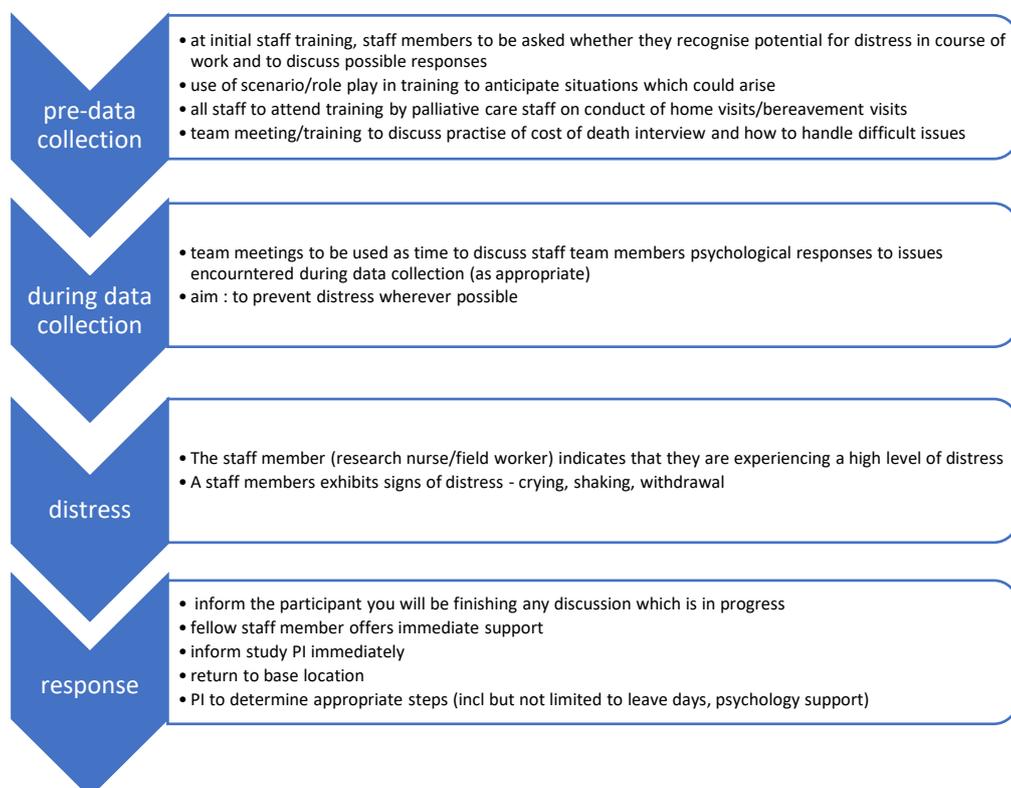
<b>Q8. Wodwala anali ndi uthenga wokwanira ndi m'mene amafunira?</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>
	<i>Problems addressed/ No problems</i>	<i>Problem s mostly addressed</i>	<i>Problem s partly addressed</i>	<i>Problem s hardly addressed</i>	<i>Problems not addressed</i>	<i>Cannot assess (e.g. unconscious)</i>
<b>Q9. Kodi mavuto ooneka ochokera ku matenda ake anathandizid wa?(monga ndalama kapena mavuto a pamoyo wa munthu</b>	0 <input type="checkbox"/>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	<input type="checkbox"/>

## 5.3 Distress Protocol

### For patient/household carer



### For staff



## 5.4 Proxy Means Test for Poverty (urban)

### Questions

**1) Please think about the person who is the head of your household. It may be you, or it may be someone else. What is the highest educational qualification the household head has acquired?**

NONE == 1 (ref: 0)

PSLC == 2 (-0.1070230)

JCE == 3 (-0.4727860)

MSCE == 4 (-0.3210555)

NON-UNIVERSITY DIPLOMA == 5 (-14.5500879)

UNIVERSITY DIPLOMA/DEGREE == 6 (-14.1740569)

POSTGRADUATE DEGREE == 7 (-13.8194385)

**2) What does the head of your household sleep on? Please select one of the following:**

BED & MATTRESS == 1 (ref: 0)

BED & MAT (GRASS) == 2 (0.6709013)

BED ALONE == 3 (0.3235319)

MATTRESS ON FLOOR == 4 (0.4599334)

MATT (GRASS) ON FLOOR == 5 (0.7354924)

CLOTH/SACK ON FLOOR == 6 (2.9858984)

FLOOR (NOTHING ELSE) == 7 (0.0000000)

OTHER == 8 (-0.6208952)

**3) How many people live in your household? Please count all the people who normally live with you and eat meals together. Include yourself when counting.**

INTEGER RESPONSE (0.6222069)

**4) Do you have working electricity in your dwelling?**

YES == 1 (ref: 0)

NO == 2 (0.9590447)

**5) Do you, either by yourself or together with another household member or someone outside your household, currently have an account at a bank, credit union, micro finance institution, village savings organization, or another financial institution?**

YES ==1 (ref: 0) -

NO == 2 (0.8831791) -

**6) In the past 7 days, did you worry that your household would not have enough food?**

YES == 1 (ref: 0) -

---

NO == 2 (-0.5573320) -

**7) Concerning your household's clothing, which of the following is true?**

It was less than adequate for household needs == 1 (ref: 0)

It was just adequate for household needs == 2 (-0.6375926)

It was more than adequate for household needs == 3 (-0.9265472)

**8) Does your household own a tape or CD/DVD player or a HiFi?**

YES == 1 (ref: 0)

NO == 2 (0.8729641)

**9) Does your household own an upholstered chair (armchair) or sofa set?**

YES == 1 (ref: 0) - NO == 2 (0.9942764)

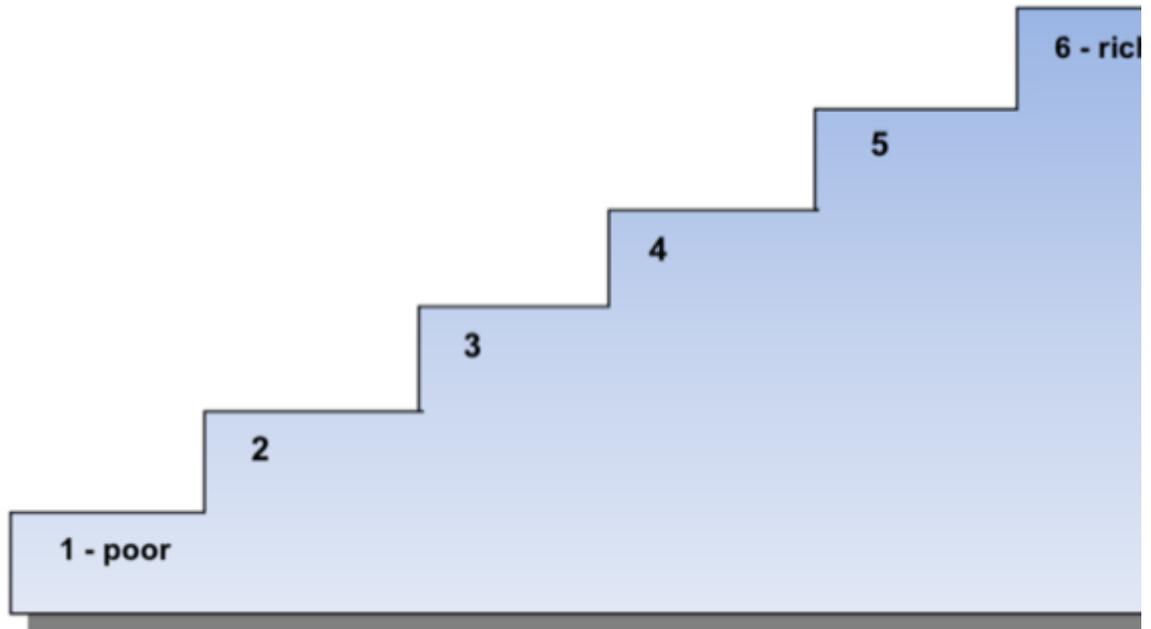
**10) Does your household own an iron for pressing clothes?**

YES == 1 (ref: 0)

---

NO == 2 (1.3393567) –

11) Imagine six steps, where on the bottom, the first step, stand the poorest people, and on the highest step, the sixth, stand the rich. SHOW THE PICTURE OF THE STEPS. On which step are you today?



STEP 1 == 1

STEP 2 == 2

STEP 3 == 3

STEP 4 == 4

STEP 5 == 5

STEP 6 == 6

---

## 5.5 Explanatory variables of regression models

In the regression model a log linear transformation of the total household costs on health variable was used. A log linear transformation was used on the dependent variable (total health expenditure) as the data were skewed. The multiple linear regression equation is stated below.

$$\ln(\text{Total health costs as a share of monthly income}) = \alpha_0 + \alpha_1 \cdot \text{Receipt of palliative care} + \alpha_2 \cdot \text{Socioeconomic} + \alpha_3 \cdot \text{Health seeking behaviour} + \alpha_4 \cdot \text{Health at diagnosis} + \alpha_5 \cdot \text{Type of cancer}$$

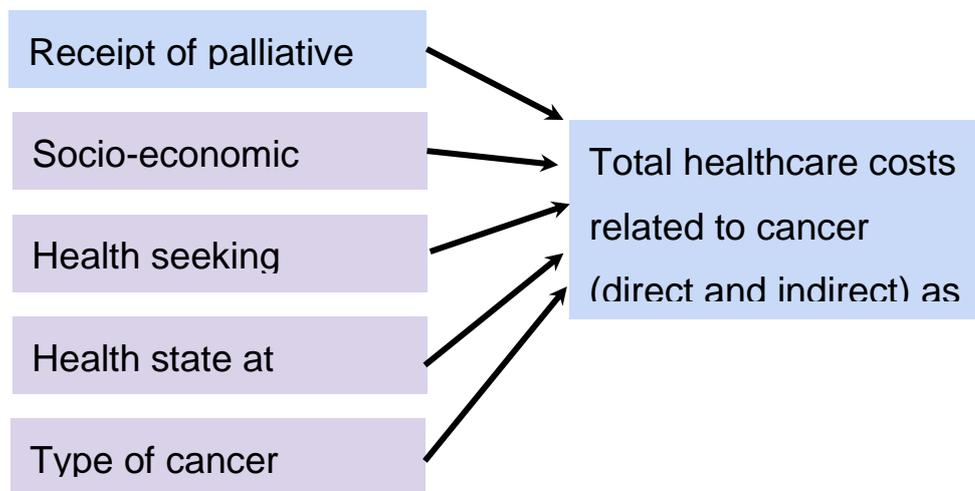
Direct costs included all out of pocket expenditure on healthcare related to cancer : transport, medication, consultations, food while seeking care, food requirements due to disease. Indirect costs were calculated using the human capital approach (hourly wage x total time taken for visits to health care providers), accounting for lost income due to health care seeking related to cancer illness. In the six month sensitivity analysis, the national minimum wage<sup>1</sup> rather than reported wage was used to calculate hourly wage included in the indirect cost calculation. The time taken for medical visits for the carer and patient were multiplied by the hourly wage of caregivers and patients. For the analysis it was assumed that all patients have a caregiver. The hourly wage of the patient was calculated from the inflation adjusted self-reported income before the onset of symptoms, and for the carer is the calculated from the mean personal income of caregivers reported at

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<sup>1</sup> 25,000 Malawi Kwacha/month = USD2019 \$34/month, December 24<sup>th</sup> 2020  
<https://times.mw/new-minimum-wage-starts-january-1/> (accessed 7<sup>th</sup> July 2021)

the time of diagnosis. For those who missed an interview, questions were asked about costs since the last interview, so that cost data were deemed to be complete in subsequent interviews. Where 0 values were reported for household revenue or THE costs incurred a value of 1 was used to enable log values to be calculated. Sensitivity analysis was done using the national minimum wage to derive patient and carer hourly wages.

The explanatory variables which are used in the regression models in the figure and the text are summarised below



We included receipt of palliative care as a dummy variable and controlled for socioeconomic status, health seeking behaviour, health state of patient at diagnosis, and cancer type as follows:

Socio-economic status: Patient age, sex, marital status, urban or rural dwelling and household size were all included as control variables. Self-reported household annual revenue before the onset of symptoms was adjusted for inflation and included as a control.

Health seeking behaviour : The average direct cost of health care sought before diagnosis per day was divided by self-reported household daily income as a control.

Health state : the length of time from symptom onset to diagnosis and the WHO performance score at diagnosis were included as control variables.

Type of cancer: Differences based on the type of cancer were controlled for.

## Appendix 6 Tables of Results

### 6.1 Demographic summary of households, patients, and carers, all recruited, those surviving to study completion, those who died, by receipt of palliative care

	all recruited		received palliative care (all)		completing follow up		received palliative care (CFU)		patient died		received palliative care (died)		loss to follow up
	#	%	#	%	#	%	#	%	#	%	#	%	#
households	150		30		89		19		55		10		6
rural	81	54	8	27	48	54	6	32	31	56	2	20	2
urban	69	46	22	73	41	46	13	68	24	44	8	80	4
most poor	50	33	7	23	29	33	6	32	21	38	1	10	
poor	50	33	11	37	28	31	5	26	19	35	6	60	3
least poor	50	33	12	40	32	36	8	42	15	27	3	30	3
>median monthly rev before illness (12,100MK)	5		5		5		5		4		4	40	
>median total health costs (37,867MK)	74	49	18	60	44	49	12	63	26	47	6	60	4
>median dissaving (20,000MK)					45	51	8	42	31	56	7	23	
>median dissaving (20,000MK)					44	49	6	32	28	51	6	22	
patients	150		30		89		19		55		10		6
male	42	28	12	40	19	21	5	26	21	38	6	60	2
female	108	72	18	60	70	79	14	74	34	62	4	40	4

	all recruited				received palliative care (all)				completing follow up				received palliative care (CFU)				patient died				received palliative care (died)				loss to follow up
	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#	%	#				
18-40 years	32	21	5	17	20	22	4	21	11	20	1	10	1												
40-60 years	74	49	16	53	47	53	11	58	24	44	5	50	3												
>60 years	44	29	9	30	22	25	4	21	20	36	4	40	2												
KS	15	10	6	20	8	9	5	26	5	9	0	0	2												
cervical cancer	75	50	13	43	60	67	10	53	13	24	3	30	2												
oesophageal cancer	46	31	5	17	19	21	3	16	25	45	2	20	2												
liver cancer	14	9	6	20	2	2	1	5	12	22	5	50													
married	93	62	16	53	52	58	8	42	37	67	7	70	4												
single/separate/divorce	21	14	7	23	14	16	7	37	7	13	0	0													
widowed	36	24	7	23	23	26	4	21	11	20	3	30	2												
carers	121		25		64		15		54		9		3												
male	34	23	5	20	17	27	2	13	17	31	3	33													
female	87	58	20	80	47	73	13	87	37	69	6	67	3												
18-39	59	39	10	40	32	36	6	32	24	44	3	30	3												
40-59	45	30	11	44	25	28	8	42	20	36	3	30													
60-89	17	11	4	16	7	8	1	5	10	18	3	30													

## 6.2 Funeral Costs by variable, mean and SD (MK and USD\$2019)

		mean (MK)	SD (MK)	mean (USD)	SD (USD)
all		156,642	82,499	214	113
sex of patient	male (n=21)	163,476	88,559	224	121
	female (n=32)	152,156	79,399	208	109
Poverty tertile	Most poor (n=21)	133,333	57,692	182	79
	Poor (n=17)	131,882	84,842	180	116
	Least poor (n=15)	217,333	82,416	297	113
	KS (n=5)	207,600	89,938	284	123
Type of cancer	Cervical cancer (n=13)	157,308	94,486	215	129
	Oesophageal cancer (n=25)	149,160	78,889	204	108
	Liver cancer (n=10)	149,000	74,603	204	102
Area of dwelling	Urban (n=22)	185,455	82,258	254	113
	Rural (n=32)	136,194	77,587	186	106
Age group	18-40 (n=10)	168,000	105,256	230	144
	40-60 (n=24)	169,458	76,154	232	104
	60-89 (n=19)	134,474	76,828	184	105
seen PC	yes (n=9)	189,444	97,930	259	134
	no (n=44)	149,932	78,581	205	107

6.3 Sensitivity analyses Effect of variables on total household costs on health as a proportion of annual household income ((log linear transformed variable), including 95% confidence intervals

	Main regression results (6 months)	Sensitivity Analysis 1 (3 months)	Sensitivity Analysis 2 (6 months using minimum wage)
Receipt of palliative care	-36.1% (-94.1% - 59.4%)	-54.0% (-95.3% - 35.1%)	-45.9% (-95% - 49.0%)
Age	-0.949% (-8.5% - 7.23%)	-1.10% (-8.16% - 6.49%)	-0.610% (-8.2% - 7.61%)
Male	-30.8% (-98% - 2330%)	-63.8% (-98.7% - 944%)	-16.3% (-97.6% - 2860%)
Urban	155% (-65.1% - 1770%)	12.3% (-83% - 642%)	145% (-66.7% - 1700%)
Married	-16.7% (-89.7% - 575%)	-77.0% (-96.8% - 66.7%)	-11.5% (-89.1% - 620%)
Household size	52.4% (-3.76% - 141%)	54.5% (0.215% - 138%)	54.2% (-2.71% - 145%)
Monthly income (before symptoms)	-0.00426%*** (-0.00672% - 0.0018%)	-0.00375%*** (-0.00607% - -0.00144%)	-0.00461%*** (-0.00708% - 0.00215%)
Daily health spending/daily income (before diagnosis)	0.0721%*** (0.0364% - 0.108%)	0.250%*** (0.171% - 0.329%)	0.0718%*** (0.036% - 0.108%)
HIV positive	22.6% (-83.6% - 816%)	17.3% (-82.2% - 674%)	25.3% (-83.3% - 840%)
Days with symptoms	0.164% (-0.0624% - 0.391%)	0.165% (-0.0482% - 0.379%)	0.154% (-0.073% - 0.382%)

Other variables included

WHO score at diagnosis and type of cancer

---

Constant	-86.1%	-62.2%	-87.8%
	(-100% - 8750%)	(-99.9% - 15600%)	(-100% - 7780%)
Observations	89	86	89
R-squared	0.395	0.522	0.423

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6.4 Self-reported income, household costs (direct, indirect, total) including dissaving on cancer related healthcare from diagnosis to six months including households in which patient died (all costs reported in Malawi Kwacha)

			A self-reported monthly household revenue before illness			B Direct OOPE from diagnosis to 6 months			C Indirect costs from diagnosis to 6 months			D Total health expenditure from diagnosis to 6 months (B+C)			E dissaving from diagnosis to 6 months		
			all	6 months	died**	all	6 months	died*	all	6 months	died*	all	6 months	died*	all	6 months	died*
Poverty tertile	Most poor	mean	10680	11655	9800	11458	11922	10110	2933	3813	378	14390	15736	10488	31758	37084	16310
		SD	12126	12081	14866	13394	10303	20604	9872	11346	1127	18692	18113	20741	52505	59717	13718
		N	50	29	20	39	29	10	39	29	10	39	29	10	39	29	10
	Poor	mean	27480	30786	23158	14394	14591	14950	7430	9973	2015	21824	24564	16965	23722	28879	12000
		SD	43845	46090	44271	15427	14228	18832	12358	14227	2557	19834	20041	19208	25987	28051	17477

		N	50	28	19	41	28	12	41	28	12	41	28	12	41	28	12
	Least poor	mean	44070	36906	62833	22479	26609	10464	27898	29298	23823	50377	55907	34287	63256	61306	68927
		SD	53061	36210	79378	40287	45772	10413	62616	69860	36244	79553	89222	38982	147792	124235	209390
	N	50	32	15	43	32	11	43	32	11	43	32	11	43	32	11	
	total		150	89	54	123	89	33	123	89	33	123	89	33	123	89	33
Type of cancer	KS	mean	20533	23500	24000	5096	5906	3900	1974	1950	2301	7070	7856	6201	17417	21125	6667
		SD	17196	18693	13416	3721	4094	2921	2592	3048	1993	4829	5632	2619	13501	14267	7638
	N	15	8	5	12	8	3	12	8	3	12	8	3	12	8	3	
	Cervix cancer	mean	20507	20400	18000	17829	17428	20230	9159	8841	11066	26988	26270	31296	36992	39339	22910
		SD	32982	31744	40829	18277	17087	25287	19738	16915	33264	29834	28574	38041	48545	51581	19192
	N	75	60	13	70	60	10	70	60	10	70	60	10	70	60	10	

	Oesophageal cancer	mean	28707	39684	20604	17857	26592	8094	24278	38924	7908	42135	65516	16003	39575	69289	6365
		SD	28433	28593	27080	41758	56182	8457	66365	88092	19099	84046	110002	21547	116266	155817	6011
		N	46	19	24	36	19	17	36	19	17	36	19	17	36	19	17
	Liver cancer	mean	67500	107500	60833	10320	3800	14667	15955	20881	12670	26275	24681	27337	141600	0	236000
		SD	96312	130815	95223	16143	141	21221	16086	5424	21505	30332	5565	42665	312174	0	401856
		N	14	2	12	5	2	3	5	2	3	5	2	3	5	2	3
	Totals		150	89	54	123	89	33	123	89	33	123	89	33	123	89	33
Sex	Male	mean	46905	45526	52619	19607	22853	14689	17905	18750	17978	37512	41603	32667	71841	68484	84689
		SD	60833	46698	73264	45497	55722	12996	25556	26483	25909	62158	74198	30392	176181	156097	230796
		N	42	19	21	29	19	9	29	19	9	29	19	9	29	19	9
	Female	mean	19829	21657	14348	15266	16737	10975	11695	13873	5342	26961	30611	16317	30295	36352	12629
		SD	29730	30618	28903	17607	17324	18095	42768	47892	21416	47993	52933	27369	43816	48582	15648

		N	108	70	33	94	70	24	94	70	24	94	70	24	94	70	24
Area of dwelling	Urban	mean	42899	40244	51652	15976	16627	13923	20979	22815	15191	36955	39442	29114	46950	41763	63308
		SD	56435	46216	75455	36292	40348	19617	56001	62226	29944	72641	81147	35612	134410	113185	191591
		N	69	41	23	54	41	13	54	41	13	54	41	13	54	41	13
	Rural	mean	14216	15229	12597	16535	19252	10730	7039	8166	4627	23574	27418	15357	34722	44449	12115
		SD	16295	16745	15793	15993	15902	14998	15880	15718	16742	24185	24255	22545	42683	47104	15597
		N	81	48	31	69	48	20	69	48	20	69	48	20	69	48	20
	totals		150	89	54	123	89	33	123	89	33	123	89	33	123	89	33
Age group	18-40	mean	37563	35350	41818	15075	14565	17625	6384	5663	9993	21459	20228	27618	76083	54800	182500
		SD	62873	49351	87157	16745	17085	17047	10448	8698	19359	20653	18091	33716	150260	75329	345024
		N	32	20	11	24	20	4	24	20	4	24	20	4	24	20	4
	40-60	mean	28291	23255	39717	15440	17276	10573	19091	20657	15376	34531	37933	25949	25971	30971	10700

		SD	36196	25690	51760	17599	17801	16739	52958	58750	32144	57591	63537	35169	31562	34595	11943
		N	74	47	23	63	47	15	63	47	15	63	47	15	63	47	15
	60-89	mean	18545	26409	10250	18585	22843	11893	7296	11057	1386	25881	33900	13279	40806	58827	12486
		SD	31796	40097	18493	41846	51751	17586	15402	18821	2214	54980	68276	18114	114790	144571	17316
		N	44	22	20	36	22	14	36	22	14	36	22	14	36	22	14
seen	no	mean	22788	24671	19443	16305	18651	10943	9512	9957	8695	25816	28608	19637	39535	50952	11689
		SD	32211	35016	289111	28149	31502	16987	20105	18484	24293	39478	43109	28794	80139	92659	14592
		N	120	70	44	99	70	28	99	70	28	99	70	28	99	70	28
	yes	mean	45900	34421	72300	16227	15803	17840	28206	33177	9314	44433	48980	27154	42383	14695	147600
		SD	67513	38319	102292	20385	21810	15645	78820	88068	16035	84810	94224	30582	140863	16358	308886
		N	30	19	10	24	19	5	24	19	5	24	19	5	24	19	5

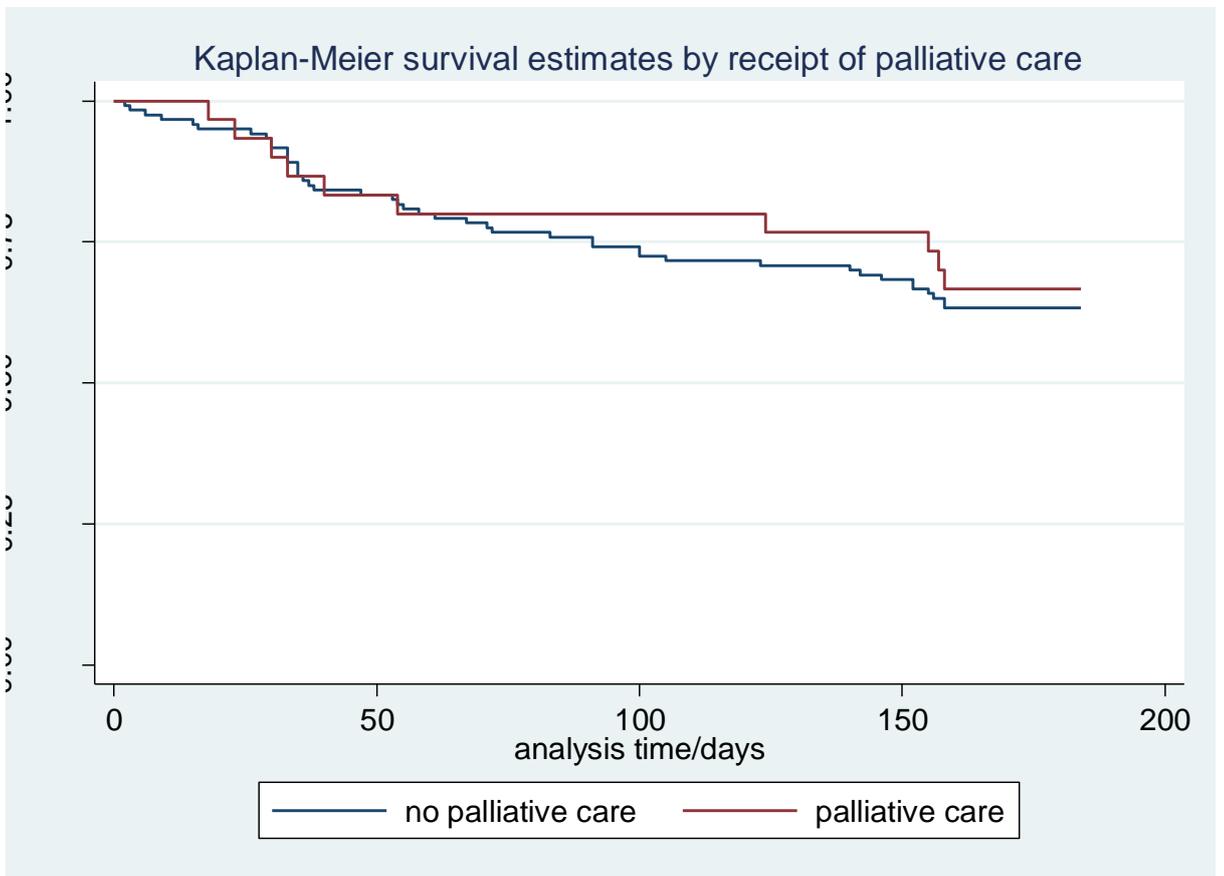
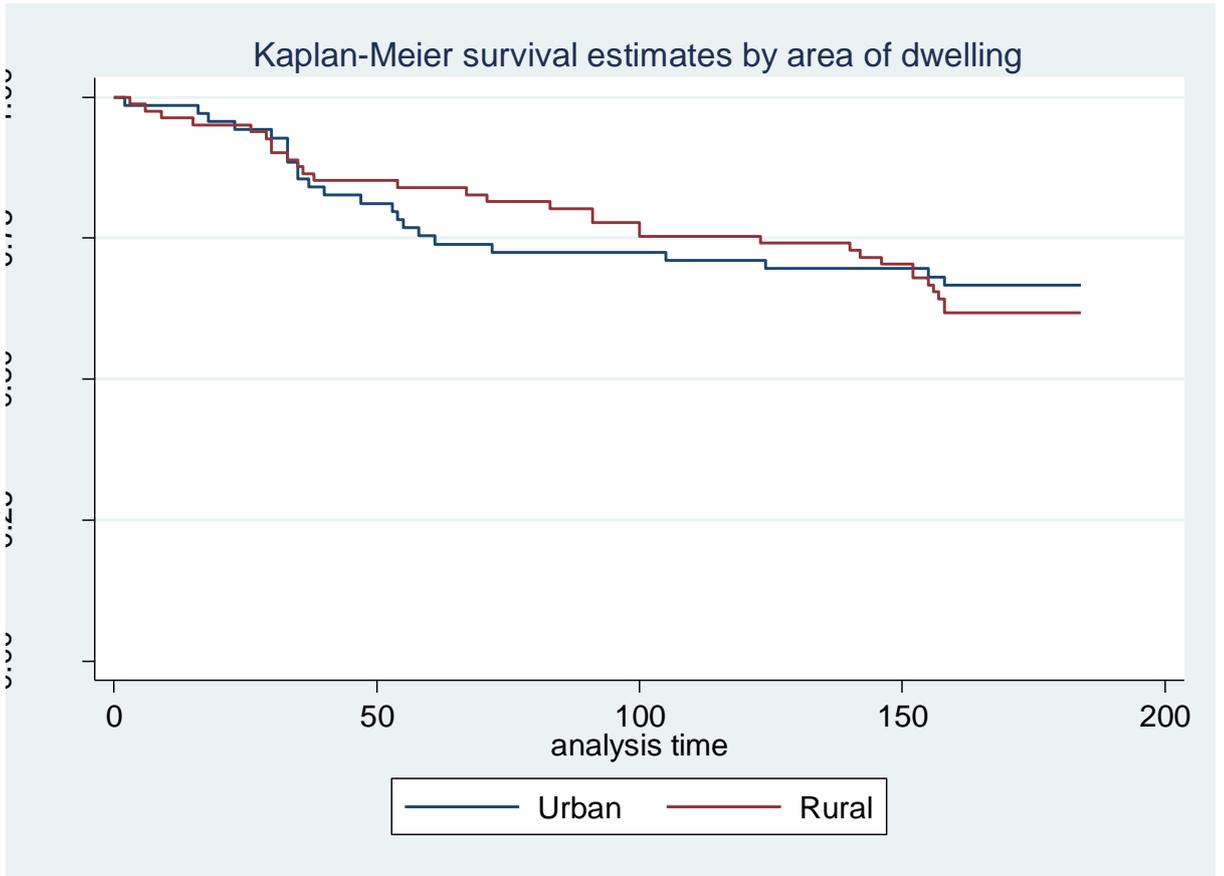
	total s		150	89	54	123	89	33	123	89	33	123	89	33	123	89	33
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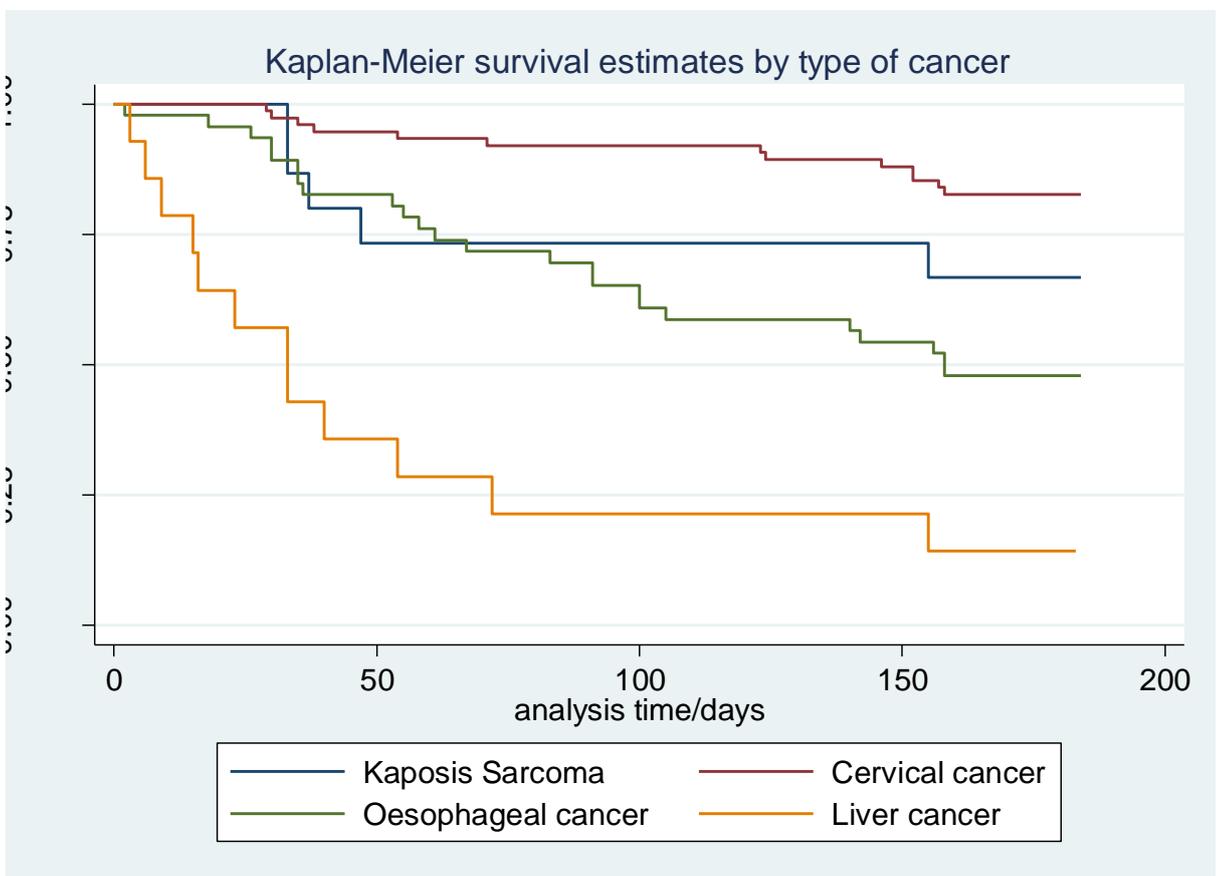
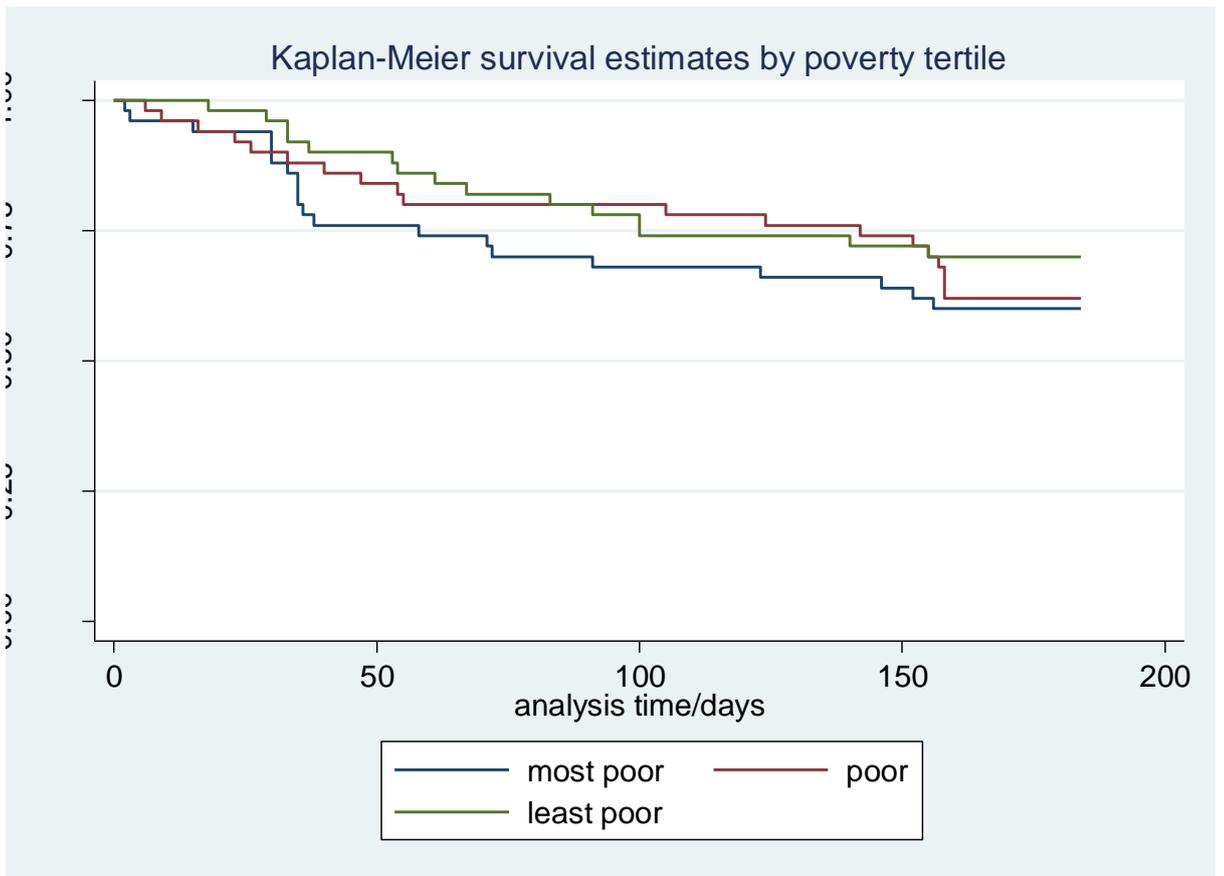
6.5 Patient and carer health related quality of life (HRQoL) utility and VAS scores from diagnosis to six months after diagnosis of advanced cancer by receipt of palliative care (mean and 95% CI), n=89

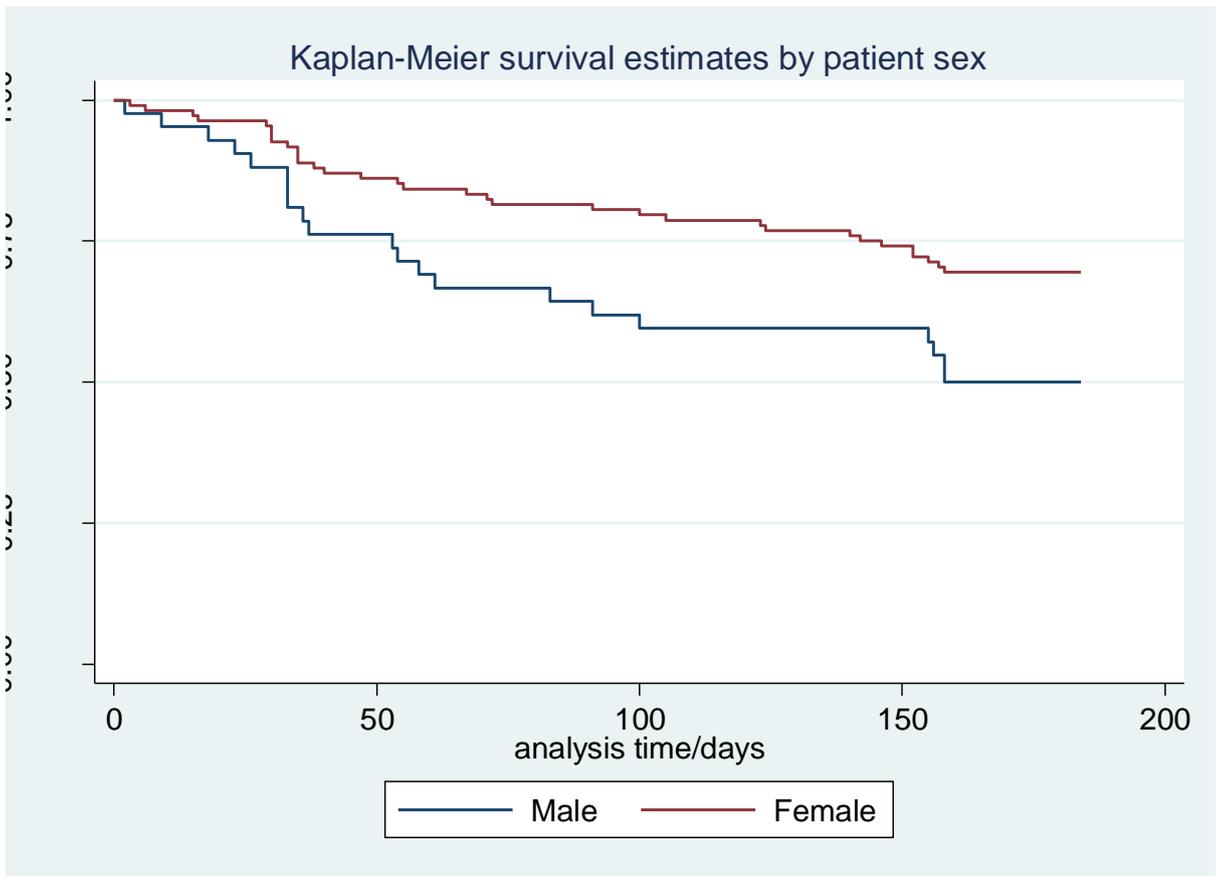
	HRQoL health index (maximum = 1)					VAS score (maximum = 100)							
	all	95% CI	not seen PC	95% CI	seen PC	95% CI	all	95% CI	not seen PC	95% CI	seen PC	95% CI	
patients	diagnosis	0.668	0.6283-0.707	0.668	0.625-0.711	0.666	0.564-0.767	39	35-42	38	34-42	42	33-51
	1 month	0.609	0.556-0.662	0.641	0.589-0.692	0.461	0.284-0.639	35	32-39	35	31-39	37	25-48
	3 month	0.647	0.603-0.691	0.652	0.602-0.702	0.627	0.523-0.732	31	27-34	30	26-33	35	25-44
	6 month	0.590	0.534-0.646	0.606	0.543-0.670	0.537	0.412-0.662	23	20-25	22	20-25	23	18-28

HRQoL health index (maximum = 1)							VAS score (maximum = 100)						
	all	95% CI	not seen		seen		all	95% CI	not seen		seen PC		
			PC	95% CI	PC	95% CI			PC	95% CI	PC	95% CI	
Carers	diagnosis	0.826	0.799- 0.853	0.827	0.793- 0.860	0.824	0.776- 0.871	32	29-35	32	29-36	33	25-42
	1 month	0.827	0.797- 0.858	0.812	0.777- 0.847	0.869	0.804- 0.933	27	23-31	28	24-33	24	17-32
	3 month	0.838	0.802- 0.874	0.840	0.796- 0.884	0.831	0.770- 0.891	25	22-28	25	21-28	25	17-33
	6 month	0.831	0.799 - 0.863	0.828	0.792- 0.864	0.843	0.768- 0.917	18	15-22	17	15-19	22	6-38

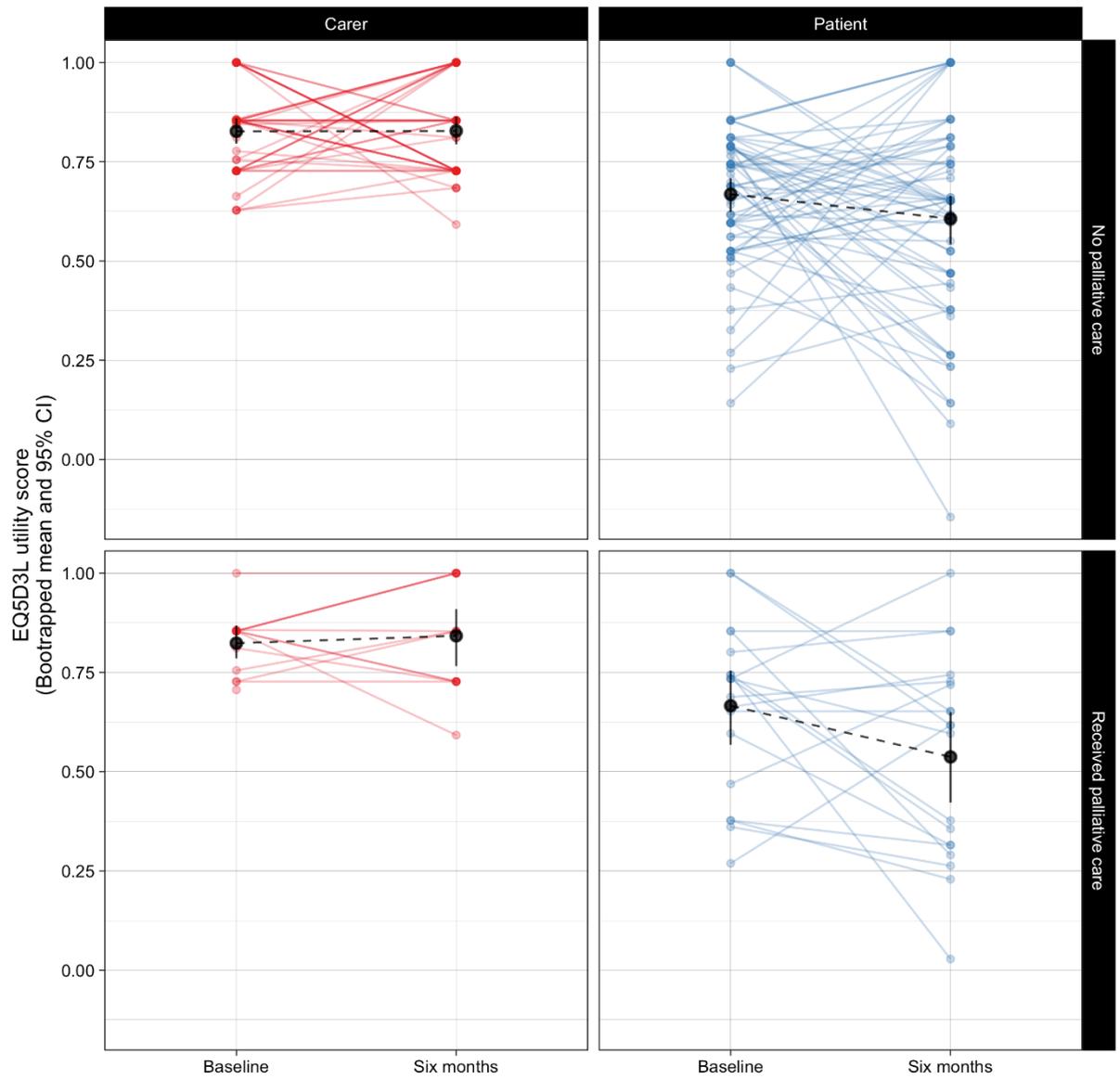
## 6.6 : Kaplan Meier survival estimates







6.7 Health related quality of life (HRQoL) utility scores for patients and carers at baseline and six months by receipt of palliative care (with bootstrapped mean and 95% CI)



## Appendix 7 Miscellaneous

### 7.1 Details of deviations from the published study protocol

The following analyses were planned but not undertaken:

- a) Poisson regression: details of the number of palliative care visits could not be reliably confirmed from available data sources (patient files, hospital records)
- b) Cox proportional hazard models were not done. Log rank testing reported no unexpected significant differences in survival. Only where disaggregated by cancer type and patient sex (Patient sex was closely linked to cancer type in this study).
- c) Changes in symptom burden using the Integrated Palliative Care Outcome Scale: this tool requires further validation in the local setting

## 7.2 Summary of relevant links

### Photovoice study

Consent forms: English and Chichewa

Participant information sheet: English and Chichewa

Oral presentation College of Medicine Research Dissemination Conference 2018

Example images

Sample captioned images

### Cohort study

Consent forms patient and carer: English and Chichewa

Patient and carer information sheets: English and Chichewa

Patient and carer eligibility criteria

PaCCCT survey: English and Chichewa

Report of national stakeholder meeting

All raw data is available at the following link:

<https://dataverse.harvard.edu/dataset.xhtml?persistentId=doi:10.7910/DVN/DNUUB>

[W](#)